

Lay Perspectives on Partner Notification:  
Perspectives of  
Men Who Have Sex With Men  
In the Context of an Outbreak of Syphilis

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of the requirements for the  
degree of the doctor of philosophy

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*Declaration*

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## **SUMMARY**

### **AIM OF THE RESEARCH**

The aim of this research is to explore the lived lay experiences and perspectives of men who have sex with men (MSM) in the context of an outbreak of syphilis occurring in Dublin, Ireland. There were three population groups involved in the study: MSM who were diagnosed with syphilis (whom I call ‘cases’), MSM who were sexual contacts of people with syphilis (whom I call ‘contacts’), and MSM who were recruited from community social venues (whom I call ‘community’). Partner notification is the process by which people who are exposed to sexually acquired infections are traced, informed about their exposure and invited to attend clinical services. It is considered to play a significant role in the control of sexually acquired infections, and as a practice, it has been conducted throughout the globe for several decades with substantial resources invested in this activity. Partner notification effectiveness is largely dependent on its acceptability to the people infected with, or affected by sexually acquired infections. Despite this, few studies have explored lay perspectives on this practice. The aim of this research is to address this gap. MSM have been presented in the literature as a ‘difficult group’ in terms of effectiveness of the practice of partner notification. Yet, few studies have focused on this group and in particular on lay perspectives of this activity. An outbreak of syphilis in Dublin occurring largely among MSM provided an ideal opportunity to conduct this important study.

### **METHODOLOGY**

Mixed methodology was employed for this study. Data were collected from the three groups (‘Cases’ ‘Contacts’ and ‘Community’) using questionnaires and individual semi-structured interviews.). Recruitment for the study took place in a sexual health clinic of a teaching hospital with extensive university links. This centre is the largest site for the screening and treatment of sexually acquired infections in the country. The second, a

community clinical site, was the only community designated sexual health clinic for MSM in the country. Finally, an innovative part of the study design was also to recruit from community social venues where MSM meet. These were two clubs, one pub and one sauna. These venues were conveniently selected as they represented popular MSM venues and recruitment coincided with a community based syphilis screening programme. Three separate questionnaires were administered to the three populations ('case', 'contact' and 'community'). Two hundred and twenty two MSM were invited to participate in the 'case' questionnaire; of these, 200 hundred agreed to participate (response rate 90%). One hundred and nineteen 'contacts' of syphilis were invited to participate in the 'contact' questionnaire, of these, 104 agreed to participate (response rate 87.3%). Finally, two hundred and fifty people were invited to participate in the community questionnaire, of these, two hundred and four agreed to complete questionnaires (response rate 81.6%). In addition to the quantitative component of the study, individual semi-structured interviews were conducted with fifteen 'cases', fifteen 'contacts', and ten 'community' participants.

## **FINDINGS**

The findings from the research support the view that MSM support in principle the practice of partner notification. This is only one perspective however; the action of partner notification is often in conflict with other life objectives and desires. The stigma of a sexually acquired infection is problematic. Partner notification is also made difficult in the context of stigmatising homosexual identities. The actual process of breaking the bad news of a diagnosis presents a particular challenge to MSM. The breaking of such bad news creates a potential risk of private as well as public humiliation. Partner notification is also hampered by the lived practice of sexuality in the lives of MSM. A gulf exists in the implicit expectations of how partner notification is expected to work in theory and how it works in practice. Desire to avoid or control infections is only one concern for MSM. A tension exists between the desire for sexual pleasure (including anonymous sex) as well as the desire to control sexually acquired infections.

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## **Glossary/Terminology**

<b>AIDS</b>	Acquired Immunodeficiency Syndrome
<b>CDC</b>	Centres for Diseases Control (and prevention)
<b>Chlamydia</b>	A sexually acquired bacterial infection
<b>CSO</b>	Central Statistics Office
<b>DOHC</b>	Department of Health and Children
<b>GDA</b>	Greater Dublin Area
<b>GMHP</b>	Gay Men's Health Project
<b>Gonorrhoea</b>	A sexually acquired bacterial infection
<b>GP</b>	General Practitioner
<b>GUM</b>	Genitourinary Medicine
<b>HA</b>	Health Advisor
<b>HIV</b>	Human Immunodeficiency Virus
<b>HPSC</b>	Health Protection Surveillance Centre
<b>HSE</b>	Health Service Executive
<b>Syphilis</b>	A sexually acquired bacterial infection
<b>SJH</b>	St James Hospital
<b>STD</b>	Sexually Transmitted Disease
<b>STI</b>	Sexually Transmitted Infection

<b>MSM</b>	Men who have Sex with Men
<b>NDSC</b>	National Diseases Surveillance Centre
<b>Pox</b>	Slang term for syphilis
<b>VD</b>	Venereal Disease

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# CHAPTER 1

## INTRODUCTION

### 1.1 Introduction

This chapter will outline the research area that this thesis seeks to explore. The objective of this thesis is to explore the lived lay experience and perspectives on partner notification amongst gay bisexual and other men who have sex with men, in the context of an outbreak of syphilis in Dublin, Ireland. This is a study of gay bisexual and other men who have sex with men. I acknowledge the diversity of the lived experiences of the individuals within these different groups. Where there are important differences between these groups I will acknowledge them, but otherwise the term men who have sex with men (MSM) will be used in the study as a collective for these three categories of men. Similarly, when the term gay community is used, it will also include bisexual and other men who have sex with men, unless stated otherwise.

A mixed methodology approach was used involving semi-structured interviews and also questionnaires. Men with syphilis ('cases'), men attending clinic as a result of partner notification ('contacts'), and men recruited from gay social venues ('community') participated. The findings from this study contribute to some extent in addressing the dearth of research on lay perspectives on partner notification in general, and among MSM in particular. The chapter will help to set some of the background context for the study by providing definitions of the main terms and background information on the syphilis outbreak on which this thesis is based and responses to this outbreak by the health authorities. In addition, it will provide a historical backdrop to understanding sexual health services in Ireland and in particular in relation to the State's response to human immunodeficiency virus (HIV).

## **1.2 What is Partner Notification?**

Partner notification<sup>1</sup> is the process by which people exposed to sexually acquired infections are traced, informed about their exposure and invited to attend clinical services. The process of partner notification employed in sexual health clinics<sup>2</sup> in Ireland, and internationally can be divided into three approaches: patient, provider or conditional referral. Patient referral is the approach most often used; it occurs when a person with infection (known as the index patient) informs his or her sexual contact of the exposure. Provider referral is the process by which a health care professional (usually a health advisor) informs the named contact directly. The identity of the index patient is not disclosed. It is explained to the index patient that his (or her) confidentiality may be compromised in circumstances where a contact has had no other partners. It is explained however, that the health professional carrying out the contact tracing, will not confirm any speculations that a contact might make regarding the identity of the index patient. Finally a conditional (contract) referral sometimes occurs. Such an approach involves a health advisor notifying a contact after an agreed time period if the index patient has not already done so.

## **1.3 What is syphilis?**

Syphilis is an infection caused by the bacteria *Treponema pallidum*. It is transmitted during sexual intercourse including oral sex. There are three stages to the disease, which are known as primary, secondary or latent. Latent syphilis, is often further divided into stages known as early latent and late latent. Syphilis is considered to be infectious when it is in the primary, secondary and early latent stages. A provisional diagnosis of syphilis is frequently made based on clinical presentation of signs and symptoms, but confirmation is done based on laboratory testing of blood and other clinical specimens. The stage of syphilis is ascertained based on signs, symptoms, blood results and previous testing. According to standard EU definitions, primary syphilis is characterised by one or

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<sup>1</sup> The word “contact” is used interchangeably with the word “partner” throughout the course of this text. Similarly the term “contact tracing” is used interchangeably with “partner notification” without any difference in meaning implied.

<sup>2</sup> Sexual health clinics are also called sexually transmitted disease (STD) or sexually transmitted infection (STI) clinics.

more chancres (ulcers) in the genital area or other mucus membranes. Secondary syphilis is characterised by localised or diffuse mucocutaneous lesions, often with generalised lymphadenopathy. The primary chancre may still be present. Latent stage of the disease occurs after these two stages and is not characterised by any signs or symptoms. The duration of that infectivity is thought to be dependant on the disease stage. This of course is an important point for partner notification as the recommendations about how far back to trace contacts, depend on the stage of infection.

Syphilis is still considered to be one of the most serious sexually transmitted infections (STIs). It has the potential to affect many systems of the body. Untreated, it results in serious morbidity and premature mortality (Van Voorst Vader 1998), affecting in particular, the neurological and cardiovascular systems. In a retrospective analysis on the natural history of syphilis (Clarke and Danbolt 1955), mortality from untreated syphilis was estimated to be 17.1% for men and 8% for women (Hopkins et al 2004). The synergy of syphilis with HIV is also an important point, as syphilis significantly increases the likelihood of also acquiring HIV. A six-fold increase in co-diagnosis of HIV and syphilis was reported in Dublin from 2000 to 2001 (Hopkins et al 2002a). Syphilis is also considered serious because of the risk of transmission from mother to baby, resulting in congenital syphilis which is potentially fatal. It has been stated that 46-60% of contactable sexual partners of people with early syphilis will also have the infection (Clinical Effectiveness Group 2002). While syphilis is a treatable infection, nonetheless its management can be a considerable burden for the individual concerned. Penicillin is the treatment of choice for syphilis. This is usually administered by injection. This may occur as a once-off dose, but more usually it is administered at weekly doses over two weeks. In some circumstances, people with syphilis may be requested to have daily injections over a time period of up to 21 days.

Like most other Western countries, Ireland has a reporting system in place for STIs. STIs including syphilis are legally notifiable. Syphilis has been notifiable in Ireland since the introduction of statutory notification of infectious diseases in 1947 (Cronin et al 2004). Aggregate information, including, age, gender and year of notification, is sent by STI

clinics to the Regional Department of Public Health, and from there to the National Disease Surveillance Centre<sup>3</sup>. The majority of reported information comes from STI clinics although a small minority of notifications come from private doctors and general practitioners. The foundations for this reporting activity are based on the Infectious Diseases Acts of 1981<sup>4</sup>.

#### **1.4 Sexual Health Services for Sexually Acquired Infections**

Ireland has a network of public sexual health clinics for the testing and treatment of STIs, which is broadly similar to the services provided in the United Kingdom. Referral from a general practitioner or other health professional is not required. All tests and medications are free of charge irrespective of health insurance or medical card status. The infectious diseases regulations attach additional confidentiality clauses to protect the data of people attending clinics. The files of those attending the clinics are stored in a separate location to the main hospital charts. The Department of Genitourinary Medicine and Infectious Diseases at St. James's hospital, which was the main research site for this research project (see Chapter 4, Methodology), is the largest centre for the provision of STI care in Ireland. It has over 25,000 patient attendances per year (Hopkins et al 2004). Patients attend the clinic through a walk in emergency service, general practitioner referral, self-referral and linked STI clinic referrals. The second research site chosen was the gay men's health project (GMHP), which is the only community based STI service in Ireland for MSM. Set up in 1992, it has more than 3,500 attendances per year (GMHP 2002). Approximately 90% of syphilis cases in the eastern region of Ireland (including Dublin) and approximately 75% of all cases in the Republic of Ireland are diagnosed and treated in these two settings (Hopkins et al 2004:317).

#### **1.5 A 'Syphilis Outbreak' Occurs**

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<sup>3</sup> The National Disease Surveillance Centre (NDSC) has changed its name to the Health Protection Surveillance Centre as part of a move into the new Health Service Executive. The HSE was established on January 1st 2005 with operational responsibility for the running of the health services in Ireland.

<sup>4</sup> An amendment to this act was made in 2003 and took effect in January 2004. The amendment introduced a requirement for laboratory directors, in addition to clinicians to notify certain infections including syphilis to the Department of Public Health. The amendment also introduced a case definition for syphilis that corresponds with standardised EU case definitions for syphilis.

Syphilis was, until recently, considered by many to be a thing of the past, associated with a bygone era of dirt and pollution. Epidemiological evidence, based on rates of newly diagnosed infection to a large extent supported such a view. Low recorded levels of syphilis in the United States of America (USA) resulted in the Centres for Disease Control and Prevention developing a plan for the elimination of syphilis. Levels recorded were considered to be so low that a debate was conducted on whether antenatal testing for syphilis, a routine practice internationally, should be carried out any longer. The costs of such an intervention in light of the low incidence of disease were becoming increasingly scrutinised.

In Ireland, low rates of syphilis were reported nationally throughout the nineties. The lowest incidence in ten years was reported in 1999 (six cases 0.2/ 100,000) (Cronin et al 2004). The following year (2000) a substantial increase in the numbers of cases of syphilis were reported in the Greater Dublin Area and an outbreak was declared. Between January 2000 and December 2003, 887 cases of syphilis were notified nationally. Of these, 61.2% were infectious syphilis cases. The outbreak peaked in July 2001 (Cronin et al 2004). It coincided with similar outbreaks that were reported in most other Western European cities including Manchester, London, Brighton, Paris and Antwerp. These outbreaks were primarily amongst MSM, including a significant percentage of HIV positive men, and the age group under 20 years did not appear to be affected. In Ireland the outbreak, like the others, was confined to specific urban locations, with Dublin seeing one of the largest reported outbreaks.

### **1.6 The Response to the Outbreak and Development of my Research Interest**

My interest in this area developed while I was the designated health advisor (Clinical Nurse Specialist) during the above syphilis outbreak occurring primarily among MSM in the Greater Dublin Area. A key component of my role was partner notification, which is standard practice in genitourinary medicine clinics internationally, as well as in Ireland.

In response to the outbreak in the Greater Dublin Area, an 'out-break control committee' was set up. The multidisciplinary team consisted of representatives from the



genitourinary medicine and infectious disease services of St James's and the Mater Hospitals Dublin, The National Disease Surveillance Centre, The Department of Public Health, The GMHP, the voluntary gay community centre and communications and administrative staff from the health board. Interventions introduced by the committee included a targeted information campaign involving community education sessions, increased service provision at clinics, and the relatively novel approach of onsite testing. The latter involved offering blood tests for syphilis at the venues (clubs, bars and saunas) where MSM meet their sexual partners (Hopkins et al 2002b).

Increased partner notification services to a level higher than that previously carried out in the Dublin clinics was a core part of this strategy (Hopkins et al 2002b). More 'intensive' partner notification involved more time, as well as a greater frequency of consultations with each index case. Memory recall was assisted through taking sexual histories in reverse chronological order. In order to assist with recall, index cases were asked about the geographical point of contact of sexual partners<sup>5</sup>. People who were symptomatic for syphilis, or for whom a diagnosis was suspected were informed of the process of contact tracing even before their result. This was to allow some time to consider all possible contacts. Similarly, those who were told over the phone that they had syphilis<sup>6</sup> were informed about the process of contact tracing, to allow them time between the phone call and their appointment to recall and obtain details of all possible contacts. Partner notification outcomes were reviewed at each follow up appointment in the clinic, and, on occasion, follow up phone calls were also conducted.

The vast majority of people with syphilis had mobile phones, so frequently people would scroll through their list of phone numbers and give details of previous contacts for provider referral. As the designated health advisor I also carried a mobile phone. This allowed those wishing to attend clinic to have rapid contact with the services and allowed for 'fast track' appointments to be made. The phone was also used for contact tracing as

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<sup>5</sup> This approach later informed the intervention of offering syphilis testing in commercial social venues.

<sup>6</sup> During the syphilis outbreak, people were informed that syphilis was a treatable bacterial infection and with their permission they would be contacted of a positive diagnosis over the phone if the result was released before their appointment. The rationale behind this was to allow for rapid access to treatment of those that were confirmed to have infectious syphilis. complexity of partner notification. Working with the syphilis outbreak, which primarily affected gay, bisexual and other

index patients stored my number in their phone and gave it to sexual contacts whom they had chance encounters with in the future. Social network referral was used in an informal way also. Men diagnosed with syphilis were encouraged to tell their friends about the outbreak and promote attendance for testing. Social network referral was used as a complementary approach to partner notification, in a similar vein to responses to syphilis outbreaks in the USA (Rothenberg et al 2000). Provider referral was employed with much greater frequency during the syphilis outbreak than was normal in routine clinical practice.

At the start of the syphilis outbreak in Dublin, I had worked for over two years as a health advisor in sexual health. My post registration training and education was in health promotion and public health, and as such, I recognised and considered important the public health function of partner notification. Nonetheless, I was aware of the MSM heightened that awareness. While there were a number of times when people would come to the clinic and hand me lists of people they wished to notify through an anonymous provider referral system, so too there were people who did not (or could not) inform any sexual partners. Testing in social venues added to the complexity of the issues, many of those who presented for testing and were subsequently diagnosed with syphilis had never previously accessed STI screening services. The difficulty was heightened for those who were in long-term relationships in which partners were not aware of their sexual contacts. Of interest also was my professional focus on MSM. This group have been singled out as 'difficult' to engage in partner notification in the research literature. Despite this, the reasons for the difficulty are poorly understood. A syphilis outbreak provided a unique opportunity to explore the acceptability of partner notification for an infection that is shrouded in much myths and stereotypes.

Although partner notification is one of the oldest strategies in the control of STIs internationally, a lack of research exists in relation to the acceptability of partner notification from a lay, non-professional perspective. The main body of literature on the subject comes from biomedical authors, who overwhelmingly focus on the subject of effectiveness. While effectiveness is important, a more fundamental question, impacting

on effectiveness, is whether the practice of contact tracing is acceptable to those whom it targets? This research study seeks to explore the perspective of non-professionals on the practice of partner notification.

### **1.7 Nursing component of the work**

Whilst partner notification is not a core nursing activity, nurses in Ireland, working as health advisors, are the sole group that carry out this activity. In the United Kingdom (UK) over half of all health advisors have nursing qualifications. This study is also of relevance to nursing because health promotion and the expression of sexuality in relation to health and healthcare are core nursing issues, included in all major nursing theories (Johnson, 1980, Roper, Logan and Tierney 1980, Roy and Andrews 1999) and explicated in the majority of nursing care plan templates.

### **1.8 Sexuality and Health Promotion: The Irish Context**

The particular social and historical context in which sexuality is constructed in a society is also relevant to an understanding of how sexual health responses, such as partner notification, are perceived. Sex is often regarded as normal, natural, healthy, good, clean, wholesome and beautiful (Evans 2001:106). However, for various reasons sex is not always seen as such; it is instead seen as a taboo. The historical influence of Catholic teaching on matters relating to sex in Ireland is said to have resulted in a legacy of ignorance and confusion (Inglis 1998). Inglis (1998) argues that many Irish adults have grown up deprived of basic education regarding sexuality, sex and relationships. Referring to his own education he states: I ...went to a good Catholic school, where I was taught all I supposedly needed to know about sex, sexuality and personal relationships- nothing (Inglis, 1998:2). It was as recently as 1979 that contraception was legalised in Ireland, and it was not until the early 1990s that condoms became widely available in various locations (Collins 2001). Almost without exception governments throughout the world have been slow to react to the HIV and Acquired Immune Deficiency Syndrome (AIDS) epidemic (Smyth 1998). Ireland was no exception. At the height of global concern about an epidemic, while campaigns were advocating safer sex, the Irish Family Planning

Association was fined IR £400 for selling condoms in Dublin's Virgin Mega store (Collins 2001).

If conservatism by government and church caused difficulties for a heterosexual population, this was even greater for those groups whose sexual orientation deviated from, what was considered by some, to be the norm. It is just over a decade ago (1993) since sex between consenting males in Ireland became legal with the introduction of the Criminal Law Act Sexual Offences (Government of Ireland 1993). Homosexuality has been socially constructed as pathological throughout most of the 19<sup>th</sup> century (Foucault 1990). Homosexual self-labelling therefore involves ascribing to one's self a negative trait, which is culturally devalued (Goffman 1963). Twelve percent, in a recent all-Ireland gay men's study, said that they wished that they were not attracted to men (Carroll et al 2002). In addition, the issue of rural and urban habitation of MSM is important, with those from a rural location perhaps experiencing more difficulty in accessing services (Galvin 2002). It is probably not surprising given the hostility to homosexuality that still exists in Irish society that much of gay and lesbian experience remains hidden (Tovey and Share 2000). Homosexuality is a forgotten area in school sexual health education. Research carried out in Cork to explore sex education among 800 young people found that homosexuality was the least addressed topic in sex education (Alliance 1997). A more recent study by Norman, Galvin and Mc Namara (2006, found that a majority of school teachers were aware of instances of homophobic verbal bullying. A significant number were also aware of homophobic physical bullying.

It is difficult to discuss sexual health promotion without making reference to the legacy of early strategies to curb the spread to the disease that initially became known as the gay plague. Such educational approaches used throughout the early 1980s re-enforced discrimination already in place. They were based on coercion and blame, rather than support and empowerment

Health promotion from a biomedical perspective was potentially deemed as simple – provide the uneducated with information and they will change behaviour. What rational

person would, after all, want to get a deadly disease? Health promotion from a lay perspective was not quite so simple; negotiating skills, self-esteem, perception of risk; power dynamics in relationships, financial and other structural factors are only some of the factors that affect the attainment of sexual health. In an Irish context, however, the government solution to HIV/AIDS was different to its international neighbours. As previously mentioned, anal sex was not decriminalised until 1993 so the government did not encourage safer sex between men who have sex with men. To do so may have been perceived as condoning criminal behaviour (Butler and Woods 1992). The Irish Government first funded a general AIDS information leaflet in 1985, three years after the first Irish case of HIV was diagnosed. The most significant response to the potential epidemic in an Irish context was from a small group of gay activists based in Dublin. Voluntary groups subsequently produced over 300,000 pieces of literature without any support from governmental bodies (Quinlan 1991). One of the recommendations in the early leaflets warned against sexual intercourse with foreigners. Smyth (1998) points out that Ireland's isolated location on the western edge of Europe did not, as might have been hoped, offer protection from disease. There are over 400 MSM living with diagnosed HIV in the Republic of Ireland (Carroll et al 2002). The background of HIV has relevance to an outbreak of syphilis in Dublin; although different, it mirrors some of the issues for professionals planning to control it and the individuals infected, affected or striving to avoid it.

### **1.9 Structure of the thesis**

This thesis is structured into seven chapters. In the chapter that follows, the literature on partner notification will be described. Importantly, the lack of the lay perspective on this practice will be explored. The extant literature from professional and non-professional perspectives will be outlined. In chapter 3, I describe the historical development of sexual health services through three contrasting theoretical lenses: namely, a functionalist lens, a post-structuralist lens and a critical theory lens. Chapter 4 describes the methodology used for the study. Chapters 5 and 6 describe the main findings of the study. Chapter 5 is about lay expression of sexual contacts. In this chapter the lived reality of sex and health for MSM will be described. Chapter 6 describes the lay perspective on the process of

partner notification. Chapter 7 is the final discussion chapter where the practice of partner notification is considered in light of the study findings and the theoretical approaches to understanding lay perspectives that were outlined in Chapter 3.

## **CHAPTER 2**

### **PARTNER NOTIFICATION: A REVIEW OF THE LITERATURE**

#### **2.1 Introduction**

It has been suggested that partner notification is the cornerstone in the prevention and control of STIs (Oxman 1994, Cowan et al 1996, Fenton 1998, Mathews et al 2002). As a practice, it stretches back over six decades and is employed in all corners of the globe. The objective of this literature review is to explore the issues pertaining to the effectiveness and acceptability of partner notification. When considering the term 'effectiveness', I will address the issue of whether or not the practice of partner notification is said to achieve its aims under various outcome measures discussed in the available research. The review will show that whilst there is a wealth of literature supporting the belief that partner notification is effective, it is also recognised that there are limitations to the evidence supporting this view and, increasingly, there have been calls to justify the process. This is particularly true in a climate of increased priority being given to 'cost effectiveness' and 'evidence based practice' in health services. The acceptability of partner notification is a different concept. Here I will be interrogating the literature for answers as to whether or not people with experience or knowledge of the practice of partner notification consider it satisfactory. By contrast to the wealth of literature on effectiveness, the review will show that there is a dearth of studies on the acceptability of partner notification. Given the paucity of such studies, the available studies will be described in some depth and some of the key emerging lay concerns identified. In addition, the increasing salience of the issue of acceptability in health policy will be noted.

I confined my search to literature published in the English language in the sciences and social sciences. My search strategy included use of the following international library databases CINAHL (1982-2007) Social Science Citation Index (1983-2007), Cochrane Database of systematic reviews, Pubmed and Synergy (Blackwell publishing 1996-2007).

I searched the above databases using various terms for sexually acquired infections such as sexually transmitted infection or sexually transmitted disease. In addition, I consulted with other sources such as, conference proceedings, personal contact with researchers in the field, hand searching of specialist journals and scanning of reference lists from published studies. I also did searches with specific names for infections, including syphilis, combined with the terms partner notification or contact tracing. I also did combined searches such as partner notification with the terms effectiveness and acceptability. In addition, in combination with the previous terms, I also did searches for MSM using terms such as homosexual men.

The literature review will consider the effectiveness and acceptability of partner notification from both health professional and lay perspectives in so far as the available literature allows for a discussion of both. Health professional perspectives include all health professionals involved in the process, usually doctors, nurses and health advisors. Lay knowledge has been defined as “the knowledge that lay people have about illness, health, risk, disability and death” (Williams and Popay 1997:270). The structure this literature review will take will be initially to explore the issue of partner notification from the perspective of the clinical professionals involved in the process. Here the majority of studies focus on effectiveness. However the limited research on the acceptability of partner notification from a professional perspective will also be considered. Lay perspectives of partner notification will then be discussed.

## **2.2 Professional Perspectives on Partner Notification- Effectiveness**

Partner notification is central to the status and identity of genitourinary medicine (Fitzgerald 1997), and has been a vital element in the control of STIs (Thin 1984). Cowan et al (1996), writing from a professional perspective, states that partner notification results in benefits at an individual and a population level. Early treatment is considered necessary



to reduce the duration of infection, and also the likelihood of long-term morbidity associated with untreated infection. This point is relevant to syphilis, as it is considered to be a treatable infection, and also because many people with the infection may be entirely asymptomatic.

Despite these affirmations of the importance of partner notification, the effectiveness of partner notification is under-researched (Oxman et al 1994, Radcliffe and Clarke 1998, van Duynhoven et al 1998). There has been an uncritical almost universal acceptance of the process of partner notification by professionals. Systematic reviews have concluded that very few methodologically sound studies on partner notification exist (Oxman 1994, Mathews et al 2002, Hogben 2007), and much of the research in this area is small scale and retrospective. Retrospective data collection in many cases is affected by poor documentation, which, results in an inability to verify contacts' attendance (Bell et al 1998). Despite good record-keeping being recommended by the UK guidelines for chlamydia infection (Fitzgerald et al 1998), Clarke and Preston (2001) also report difficulties with documentation in their multi-centre audit of nine genitourinary medicine (GUM) clinics in the Yorkshire region. Nonetheless, it is worthwhile taking a closer look at some of the key studies, which have tried to measure the effectiveness of partner notification along a number of outcome measures. The frequency with which partner notification practice is performed has been studied as a measurable outcome of effectiveness. Dale et al (2001) found in their research that 80% of index patients had details of partners recorded in the medical notes and in 61% of cases the partners were epidemiologically<sup>7</sup> treated for Chlamydia. Clarke and Preston (2001) also found high levels of partner notification activity. In a multi-district audit against national guidelines (UK) for the management of uncomplicated *Chlamydia trachomatis* infection, they found that overall 91% of index patients had partner notification discussed with them, at the time of their diagnosis. Fenton et al (1997) in their research of 59 GUM clinics in England found that although partner notification was discussed with most (75%) of index patients newly

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<sup>7</sup> Epidemiological treatment – in this context refers to the practice where a partner/contact also receives treatment for infection.

diagnosed HIV positive patients, there was no evidence of documented outcome of partner notification in 58% of patients seen during the one year study period.

Van Duyhoven et al (1998) looked at referral outcomes in gonorrhoea and chlamydia infection. Their number of index patient participants was 250. The outcome of partner notification for the 502 eligible partners was 20.5% verified attendance, 20% believed attendance, and 59% with unknown follow up. In his audit of partner notification for bacterial STIs, Elliott (1999) reported much higher rates of contacts attending. The National Audit Development Project in the UK (reported by Fitzgerald 1997) contacted every clinic in the UK 79% (155 clinics) replied..It was found that index patients report on average 1.5 contacts each but overall only 0.5 contacts attend the clinic for examination.

Many researchers have carried out comparisons between provider and patient referral. Oxman et al (1994) in their extensive literature review on partner notification concluded that there is moderately strong evidence that provider referral is more effective than patient referral for HIV. They also state that there is weak evidence that provider or conditional referral is more effective than patient referral for syphilis. Similar findings were put forward by Mathews et al (2002) in a later systematic review of the literature. Patient referral however was found by Elliot (1999) to be the method most usually employed in clinical practice. He found that 90.5 % of contacts attended as a result of patient referral, with the remaining 8 (9.5%) attending by provider referral. It was noted that patient referral was the preferred method for regular partners with provider referral being the method of choice for casual or for ex-regular partners. Similarly, Landis et al (1992) reported that while HIV positive person favoured provider referral, most participants in their study chose to inform at least their current partner themselves.

Partner notification throughout the literature is found to be more effective with women than with men. Clarke (2001) points to research on partner notification carried out in her clinic. She found that women were more likely to cooperate with contact tracing. The research was in relation to the effectiveness of partner notification for gonorrhoea and found that only one of 28 index female patients declared her contact untraceable contrasting with 39

out of 73 male index patients. Framed in a context of reproductive health, partner notification was found to be more acceptable to clients than in sexual health settings (Gichangi et al 2000). This evidence is also linked to a broader body of evidence on gender and health, which suggests that men are less likely to access primary health care and are more likely to adopt high risk health behaviours (Green and Pope 1999, Robertson 2003, Lohan 2007). Men's knowledge with regard to sexual health is often poor (Banks 2001). Banks refers to a survey by the *Doctor Patient Partnership* with the Men's Health Forum, which found that 18% of men thought that a GUM clinic dealt with dental health problems and over 50% had no idea what a genitourinary medicine clinic was. Banks (2001) also cites research by Biddulph et al (2001), of young men's health seeking behaviour for sexual health services. They concluded that the average young man is unlikely to access help from anyone if he perceives he has a problem. As I will describe further in Chapter 6, this has much relevance to health seeking behaviour of MSM.

Men who have sex with men are identified throughout the literature as a particularly difficult group in terms of contact tracing effectiveness (Munday et al 1983, Bell et al 1998, Van Duynhoven et al 1998, Rogstad et al 1999, Singh et al 2006, Arumainavagam et al 2007). Bell et al (1998) point out that a greater proportion of the cohort that were without data in their research were from homosexual men reporting multiple partners who could not be discussed individually. Van Duynhoven et al (1998) also state that homosexual men reported higher numbers of sexual partners. The failure by MSM to refer partners may be attributed, they say, to the high frequency of anonymous sexual contacts (73% of homosexual relationships were "one-night stands" compared with 42% of the heterosexual relationships). Munday et al (1983:314) in their research on partner notification of hepatitis B positive people concluded that named contacts in stable relationships were more easily traced than "young homosexuals with frequent anonymous contacts". Rogstad et al (1999) in their retrospective analysis of partner notification for 278 cases of gonorrhoea found that the proportion of contacts attending for heterosexuals (56%) was only just below the UK National Guidelines of 60% recommended for 1996, but was much less for homosexuals (38%). The authors concluded that success in partner notification among homosexuals

“remained disappointingly low” (Rogstad et al 1999:249). Difference in success between heterosexual and homosexual groups, however was not reported by the European Partner Notification Study Group (2001). They stated that the outcomes of HIV partner notification for current partners were similar whether the index patient acquired infection by homosexual or heterosexual contact; differences were noted, however, among current and ex-partners. Forms on PN outcome were received for 166/200 (83%) reported current partners, but only 124/508 (24%) ex-partners. Similarly, Samoff et al (2007) conducted a study to compare contact tracing outcomes among male syphilis patients reporting sex with men or women only. The researchers found that there was no significant difference in the mean number of contacts of the MSM and men who have sex with women only (MSWO) diagnosed with syphilis. They found that interviews with MSM resulted in higher mean numbers of contacts named and located per index patient than interviews with MSWO. They also found that the mean number of unlocatable sex partners per case was slightly higher for MSM than MSWO.

Ethnicity has been found also to be a factor in effective partner notification. Rogstad et al (1998) found that Afro-Caribbean women were less likely to give contact information than other ethnic groups and both Afro-Caribbean men and women had a smaller proportion of contacts attending. Casual contacts are less likely to be notified than regular partners. Bell et al (1998) point out that where relationship status was recorded ‘casual’ partners were less likely to attend for screening than those classified as ‘regular’. This was also found by the European Partner Notification Study Group who collected data on outcomes of partner notification for 365 index patients newly diagnosed with HIV in six European countries from 1995 to 1996. Forms on partner notification outcome were received from 83% of reported current partners, whereas only 24% of forms were received for ex-partners. Multiple, untraceable contacts have been found for syphilis also. Andrus et al (1990) found in their research that patients who had syphilis had a larger number of sexual encounters with persons who subsequently could not be identified as compared with patients who had gonorrhoea. An interesting example where partner notification proved possible despite multiple contacts, is the case of an American sex worker nicknamed “syphilis Mary.” A diary that she kept assisted in tracing 168 out of 310 sexual contacts, all of whom were

long distance truck drivers spread throughout the United States, Canada and Mexico (Guthe and Wilcox 1971).

Timeframe from diagnosis to sexual contact is raised as an important issue. Cowan et al (1996) argue that partner notification is a relatively ineffective method when there is likely to be a considerable delay before contacts can be traced. Van Duynhoven et al (1998) also found that for steady partners, contact findings decreased if the last sexual contact was more than 30 days previously.

Cost-benefit analysis is also relevant to effectiveness. A study carried out in Harare suggested that partner notification was labour intensive and costly (Grosskurth et al 1993), in the sample only twenty contacts were located in three months by six members of staff. It is worth noting, however, that an African setting is understandably different to a European or North American one. Several studies in other settings have shown partner notification for HIV to be cost-effective (Varghese et al 1999, Giescke et al 1991, Pattman & Gould 1993). Macke et al (2000) point out that STI services that have a higher number of HIV and non primary and secondary syphilis probably dedicate more resources to contact tracing. In their research comparing a provincial and metropolitan clinic, Bell et al (1998) found that human resources and other facilities had an impact on the outcome of the numbers of people contact traced. They compared two clinics, one in Sheffield and one in London. In the Sheffield clinic, there were five health advisors available for two hundred and forty nine cases of gonorrhoea with access to three interviewing rooms. The London clinic, however, had seven health advisors providing services for six hundred and forty eight cases of gonorrhoea with access to only two interview rooms. While the research points to other variables, the outcome of partner notification in both clinics varied, with twenty percent of contacts in Sheffield confirmed to have been screened as opposed to five percent in the London clinic sample.

New strategies to address the limitations of traditional partner notification practice have been studied by a number of researchers. These include social networks (Rothenberg 2002), use of the internet and new technologies (Klausner et al 2000, Tomnay et al 2005), and expedited partner therapy (Schillinger et al 2003, Packel et al 2006). The latter is the

practice of treating the sex partner of individuals with sexually acquired infections without an intervening medical examination or professional prevention counselling. (Centers for Disease Control and Prevention 2006:4). Trelle et al (2007) report a systematic review of strategies to improve partner notification. Discussing this review, Mathews and Coetzee (2007) point to a crucially important point, namely that none of the novel interventions discussed tackle the fundamental barrier to patient referral strategies: the difficulty that people have telling their partners that they have a STI.

### **2.3 Professional perspectives on the acceptability of partner notification**

Acceptability from a professional perspective is an area worthy of some consideration. The emergence of HIV has renewed the debate about the ethics, acceptability and effectiveness of partner notification both for the individual involved, and for society in general (Cowan et al 1996). Partner notification has been advocated for the control of HIV (Potterat et al 1989, Cates et al 1990). An important study on professional perspectives of partner notification was carried out by Fenton et al (1997). They administered questionnaires to senior consultants in English genitourinary medicine clinics (n=59). They asked if HIV partner notification had become an acceptable part of their clinic's practice. Seventy three percent of respondents cited lack of acceptability of HIV partner notification to patients. This was, the authors said, by far the largest reported barrier to HIV partner notification. Other reasons cited include, unacceptability to health advisors and doctors, time constraints, or ignorance of Department of Health guidelines<sup>8</sup>. Allen and Hogg (1993) also point out that acceptability of partner notification for HIV appears to be less for health advisors than any of the other staff groups that were interviewed<sup>9</sup>. This is of interest as health advisors are the largest group to have partner notification in their job description. A possible explanation for this finding that has been offered by the authors, is the inherent conflict in the health advisor role between counselling index patients and partner notification responsibilities – this professional perspective highlights the importance of looking at the lay perspective.

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<sup>8</sup> It is worth noting that this was almost 5 years after the Department of Health (UK) first issued guidelines for partner notification for HIV (The Irish guidelines were published almost 10 years later).

<sup>9</sup> The other groups that were interviewed were: medical staff, nursing staff, administrative, clerical and reception staff.

## **2.4 Lay perspectives (of index patients and contacts) on the acceptability of partner notification**

Systematic reviews conducted on partner notification have highlighted the notable paucity of research on the acceptability of partner notification from a lay perspective (Oxman et al 1994, Mathews et al 2002). From my own searches I can confirm that a mere handful of studies internationally have explicitly looked at lay perspectives on partner notification in the context of any STI. The studies that have been carried out have largely been centered on partner notification in the context of HIV. This research arose in the early days of HIV. The debate raged over issues of confidentiality, stigma, and the potential for partner notification to be a barrier to testing (Keenlyside et al 1992). Balanced against this in this debate, however, was the issue of public health and the duty to warn people of exposure to infection.

Jones et al (1990) conducted a study, in South Carolina, which aimed to address partner notification from the point of view of contacts notified by a ‘provider referral’ method. The contacts had been informed by the Department of Public Health that they had been exposed to HIV. The research was carried out on people who had presented at clinic (n=132). The researchers asked whether they felt that the Department of Public Health had done the right thing notifying them; 77% answered in the affirmative, 7% indicated that it was harmful and 16% said they were not sure. Those who said it was harmful offered reasons. Depression was cited most commonly, with one individual expressing fear about confidentiality. A further question asked whether or not the department should continue its practice of partner notification for HIV; to which they received a response of 97% in favour. It is interesting to note that some of those who said it was harmful still were in favour of this practice continuing. Jones et al (1990) point out that acceptability has been found if partner notification is conducted in a professional and highly skilled manner. The interpretation of these terms “professional” and “highly skilled” is however subjective. With regard to this study it is also worthy to consider that acceptability is measured from the perspective of people who have attended the service. It does not

measure acceptability of those people who were informed but who never attended. Perhaps they would have a very different story to tell.

A qualitative study was conducted by Gorbach et al (2000) to explore why only some partners are notified in partner notification programmes. The goal of the study was to describe patterns of partner notification reported by persons with STD infection. The typical notification pattern was to notify a main partner and not others. Least likely to be informed were the oral sex and anonymous contacts of MSM.

One of the few studies on lay perspectives on partner notification in relation to STIs outside of HIV was carried out in Sweden (Tyden and Ramstedt 2000). It looks at perceptions of partner notification from the viewpoint of index patients diagnosed with Chlamydia (n=192). Sweden's approach to partner notification had been unique: in the past, legislation allows for police enforcement if a notified contact failed to attend a clinic. One of the components of the study was to seek views on the legislation. It is interesting to note that 18% of people admitted in the questionnaire that they had avoided giving the names of their partners, although a third of these planned to tell the contact themselves. Ninety percent of those interviewed said they supported the legal enforcement of partner notification although less than half of those accepted a measure as harsh as police enforcement. In fact, police enforcement was subsequently removed from the legislation regarding contact tracing, in part as a response to this research.

A quantitative study by Apoola et al (2006) explored the patient preferences for partner notification method used. Patient referral was preferred by 65.8% of the participants compared to provider referral. Notifying by letter was preferred as a means of provider referral. It was considered more acceptable than phoning, text message or email. The content of the message was also important; the preference by the majority was to be told to contact the clinic and saying 'you may have a sexually transmitted infection.' A further quantitative study by Tomnay et al (2004) aimed to explore the estimated proportion of contactable partners but also explored clients' preferred approach for partner notification.



The most preferred approach was a website address and the least preferred was provider referral.

A different quantitative study by Golden et al (2003) explored support among persons infected with HIV for routine health department contact for HIV partner notification. Ninety-five people completed an anonymous self completed questionnaire. Seventy-five (79%) indicated they would be somewhat or very likely to provide information to a doctor, case worker or health department employee for the purposes of partner notification and 19 (20%) indicated they wanted help in notifying a recent sex partner. Carballo-Dieguez et al (2002) conducted an anonymous questionnaire study to assess the willingness of individuals seeking HIV testing to give counsellors contact information about partners if infected and to assess their willingness to contact partners on their own. Ninety percent of heterosexual individuals and 80% of MSM expressed willingness to provide their partners' contact information. Respondents preferred to be notified by a sex partner than a health care worker. In relation to those traced, patient-referred clients reported being more comfortable with the referral than provider-referred clients.

A more in-depth qualitative study was conducted by Anthony Pryce, a sexual health nurse researcher. Pryce (2000) conducted a study exploring the narratives of patients attending two metropolitan GUM clinics. He was concerned with the stories told in semi-structured individual interviews and included the experience of men attending clinics. While it was not a study exclusively on partner notification, the study included experiences and perceptions of the practice. The clients describe their sexual biographies and the experience of telling and re-telling their personal activity and history. Following Foucault (1973) and Armstrong (1983), Pryce argues that the body is subjected to the clinical gaze – the clinic itself a site of surveillance 'par excellence'. A significant part of this surveillance is the incitement to confess which he argues is particularly evident in the lay- professional interactions within the clinic. Included in this, is the role of the health advisor which may include that of counsellor who uses clever techniques from psychology and formal counselling to open up the private world of the individual, whereby the client 'speaks the sin by naming it' (Pryce 2000:105).

## **2.5 Confidentiality, Partners' Reactions and Stigma**

Looking across these studies, fear in relation to confidentiality, the impact on relationships and the stigma associated with sexualities which may be constructed as 'deviant' or stigma associated with sexually transmitted diseases stand out as emerging themes. The World Health Organisation (1986) state that confidentiality is central to humane health care and maximum efforts should be made to protect privacy. Confidentiality is an important issue and is laid down in the work ethics of health care professionals such as nurses, doctors and social workers. The Venereal Diseases Regulations UK (Department of Health and Social Security 1974) and the Infectious Disease Regulations in Ireland (Department of Health 1981) highlight the sensitive nature of the work that goes on in STI clinics and provides some assurance that where reasonable, confidentiality will be provided. It is important to note however, there are times when confidentiality will be breached, for the good of public health. It might be argued that such occurrences are rare; conversely the potential may be enough to act as a barrier for people to attend. A study in New Jersey (Chervenak and Weiss, 1989) found that 68% of women with HIV were willing to give names of their sexual partners if they were assured that their confidentiality would be maintained, whereas only 20% would agree to partner notification if their names were released to their sexual contacts.

The issue of the impact on relationships is hinted at in the research literature but very under-researched. Temmerman et al (1995) state that women who inform their spouses of having a STI often face break-up of marriages. The Department of Health (Ireland) in their guidelines for confidentiality in relation to HIV acknowledge that a person living with HIV may fear rejection by their partner if they disclose their HIV status (DoH & C 2001). Thompson et al (1997) in their research in Victoria, Australia found that reluctance to tell current or past partners was because of a fear of blame. They found too, that doctors reported reluctance to raise the issue of sexual contacts because of concern for the index patient's relationship. While lack of security in relationships or blame for passing on

infection is cited as a reason for unacceptability of partner notification another important issue is violence or potential violence towards partners. The Society of Health Advisors in Sexually Transmitted Diseases (UK) cites in its guidelines that the threat of violence is an indication not to pursue partner notification activities (SHASTD 1995) reference added. Concerns about violence are an important consideration in relation to contact tracing (Temmerman et al 1995, Gichangi et al 2000). It was found in one study that three out of 120 MSM experienced violence as a result of telling others about their HIV status (Brown et al 1990). Work with pregnant women in Nairobi found over 6% (12/184) of the women had not informed their partners because of fear of violence or being blamed for the illness (Gichangi et al 2000).

Much of the literature on STIs makes reference to stigma (Green 1995, Taylor 2001, O Farrell 2002, Liu et al 2002, Lee and Craft 2002, Lichtenstein 2003). For a man who has sex with men, the feeling of being stigmatised may be heightened by fear of publicity of a sexual orientation that may be considered to be deviant. The issue of stigma relating to sexual health has been highlighted by the UK sexual health strategy (DOH England 2001), which sets a reduction in the stigma associated with HIV and STIs as one of its five aims.<sup>10</sup> Various interpretations of stigma in the broader social science literature exist. The work of Erving Goffman on the processes of managing stigma is often cited in the sexual health literature. Describing stigma he refers to ‘the less desirable person, considered, bad, dangerous or weak’ reduced from a ‘normal’ person to a ‘tainted discounted one’ (Goffman, 1963:12). Central to stigma is the issue of deviance or of being marked out as unfavourably different (Alonzo and Reynolds 1995). Concealment is a strategy employed to avoid stigma. Goffman (1963) describes this as “passing”. The rewards of appearing normal are so great that most people will pretend to be normal. An individual may choose to deny his sexual orientation to many (or perhaps everyone). He may also choose not to disclose to anyone if he is diagnosed, or even exposed to syphilis. Referring to HIV (but with relevance to syphilis) Alonzo and Reynolds (1995) state that the act of concealing diagnosis from others has a number of effects; it results in a lack of the social supports that

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<sup>10</sup> The other four aims of the strategy are to reduce transmission of HIV and STIs, reduce the prevalence of undiagnosed HIV and STIs, reduce unintended pregnancies and improve health and social care for people living with HIV.

are normally in place, and it may result, they say, in hostility from sexual contacts, if they are subsequently diagnosed with infection or disease. The individual concealing HIV may avoid activities that might signal diagnosis such as attending a clinic. In addition, Alonzo and Reynolds (1995) state that an individual may participate in activities that he participated in prior to diagnosis such as having unprotected sex with unknowing partners.

Disclosure is another possible action. It can often result in negative reactions for the individual affected. The negative effects of stigma were a key focus of the work of Jones et al (1984). They suggest that emotional reactions to those stigmatised include humiliation, depression, anger, fear, and anxiety. Such problems may have further consequences; Evans (2001) points out that those experiencing low self-esteem resulting from the process of stigmatisation are particularly at risk for unprotected sex, often associated with drug and alcohol use. Offering explanations for this, he states that the stigmatised have insufficient self-regard; they fear rejection and crave any form of affection.

The influence of stigma has potentially huge relevance to health seeking behaviour at a sexual health clinic (Malta et al 2007, Mullholland and Van Wersch 2007). Stigma (real or perceived) also can influence decisions on those persons at risk of STIs who are contemplating attending sexual health services. While it does not affect everyone equally and it changes over time, what becomes clear is that stigma can have significant effect on the individual.

## **2.6 Conclusion**

The role of this chapter has been to explore the empirical evidence on the effectiveness and the acceptability of partner notification. It has been noted that the issue of the effectiveness of partner notification has reigned dominant over acceptability, particularly in the health professional literature. What emerged from the review is that the effectiveness of partner notification is unclear despite the centrality of the practice of partner notification to sexual health service provision. There is a lack of any sound evidence to support the assumed overall effectiveness of the practice. Methodological weaknesses in the available studies have been highlighted as being a considerable barrier

to the development of the evidence. Much of the research is retrospective and dependent on good partner notification documentation, which is not always available. Prospective studies are lacking.

However, bearing in mind this weakness, the available literature on effectiveness nonetheless allows for some consideration of the factors that influence its success or otherwise. Provider referral is regarded as being moderately more effective than patient referral, although the latter is usually the preferred referral system by users. Women are more likely to comply with partner notification and this is particularly true when it is framed in the context of reproductive health. Many researchers label MSM as a particularly 'difficult group' with regards to partner notification. It has also been suggested that those with casual relationships are less likely than those with regular (steady) relationships to be able to notify their sexual partners. This is perhaps linked to the issue of time frame, which has also been discussed in this review. Finally, the effectiveness of partner notification has been shown to be influenced by the level of resources invested in the service; the greater the resources in terms of staffing, the higher the yield.

In relation to the acceptability of partner notification, the main conclusion to note is the general paucity of research. The studies that exist are predominantly in relation to HIV and there have been no studies carried out specifically inquiring into the views of MSM in relation to partner notification. The majority of studies in the extant literature has been quantitative only, which, by their nature, have canvassed broad opinions rather than being in-depth studies inquiring into the lived experience of partner notification systems. Nonetheless, this small body of studies is of interest and use in informing my study. Of particular note is that, across these isolated studies, there appears to be broad lay support for partner notification, albeit in the context of HIV. In addition, I have noted some emergent themes – notably lay concerns in relation to the confidentiality of the service, fear in relation to partners' reactions (including violent reactions) to partner notification and the stigma of homosexuality and STIs.

Lay perspectives on health have in the past been deemed insignificant. Writing in 1985, Gillick states, “Lay knowledge is at best unreliable and at worst irrational” (Gillick 1985:700) (reference added). Contemporary health policy documents, however, highlight the principle of involving clients in the design and delivery of health services. Describing a vision for the health service, the Irish National Health Strategy proposes a health service that: “encourages you to have your say... listens to you... and ensures that your views are taken into account” (Department of Health and Children 2001:8). I would argue that it is no longer acceptable (or fruitful) to perform a practice in isolation from the people who are most affected by it. Research is needed to address the major gap in the literature in relation to the ‘cornerstone’ practice of sexual health – partner notification.

## **CHAPTER 3**

### **SEXUAL HEALTH AND PUBLIC HEALTH: THE ABSENCE OF THE LAY VOICE**

#### **3.1 Introduction**

As outlined in the previous chapter, there is a clear absence of the lay voice on matters of sexual health and in particular in relation to the core practice of partner notification. In order to understand the lack of the lay perspective in contemporary sexual health, I will first of all examine the broad historical development of public health and associated sexual health services in western developed countries. Sexual health and public health have been, and continue to be, mutually shaping health domains. They involve the health and well being of individuals, as well as populations. Social theories will then be used to provide a lens through which to consider the absence of lay perspectives in sexual health. The use of contrasting theoretical perspectives helps provide a framework or models of explanations for the absence of the lay voice. Turner (1995), among others, employs such an approach in order to view a complex situation from different angles. As Giddens (1989) points out, human behaviour is complicated and multidimensional. Theoretical variety, he suggests 'rescues us from dogma' (Giddens 1989:715). The chapter shall begin with an introduction to public health and sexual health. The history of public health will be discussed, the contemporary situation of public health including current tensions between the collective and the individual will be considered. The social theories of Parsons, Foucault and Habermas will be presented and their relevance to understanding of sexual health services explored.

#### **3.2 Public Health and Sexual health: A Critical Historical Perspective**

Public health is an umbrella term for a wide range of activities that involve various disciplines. Public health however, as it is presented in western developed countries has been led primarily by medical sciences, although this is increasingly being challenged. (Evans 2003:959). It will be argued that in the past, the lay perspective in public health had been considered to be important, but with the development of modern medicine in

western developed countries in the late eighteenth century, the voice of the lay perspective has, arguably, become silenced.

Public health has not always been medicalised. Blaxter (2004:11) suggests that there have been two ways of thinking about health and ill health throughout history. The first suggests that pathology occurs almost independent of the patient; the second suggests that the patient, with his or her personal individual life circumstances, is of primary importance. Prior to the development of modern scientific medicine, understandings about health and illness were divided broadly into personalistic and naturalistic systems (Forster and Anderson 1978 – cited by Morgan et al 1985:13). A personalistic system views punishment as being the reason for illness. The naturalistic systems approach to illness, on the other hand, is concerned with equilibrium of the basic body elements. Morgan et al (1985) point out that the three main naturalistic approaches are the humoral pathology of ancient Greece, the ayurvedic medicine (which comes from India), and Chinese medicine. The early Hebrew civilisation placed great emphasis on public health and sanitation. Between the 12<sup>th</sup> and 15<sup>th</sup> centuries BC the Greeks followed the preventative philosophy of the goddess Hygeia, whose legends focused on the importance of protecting the health of both mind and body. Hippocratic writings from the fifth century BC stressed the importance of the environmental forces in disease causation (Corneil et al 2001:viii).

Hyde et al (2004: 277-278), following Ashton and Seymour (1988), outline four phases in the historical development of public health. The first of these occurred in the late eighteenth and early nineteenth century where large numbers of people moved from rural areas to inhabit urban centres. In this first stage in public health's development, poverty and poor living conditions provided the impetus for the development of services. The second phase occurred in the latter half of the nineteenth century. It is associated with the development of the germ theory of disease causation and developments in clinical medicine. The history of the development of biomedicine reflects a shift in focus, from diseases occurring in natural environments, to diseases occurring and examinable, in the clinical setting of a hospital. This third phase in the development in public health has



been described as the 'therapeutic era' (Ashton and Seymour 1988, Hyde et al 2004). Public health during this time (1930s) became ancillary to hospital-based medicine. Jewson (1976) points out that, unlike previous times, where doctors were dependant on patients for patronage, during the therapeutic era patients were considered to be readily available and willing to be examined. The large numbers of patients in urban centres changed the power balance between patient and doctor. The patients would have to wait for the doctor, and not the other way around, as had previously been the case. The amount of time that doctors could spend with patients is likely to have also been reduced. The focus had shifted from a patient existing in a social world, where a holistic approach is taken; to a patient existing in the clinical environment of a hospital where the doctrine of specific aetiology was offered to explain illness. Diseases came to have much more specific labels than previously (Morgan et al 1985:13). The consultation in hospital medicine had an additional component, as well as symptoms; the signs of illness could be collated and compared with the signs of other patients by astute physicians (Armstrong 1995:393). The ritual of the clinical examination became an important role of the physician. Following Foucault, Armstrong (1983:73) says that the history of medicine from the end of the eighteenth century is a history of a reductionist gaze into the body of the patient. The mind and body were no longer considered to be closely associated. Increased attention was paid to the diagnostic process and much less to the patient's feelings, emotions and perceptions of the problem (Morgan et al 1985:14). The focus of public health at this time was on an individualistic approach to health education. The fourth and final stage in the historical development of public health was associated with a paradigm for 'New Public Health'. Emphasising (once more) environmental issues but combining this with individual responsibilities. Health promotion became part of public policy endorsed internationally through the first health promotion conference and the signing of the Alma Ata Declaration in 1978.

The control of sexually transmitted diseases can be considered as a public health issue and can be contextualised in the time frame in which it occurred. Efforts to control STIs (or venereal diseases, as they were once called) have been carried out since the Middle Ages (Oriol 1994:191). With the germ theory of disease, understanding about cause of

infection and means of control was transformed. The Contagious Diseases Acts of 1864, (amended in 1866 and 1869) had as its object, the identification of infected women and removal of them 'from circulation' until they were cured (Oriol 1994:193). The original Act applied initially to a few major ports and garrison towns in England and Ireland, although the number of these was increased in later amendments. Under the Acts, women could be stopped by police, asked to sign a register if they were prostitutes, and undergo compulsory medical examination. The medical examination alone, according to Oriol (1994:193), left a lot to be desired. Privacy was not considered, and in many cases, bystanders peered through the windows (Oriol 1994:193). The examination consisted of a naked eye examination of the genitalia for signs of pathology. Those diagnosed with disease were incarcerated in Lock hospitals (Stacey 1988:74). While the intervention for other contagious diseases was quarantine, it was not suggested that soldiers or sailors be confined to any specific locations for sexually transmitted diseases. Mort (1987 cited by Oriol 1994:193) says that the examination of service men was avoided because it would be difficult to do, and would "destroy the men's self respect". The Contagious Diseases Acts caused resistance, particularly by women's groups. The Acts were finally repealed three years later, despite objections from leading medical journals and the medical establishment. It is interesting to note also, that the acts had little effect on reducing the incidence of infections (Oriol 1994:194).

Partner notification became a central policy of STI control in the twentieth century. Despite this, Davidson (1996:195) points out that the history of this practice in Britain before the 1970's has largely been ignored. He offers lack of adequate archives, and reluctance to publicise the practice due to legal concerns as possible explanations. In a comprehensive article, Davidson (1996) describes a search of professional archives and obtains oral evidence from former practitioners in the field to address this deficit.

The first timeframe discussed by Davidson is 1918-1939. Despite the establishment of a free and voluntary system for STI diagnosis and treatment, partner notification during this interwar period was very restricted. Nurse almoners made domiciliary visits to persuade spouses of patients with infection to seek examinations and treatment. In the

wider community, partner notification efforts were *ad hoc* and largely depended on the efforts of patients themselves to inform partners. Davidson (1996) points out that earlier acts were abolished as they were deemed to be discriminatory, particularly by women's organisations. A reported increase in gonorrhoea infections in the 1930s resulted in nurse almoners taking on a greater, and more formal role in partner notification where the practice was seen as essential to any 'well run' clinical service.

During the period 1939-1947 there was a concern by government and military authorities with the location and treatment of contacts. The Defence of Realm Act was introduced in 1942, it allowed for 'special practitioners' to notify medical officers of all contacts named by patients confirmed to have a STI. Failure by contacts to attend for examination and treatment resulted in a fine and/ or imprisonment. Fierce public debate surrounded this Act as it was deemed to be specifically targeted at women.

The final timeframe discussed by Davidson (1996) was partner notification in the era of health boards from 1948-1971. During this period, concern about the legal status of partner notification inhibited the effective formation of policy. Lack of government initiatives resulted in a decline in partner notification in the 1940s. However by 1949, increasing concern with emerging resistant strains of gonorrhoea resulted in a call to intensify partner notification efforts. A tension nonetheless existed between collecting data and maintaining a code of confidentiality. It becomes apparent then, that partner notification history in the twentieth century is marked with periods of moral panic as much as with concern about the health implications of sexually acquired infections.

The epidemiology of sexually acquired infections is the study of diseases in populations. Strongly influenced by the biomedical clinical sciences model, it has adopted an approach to disease that is reductionist and based on the probability of risk. Such an approach has moved public health away from its original focus on the wider social economic and other structural factors that influence health. As such, it is a decontextualised approach to public health (Inhorn and Whittle 2001:553). It assumes

that control over health and illness is a matter of free choice, and as such, undermines the complexity of people's lives and ability to make decisions regarding their health.

Epidemiology is centrally concerned with risk (Inhorn and Whittle 2001:555). The work of Anthony Giddens (1991) and Ulrich Beck (1992) offers an understanding of the ubiquity of risk in modern societies. Essentially, they say, we are living in a neo-liberal state in which the individual is not protected by the state – rather the individual is increasingly expected to take measures to protect his/her own welfare. In addition, Beck (1992) argues that in traditional societies risks were personal and visible, whereas, in modern societies, risk can be concealed and is global. Environmental dangers are one such example; all people are potentially affected irrespective of their social class, ethnicity and other life circumstances. Turner (1995: 219) argues that the process of modernisation involves an intensification and multiplication of social risks both at the level of the individual and at the collective level. Epidemiology is both contributing to, and an outcome of, what Beck refers to as 'risk society'. Risks are considered to be heightened, concealed (deep within the recesses of our bodies and genetic make-up), and individualised (the individual is required to take responsibility). In a risk society also scientific knowledge and expert opinion become highly valued and highly politicised. In the arena of public health, risk, can be considered to be everywhere. Sexual health, but in particular, the risk discourse around HIV and AIDS highlights the social construction of risk. All people are not affected equally or perceived to be 'at risk'. The groups primarily affected by infection are often marginalised members of society that are already experiencing discrimination. It becomes easy then, to blame such groups, for putting themselves in 'risky situations'.<sup>5</sup>

Running through the history of public and sexual health has been a central tension between the health of individuals and the collective health: the tension between the right to individual autonomy and the public health imperative to control disease. This is because of public health's remit over the collective. The discipline of public health values health above all other factors (for example, sexual desire) and assumes that this motive justifies its actions. According to Skrabanek, through public health, 'healthism' becomes

part of state ideology (Skrabanek, 1994). Similarly, Hall (1992) suggests that the reason that public health practitioners neglect the individual ethical issues of their jobs is because they have been trained to address the health of groups of people. The paradox however is that a prevention measure that brings benefit to the wider population, offers little to each participating individual (Rose 1985:138). Critiquing the collective motive, Baggott (2000:4) suggests it is unfair for individuals to sacrifice their own freedom for an illusory common good.

### **3.3 Social Theory Perspectives On The Role Of Patients And The Lay Voice In Health Care**

Social theory provides a new approach to considering the lack of a lay voice in public health and sexual health services. Referring to the lack of any theoretical base in epidemiology, Pearse (1996) (cited by Inhorn and Whittle 2001:553) suggests that epidemiology is suffering from 'rigor mortis'. Inhorn and Whittle suggest that epidemiology will benefit from forging alliances with more theoretically informed disciplines such as anthropology, sociology, historians and feminist scholars. In addressing social theory in this chapter, there are three theories, which I would argue, help explain the role of the lay person in sexual health services. Employing these theories helps frame public health and sexual health in contrasting ways. It sets up contrasting alternative models that allow us to see public health and sexual health from different standpoints. The following theoretical frameworks will be explored. The first is the functionalist perspective, the second the Foucauldian perspective, the third is the critical theory perspective, particularly, the work of Habermas and his theory of communicative action; finally, studies on masculinities and Queer Theory will be explored. These theories will form a backdrop to my thesis. It might be asked why these social theories have been used? Social theory has been previously used in nursing research to explain the lay perspective in sexual health clinics. To date most critiques of sexual health have been conducted using Foucauldian theory (writers such as Pryce 2000, 2001 and Holmes and O Byrne 2006) but I was interested in a range of social theories to offer differing view points; This thesis shall, therefore incorporate a Foucauldian approach along with

contrasting theoretical positions. Parsons, it could be argued is a polar opposite to Foucault, and also very topical in terms of understanding trust which is a strong theme in current scholarship. Habermas on the other hand, offers another different perspective on rationalising.

In the course of my analysis of questionnaire responses and the narratives of the participants gained in the interviews, I will be examining the relevance of these theoretical frameworks. For each individual, sexual health services may be framed in different ways depending on circumstances and it may be possible to see more than one discourse running through their narratives.

### **3.4 The Structural Functionalist Perspective: Parsons and the Sick Role**

The American sociologist Talcott Parsons (1902-79) belongs to a strand of sociological theorising called structural functionalism. Society viewed from this perspective consists of interconnected functioning parts. Parsons was and remains, the pre-eminent American sociologist, noted primarily for his broad scope and analytical depth of his theory of human social action (Lindz 2000:388). Parsons was interested in social cohesion and the development of a theory for society that falls between the self-interest of capitalism and the collective interests of socialism. He suggested that somewhere between these two ideologies, professional role relations were located. Lindz (2000:388) suggests that Parsons was interested in developing a theory that would address all aspects of human social organisation and would be open to progressive refinement as the advancing discipline of sociology gained in ability to relate theory to empirical knowledge. His aim was to develop a conceptual framework that could be applied in various times and places.

The social system (Parsons 1951) is one of his most important pieces of work and offers, even now, a considerable amount to our understanding of health and illness. It is based on his empirical work in which he spent over a year observing medics and patients interacting at Boston hospitals. Parsons suggests that medicine's role extends beyond the remit of diagnosing and treating diseases. He recognised that illness may be seen as a

form of deviance by society. He also recognised that, because of the pressures of a changing society, people may wish to evade these responsibilities. He argued that all people have social roles and that medics were granted the power to exempt individuals from their normal role responsibilities. From a Parsonian perspective, the physician was a technical expert in matters of health and illness. The system of professional entry finely selected individuals for the role and the recruits underwent lengthy training to allow them the elite position in society, which they enjoyed. Parsons suggested that their motivation was purely altruistic.

Parsons pointed out also that there were conditions ascribed to both parties in the patient-doctor encounter. The doctor was considered to have principles of 'universality', in which all patients were treated equally, irrespective of circumstances. Medics were considered affectively neutral and also functionally specific. To be deemed legitimately ill, and therefore allowed access to the sick role, certain conditions were attached. These conditions included that patients were exempt from their normal social role responsibilities, they were considered not to be blamed for their illness, they were deemed to have a desire to get well as quickly as possible and finally, they had a responsibility to seek and comply with medical advice (Parsons 1951:437).

While Parson's work on the 'sick role' was first published over five decades ago and informed by research in a US health system, it still holds relevance to our understanding of health and illness in the present day. His work was seminal in highlighting that the concerns of physicians extend well beyond the management of diseases in individuals. Not surprisingly, his work was also the subject of much criticism. Two main criticisms can be identified. First, Parsons ignores the self-interest motive of medics, the medical establishment and their close allies in the pharmaceutical industry. The 'sick role', as described by Parsons, obviates the power that the medical establishment possesses and implies that a consensus exists between physicians and patients in which unequal power relations are not challenged. The claim to universal criteria can be strongly criticised; all patients are not treated equally and medicine can cause, or at least reinforce, the status quo of discrimination that can exist in society for certain marginalised groups. Second,

Parson's sick role offers little understanding to the management of chronic diseases (which imply an on-going relationship with the doctor and the line between 'sick' and 'healthy' is more blurred), or conditions that are associated with stigma. This is a crucial point since stigma is especially relevant to the case of sexual health, as the cost of disclosing an illness associated with stigma may be too great for an individual.

How relevant is Parsons' description of the sick role to lay professional perspectives of sexual health services? His theoretical perspective offers something to our understanding of the lack of the lay voice in public health and sexual health services. Parsons touched on the issue of professionals obtaining intimate details of their patients' private lives. In particular, he discusses sexual relationships. Parsons describes this information as 'essential to the performance of the physicians function' (Parsons 1951:452). His view of the professional as the key source of knowledge was arguably at the cost of the lay perspective. A Parsonian framework suggests that health professionals are still considered the experts and a compliant patient will attend to receive treatment and advice keeping the mythology of the beneficent god-like physician dominant (Lupton 1994:1).

This perspective is very interesting in relation to the professional expectation of health seeking behaviour of clients/patients at sexual health clinics for STIs. A targeted approach to public health for STIs recommends regular attendance at clinics by those considering themselves 'at risk'. Perhaps as a legacy to the HIV/AIDS panic, this has been directed in particular at MSM. The 'regular check-up' message has been absorbed by many as a responsible thing to do. The sick role is important, but also the potential sick role, disease may be lurking, although there may not be any signs or symptoms. What should not be overlooked are the limitations of Parson's approach. For various reasons, people choose not to attend a clinic, or not to follow the advice of doctors or other health professionals. The perspective of Parsons is based on the assumption that the views of lay and professionals concur. This view has increasingly been challenged however, because of increased consumerism in health care, a more informed public, and increased awareness of public health scandals. A critique of the power of health



professionals is best considered through the second theoretical perspective: that of Michel Foucault and in particular his work on surveillance.

### **3.5 Foucault: Sexual Health as Surveillance**

The French philosopher Michel Foucault (1926-84) provides a contrasting approach through which to view the lack of the lay perspective in sexual health. His work has been described as a history of the present. He was particularly concerned with the issues of knowledge and power. He argued that modern systems are associated with disciplinary power. Surveillance, he argued, is an important component of that power. Surveillance refers to a form of scrutiny and observation but one that does not necessarily depend on the physical proximity of the watcher or the watched (Barry and Yuill 2003:32). The practice of surveillance medicine imposes ideas of threat as well as possibilities of control (Lauritzen and Sachs 2001:514). Surveillance is everywhere in modern societies according to Foucault. Technological developments increasingly make this possible. People can be observed and endless amounts of personal data can be stored and easily retrieved by others. Modern societies are bureaucratic and surveillant (White 2002:118). In addition people can internalise the control that is over them. Foucault uses the image of Jeremy Bentham's panopticon to illustrate this point; the panopticon was a design for a prison that had circular shaped cells and an inner control tower. People would not be able to ascertain when they were being observed and for this reason would constantly act as though they were under surveillance.

Foucault draws explicitly on the case of health care settings and is heavily critical of the hegemony of medical science. For Foucault the internalisation of norms of hygiene, and the development of a state administrative structure to enforce and coordinate public health are all aspects of Weber's *iron cage* (White 2002:119). The concept of the iron cage was an important part of Weber's account of the growth rationalisation and bureaucracy in industrial societies (Turner 1995:225). Foucault's work in the *Birth of the Clinic* (1973) identifies the hospital clinic as the place where potentially diseased bodies can be inspected and subjected to what he describes as the 'clinical gaze'. Armstrong in his work on the political anatomy of the body takes a Foucauldian perspective and points

out that the modern body has become the docile object of clinical practice (Armstrong 1983:2). Surveillant medicine, he says, involves a fundamental remapping of the spaces of illness. Public health casts its watchful eye on whole populations where everyone is targeted (Armstrong 2002:113). The techniques of surveillance medicine include surveys, screening and public health campaigns. According to Armstrong (2002) these all have potential side effects. Screening is one such example. It does not prevent disease it merely diagnoses disease in those who fail to fall within a scientifically determined range of 'normality'. Negative effects of screening include false positive or negative results, embarrassment, inconvenience and anxiety.

Sexual health clinics are an example of surveillance (Armstrong 1983, Pryce: 2001). A Foucauldian historical analysis of sexual health services highlights the surveillant practices that have taken place over time. As already mentioned, legislation in some countries in the 19<sup>th</sup> century resulted in compulsory registration and police supervision of all sex workers. In addition they were regularly examined for STIs and even faced compulsory hospital detention (Adler 1987). The question might be asked, however, about how relevant is a Foucauldian analysis to public health practice as it operates in current day sexual health clinics? Legislation protects people's privacy to some extent. The Infectious Diseases Act (1981) in Ireland and the Venereal Diseases Act (1974) in the United Kingdom, and similar legislation in most other European states provides some protection to people's privacy. Legislation means that the record of an individual's attendance at an STI clinic is not divulged to General Practitioners, insurance companies or other parties. There are exceptions attached to this legislation, however, and the 'good of public health' can take priority and is considered grounds in which to divulge information that might otherwise be kept private. The General Medical Council (GMC) (UK 1997: 9) offers an example where this can occur. They suggest that a medic may disclose information about a patient, whether living or dead, in order to protect a person from risk of death or serious harm. For example a doctor may disclose information of a known sexual contact of a patient with HIV, where the health professional has reason to believe that that index patient has not informed that sexual contact and cannot be persuaded to do so. In such circumstances, the GMC recommends that the health

professional should tell the patient before making the disclosure and he or she should be prepared to justify a decision to disclose information.

Surveillance happens in other ways. While patients might get loose guarantees of confidentiality, surveillance cameras in clinics mean that as well as worrying about who might see them sitting in the waiting room, they may also have concerns about who also might see the security video tapes. Attendance at a sexually transmitted infection clinic usually means an encounter with various clinic staff including receptionists, nurses, doctors, health advisors and counsellors all of whom have some questions to ask. Taking a sexual health history involves ascertaining risk factors for disease, in particular HIV. Therefore as Pryce (2000, 2001) following Foucault says, there is an incitement to confess. Detailed sexual histories are taken and recorded and stored. In the process of contact tracing intimate details of partners are also revealed. Surveillance scientists and epidemiologists are charged with collating data on National databases. Clinics and other health professionals who diagnose STIs have an obligation to report them, for which they receive a nominal sum. Surveillance data are considered necessary to inform strategies towards control and prevention of disease. Surveillance has been described by public health professionals as 'critical' for monitoring outbreaks and in alerting the authorities of the need for action (Walley et al 2001:2). In the current day clinic, detailed sexual histories may be taken and private data may be stored on potentially insecure databases. Surveillance can also take the form of self-monitoring. Monitoring of signs of infection may be carried out by people who have attended clinics in the past or are worried about STIs. The 'regular check up' message that has been advocated for certain groups such as MSM is a further example of surveillance and medicalisation of everyday life. It would seem with little doubt then, that surveillance is very much a feature of sexual health and extends beyond the remit of the clinic doors through public health campaigns and partner notification.

So far, the two theoretical positions that have been considered share commonalities and differences. While both Parsons and Foucault acknowledged that health and illness are not merely biological phenomena, they also asserted that health professionals have an

impact beyond that of assessing, diagnosing and treating people for disease. How they interpreted this was different: Parsons, a structural functionalist can be considered to be a consensus theorist; he did not see the imbalance between lay and professional as being problematic. He merely considered them as different roles in society, the medic was awarded his position of technical expert after a lengthy training and it would seem deserving of it. According to Parsons, medics deserve this position of expertise. Parsons acknowledged that sexual health information could be taken in the context of medical consultation and considered this quite acceptable. From the perspective of Parsons the medic is an expert and this is unlikely to be challenged by patients as it is medics who are in a position of power.

Foucault's thesis is more challenging of the medical model. Foucault challenges the status of professionals. He presents a view of the medical establishment as an industry for the surveillance of bodies. It would seem from such a perspective that there is no place of refuge from the constant glare of the disciplining gaze. Foucault did not have prescriptive solutions and would also have had difficulty with the 'lay expert' (a term that is emerging in recent times (Prior 2003:41)). It could however, be argued that Foucault might see a lay expert as a point of resistance, viewing it as a counter or alternative discourse to the professional discourse. A converse perspective to this can be offered however, Foucauldian social constructionism rejects the privileging of counter lay claims to knowledge, because he see it as just another form of discourse or knowledge/power complex. It is opportune then to turn attention to the third theoretical perspective: the German critical theorist, Habermas and, in particular, his theory of communicative action.

### **3.6 The Critical Theory Perspective: Creating Dialogue Between the System and Lifeworld**

Critical social science arose in response to the enlightenment's focus on the authority of science and technology (Trede and Higgs 2003:68). Jürgen Habermas is probably the most influential of all the critical theorists. His work stretches over four decades and is

wide-ranging and diverse. While it is true that his early work does not make direct reference to health or medicine, it may be applied to offer a useful analysis of healthcare in society. This is evident in the increasing numbers of health researchers that are considering his conceptual framework. Graham Scambler (2001) states that the conceptual framework of Habermas has a fulsome and largely untapped potential to shape and inform theories of the changing character of healthcare in contemporary society (Scambler 2001:20).

A central focus of critical social theory, in a similar vein to Foucauldian theory, is to question the taken for granted assumptions about the world around us. Critical theory however, goes beyond this Foucauldian deconstruction to also have an emancipatory function. Jürgen Habermas, in particular, was concerned with the changes in late industrial society. His work entitled *Knowledge and Human Interest* (1972) challenged the positivist view that objective knowledge is the only valuable form of knowledge. He identified three forms of knowledge, which he argued were interconnected. These are technical, practical and emancipatory. Technical knowledge is concerned with hypothetical deductive theories; practical knowledge relates to the lived experiences of individuals, and finally emancipatory knowledge offers a critical self-awareness that challenges domination in people's lives. The Theory of Communicative Action (Habermas 1987), which is one of his most important pieces of work, expands on his interest in emancipation through communication (Ekstrom and Sigurdsson 2002:290). It was first published in Frankfurt in 1981 as *Theorie des Kommunikativen Handelns*. Before expanding on the details of the theory it is relevant to outline firstly what Habermas meant by the term lifeworld and system. Society from a Habermasian perspective consists of the life and systems world. The lifeworld according to Habermas is a symbolic space where culture, social integration and personality are sustained and reproduced (Thompson 1984). It consists of the public and private subsystems which are concerned with influence and commitment and is characterised by communicative action which has also been described as action orientated to understanding. The system on the other hand consists of the subsystems of the economy and state, which are concerned

primarily with money and power respectively. It is characterised by strategic action or in other words action orientated to success.

Habermas argues that both of these worlds are necessary for normal functioning of society but what particularly concerned him was the imbalance between the life world and system in modern societies. He argues that the increasingly complex technical focus of the system has begun to dominate the lifeworld. The system has begun to encroach on parts of daily life that are considered to be part of the values focus of the lifeworld. Emphasis, it seems to Habermas, has been placed on strategic rationality at the expense of the lifeworld. He called this the uncoupling of system and lifeworld with a colonisation of the latter by the former. This, he argued, was not a feature of primitive societies.

Habermas shared with his critical theory predecessors at the Frankfurt school, a premodern concern with the changing society and the loss of human life experiences in a sea of bureaucracy in modernising societies. Arguably, Habermas, while refuting claims to be utopian, held out more hope than his predecessors that a balance could be restored between the systems and lifeworld. He believed that a reconstruction of society was possible. The key to this, he proposed, was through rationalisation of the lifeworld through communicative action.

The rationalisation of the lifeworld through communicative action can be managed through the creation of what Habermas refers to as 'the ideal speech situation'. In every ideal speech situation there is an expectation of intelligibility, trustworthiness, legitimacy and sincerity (Habermas 1984:273- 337). The impetus is for mutual understanding. Coming to an understanding [Verständigung] means that participants in communication reach an agreement [Einigung] concerning the validity of an utterance (Habermas 1987:120). The aim of the ideal speech situation is not manipulation or coercion. The outcome of the interaction cannot be predicted at the outset. The process therefore is creative and the ultimate aim is genuine consensus through dialogue.

Habermas' theory has been subjected to criticism. From a Marxist perspective, he is charged with not giving enough consideration to the material factors that impact on health and ill health. From a Foucauldian perspective, he is accused of not considering the complex issue of power adequately. Another common critique of his work is that it is utopian (Brand 1990). The question can be asked at this point: how useful is the critical theory perspective of Habermas to our understanding of health and illness and in particular the absence of the lay voice in sexual health?

When applying a Habermasian framework to lay-professional relations in public health and in sexual health services there are two important issues. The first relates to knowledge and the second to communicative action. Habermas' theory raises the important question of whose knowledge counts? According to Habermas there is a danger that the technical expert systems are held as the authority and the voice of the general public can be omitted because they do not speak the language that is associated with expert knowledge. The theory of communicative action is a theory of reconstructing reality. Medical health care systems are dominated by strategic rationality (Wells 1995). But the question can be asked is this really appropriate when much of public health care depends on its acceptability to individuals. Health care, as we know it, is increasingly being challenged (Gabe et al 1994). As mentioned earlier, there is increased consumerism in health care and also an increased awareness of public health scandals. In addition, there have been calls for increased 'evidence based practice' in health care. The voice of the lay perspective, as outlined in the previous chapter, is increasingly gaining credence in mainstream health policy documents. How much does this actually happen in practice? Is this tokenism or real? Arguably, there is a lack of the lay voice in public health care. Therefore, Habermas' theory of communicative action provides a useful framework to consider the case of sexual health. It offers potential for reconstructing reality through dialogue between elites and non-elites. Using this approach it is suggested that sexual health and public health needs to reconstruct services to redress the current imbalance between lay and professional concerns and to respond to the lifeworld objectives of individuals in order to be able to respond humanely to the needs of the people it aims to

serve. There are two further inter-related areas of theoretically informed research that can serve to open up the 'lifeworld' referred to by Habermas. These are the study of men and masculinities and Queer theory.

### **3.7 Masculinities and Queer Theory**

It could be argued that the perspective of men has dominated social science and other scientific literature for decades. However, the study of men and masculinities concerns itself more with the private everyday world of men and the ways in which men's lives are also gendered. The study of men and masculinities deconstructs the notion of gender as being synonymous with women. In particular, as outlined in the previous chapter, men's health beliefs and behaviours have been shown to be gendered. Courtenay (2000) suggests that through their health behaviour, men re-enforce cultural assumptions about men being strong and less vulnerable to disease or illness than women.

Hearn (2004: 98) notes that the study of men and masculinities should not be at the cost of re-excluding women. Hearn distinguishes between 'men's studies' and 'critical studies on men'. The former he says is, at best, ambiguous, falsely suggesting a parallel with women's studies, and at worst it is anti-feminist. He suggests the latter term is more helpful as it has the issue of power as a central concern (Hearn 2004:98). Critical studies on men, he goes on to say, refers to the range of studies that critically address men as beings in the context of gendered power relations. The emancipatory purpose of the study of masculinities explores the way in which hegemonic concepts of masculinity are constructed in relation to non-hegemonic concepts such as strong versus weak. The objective is to show diversity and plurality in men's lives. For the purpose of this study the value of the study of men and masculinities is to open up the study of the private and intimate everyday world of men. It is to explore the 'lifeworld', as Habermas refers to it as, of MSM in relation to sexuality, risk and their perspectives on the treatment of sexually acquired infections.

Queer Theory has also much to offer to our understanding of the 'lifeworld' issues for MSM who access or choose not to access health services for sexually acquired infections.



Steven Seidman suggests that Queer Theory has opened up new avenues for sociology. Queer Theorists approach identities as thoroughly social and pluralistic, they encourage analysis of the ways sexual categories operate in a wider range of institutions beyond that which is explicitly sexual (Steidman 1996: 17). The term Queer Theory was first described by 1991 by Teresa de Lauretis in an article appearing in *Differences* she describes it as “another discursive horizon- another way of thinking the sexual” (de Lauretis 1991:iv cited by Anna Marie Jagose 1996). Queer theory is informed by post structuralism and critical feminism. Post-structural theory challenges conventional ways of thinking about the relationships between knowledge, power, truth and subjectivity (Petersen 2003:55). Peterson states that the dualistic distinction that underlies descriptions of the world such as subject/object, self/other, nature/culture, mind/body, private/public, sex/gender, and heterosexual/homosexual, has been vigorously interrogated by poststructuralists and, in particular, queer theorists (Peterson 2003:55). These labels highlight the regulatory mechanisms of the dominant culture (Yep 2003). The work of Michel Foucault and in particular his work entitled the *History of Sexuality* (Foucault 1990), has influenced many Queer theorists. Queer theory challenges the construction of identities especially sexual identities and sexual expression. It seeks to deconstruct the binary conception of sexuality as being either heterosexual or homosexual, and gender as being either male or female. In addition, it seeks to challenge the underlying power dynamics associated with the construct. Stein and Plummer suggest that for many, the term *lesbian and gay studies* was not inclusive enough; it did not encapsulate the ambivalence towards sexual categorisation which many lesbian/gay scholars felt, and the difficulties they faced in fitting sexuality into the “ethnicity model” which provided the template for identity politics (Stein and Plummer 1996:133). The publication in 1990 of ‘*Gender Trouble*’ by Judith Butler was considered to be particularly important. It has been suggested by Clough (2003) that Butler’s post-structural reading of feminist theory identified and challenged the assumed heterosexuality of modern Western Philosophy.

What can be said then, about masculinities and the application of queer theory in the context of sexual health and public health? The scholarship in this field suggests that

masculinities are not fixed, and indeed multiple and possibly contradictory masculinities exist within individuals. The scholarship also suggests that masculinities can be reconstructed in various settings and differing times. Until recently, it would seem that a simplistic approach has been taken to men's health (Robertson 2003, Williams 2003). The theoretical work on masculinity will be applied in my thesis to illuminate the complexity of masculinity and its impact on health and well-being. Queer theory has been influenced, and has influenced, the gay liberation movement. In the context of HIV/AIDS panic in the late eighties, the gay liberation movement became one of the most important social movements in Western developed societies driven primarily by MSM. The movement highlights the possibility of the mobilisation of a lay voice to challenge the status of health professionals as experts in an arena of sexual health.

### **3.8 Conclusion**

The role of this chapter has been to present both a critical historical perspective on the development of public and sexual health and, in particular, to examine the historical position of the lay voice. In addition, this chapter served to open up different theoretical perspectives in order to model differing explanations and understandings of the absence of the lay voice effectively.

The brief critical historical overview suggests that the lay perspective of health and illness has not always been absent from health care. Instead, the literature suggests that, prior to the development of hospitals; the medical practitioner was often the least powerful in the patient-doctor encounter, depending financially on him or her for patronage. Under biomedicine, however, the situation had changed. The patient came to be viewed by the medical profession more as a passive object in which the underlying pathologies could be explored. Under biomedicine also, technological and organisational developments in hospital and laboratory medicine have also resulted in greater power for health professionals.

Social theory has been employed to offer explanations for this situation. The first theory to be considered was Parsons and functionalism. This theory seeks to explain, and apparently legitimate, the position of health professionals – but especially physicians – as dominant experts in lay-professional health encounters. Parsons' theory presents an understanding of the processes of cultural socialisation, which have led to professional dominance over the lay perspective (Lohan and Coleman, 2005). However, it is inadequate in explaining change in these relationships and in particular the growth of patients as empowered consumers.

The work of Michel Foucault, by contrast to Parsons, challenges the power of modern bureaucratic societies and in particular the growth of bureaucratic medicine. Health care settings are recognised by Foucault as bureaucratic organisations where health care workers survey bodies for signs of disease. Surveillance, he argued, was everywhere. While in the past he argued that this was more obvious, it was now more subtle and included internalisation of a surveillant state by individuals. People subsequently act as though they are constantly being watched. Surveillance is very much a feature of sexual health clinics but also extends well beyond the confines of the hospital settings. Public health campaigns are targeted at communities; individuals are encouraged to monitor themselves or sexual partners for signs and symptoms of STIs. Through partner notification, partner details may be divulged to health advisors without the partners' expressed consent. Foucault's work provides a useful perspective to question critically what health professionals view as acceptable interventions. He fails, however, to offer any prescriptive advice on how the problem of a lack of a lay voice can be addressed.

Habermas' theory of communicative action was also drawn on. Modern society according to Habermas is divided into two worlds: the lifeworld represents the place where people experience life and includes personality, interactions and culture. The lifeworld is motivated towards understanding. Communicative action is the means through which this is achieved. The motivation behind the systems world on the other hand is strategic rationalisation that aims for success. It is concerned primarily with economy and state. Habermas suggests that in late industrial societies the lifeworld objectives are being lost

in a world that is focused on systems. He refers to this process as the 'colonisation of the lifeworld'. When applied to public health and sexual health it has been suggested in this chapter that the lifeworld objectives are more likely to be represented by the lay perspective while the systems world represent the public health professionals' viewpoint. Habermas proposes the 'ideal speech situation', or a communicative structure, which could act as a means of creating equitable debate between these two worlds or perspectives. Habermas, therefore, not only offers an explanation of the situation but also offers a way to resolve it. In a sense, the aim of my research is about opening up a dialogue between lay perspectives and relevant health professionals, which in some small way might contribute towards this dialogue.

Finally, the theoretical issues relating to the study of men and masculinity and Queer Theory were addressed because of their relevance in opening up the lives and lived experiences of the population of interest: MSM. The theories that have been presented will offer a framework to consider the lay perspective in the empirical data of attendees at sexual health services throughout the thesis. The relevance of the contrasting theoretical positions will be explored in the narratives and quantitative data of attendees at sexual health clinics and discussed again in the closing chapter.

## **CHAPTER 4**

### **METHODOLOGY**

#### **4.1 INTRODUCTION**

The aim of this chapter is to outline the methodological approach taken for the study. In order of sequence, it commences with a discussion on mixed methods methodology followed by a discussion on the rationale for the study design. This is then followed by a description of the setting of the study. I then discuss the ethical processes and issues raised by the study. The chapter then divides into the quantitative and qualitative components of the study. I first describe the development of the data collection tools for the quantitative component. Three separate questionnaires were constructed for these sub-populations described above – cases, contacts and community. The design, piloting and administration of these three questionnaires is outlined in the course of this chapter. The issue of negotiating research access is also explored. Following this, the qualitative component of the study is discussed. Semi-structured individual face-to-face interviews were conducted with the same sub groups of ‘cases’, ‘contacts’ and ‘community’ participants. After outlining how I recruited for this part of the study, I describe the profile of the sample. The process and style of these interviews is then outlined and my position as a researcher together with the quality assurance and the processing and analysis of qualitative data is also described. The chapter concludes with a discussion on the strengths and weaknesses of the methodological approach taken.

#### **4.2 MIXED METHODS METHODOLOGY**

Mixed methods has been broadly defined as research in which the investigator collects and analyses data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or a program of inquiry (Tashakkori and Creswell 2007:4). The qualitative versus quantitative debate has interested researchers for more than a century. From these debates, purists have emerged on both sides (Johnson and Onwuegbuzie 2004:14). It is proposed, however, that rather than be an ‘either or’ debate, qualitative and quantitative research can complement each other. According to Johnson and Onwuegbuzie (2004:14-15), the goal of mixed methods

research is not to replace qualitative or quantitative methods, but instead to draw on the individual strengths of each approach, whilst also minimising any weaknesses. It is considered to be inclusive, expansive and complementary. The value of mixing methods was recognised as useful for answering research questions by anthropologists and sociologists for the first 60 years of the 20<sup>th</sup> Century, although the term ‘mixed methods’ was not used until much later (Johnson et al 2007:113).

Mixed methods research is recognised as increasingly important in health and social sciences, as evident in the number of books and articles on the subject, as well as the recent establishment of a Journal of Mixed Methods Research. Many nursing scholars also lend their support to the suggestion that mixed methods offer much to address research questions that are pertinent to nursing (Happ et al 2006, Giddings and Grant 2007, Flemming 2007). Combining qualitative and quantitative research methods in a single study helps address the complexity and context of nursing and the research questions it seeks to explore.

There are many approaches to mixing methods. Data may be collected sequentially with either qualitative or quantitative coming first, or it may be collected concurrently. Another factor which influences the strategy of mixed method design is whether qualitative or quantitative approach is given greater priority (Creswell 2003:212). In the present study, I have used mixed methods, combining qualitative and quantitative approaches to explore the complexity of the lay perspectives of partner notification. At the planning stage of the study it was envisaged that the study would explore the effectiveness as well as the acceptability of partner notification. The initial plan was that interviews would be conducted first, and the findings from this phase, would be used in the construction of a questionnaire for the quantitative component of the study. The ethics committee made a request for a copy of the questionnaire *before* any research could commence, and for this reason, it became necessary to change the design to conduct the qualitative and quantitative components of the work concurrently. As I progressed through the study, the focus shifted more clearly to the lay perspectives of partner notification, in particular acceptability, and away from the earlier focus on effectiveness.

The designed questionnaires did not solely focus on acceptability – they focused on effectiveness, and acceptability and other ancillary information. Effectiveness is covered in many studies (see literature review for further discussion). The limitations of these studies is discussed in the text and effectiveness could only be poorly studied in this (retrospective ) study design. Lay perspectives on partner notification, on the other hand, were poorly researched and this was an original part of the study. The analysis as it stands takes the approach of attempting to tell a coherent story about the lay perspective of partner notification (including the contradictions within that story). I tried to weave the quantitative and qualitative results in order to tell that story rather than, a conventional approach where quantitative and qualitative results are presented separately. Some of the quantitative results have been excluded if they are not central to the thesis.

#### **4.3 THE RATIONALE FOR THE STUDY DESIGN**

As discussed in the introductory chapter, the aim of the study was to explore the non-professional (lay) perspective on the subject of partner notification in the context of an outbreak of syphilis. MSM were chosen, because the vast majority (85%) of syphilis cases diagnosed during Dublin's outbreak occurred among this group (Hopkins et al 2004). This is similar to other European syphilis outbreaks, which also found that the majority of cases occurred in this population (Couturier et al 2004; Marcus et al 2004; Righarts et al 2004; Sasse et al 2004). In relation to partner notification, men who have sex with men have been identified in the literature as a 'difficult group' (Bell et al 1998). Many reports state that partner notification is less effective in this population than among heterosexual groups (Carballo-Dieguez et al 2002, Tomnay et al 2004). Despite this, the perspective of MSM on the practice of partner notification has not been explored in research studies.

As discussed earlier, it was not possible to conduct the qualitative component of the study prior to designing the questionnaires. For this reason questionnaires were designed based on previously used instruments in sexual health including the British National Survey of Sexual Attitudes and Lifestyles (Johnson *et al* 1994) and Vital statistics Ireland, which is

a study of Irish MSM (Carroll et al 2002). Literature specific to partner notification further informed the development of the questionnaires.<sup>11</sup> Qualitative and quantitative components of the research study were carried out concurrently. I return to this issue in the final section of this chapter on strengths and weaknesses of the study.

An innovative part of the study design was to extend the study beyond clinical settings, giving me the third sub population for this study – the community population. Overwhelmingly, research on the subject of sexual health in general, and sexually acquired infections in particular, is conducted in sexual health clinics. An extensive literature review did not reveal any studies on partner notification conducted outside of clinical settings. Exploring the acceptability (or indeed the effectiveness) of partner notification within clinical settings automatically excludes the population who do not attend for sexual health services and refuse to participate in partner notification. Arguably, those that find partner notification unacceptable are potentially those that were least likely to attend clinical services. In extending the research study beyond the clinical walls, I aimed to achieve a greater diversity in MSM participants than might otherwise have been the case. I sought to obtain a ‘snap shot’ of the views of MSM in diverse social settings.

Going outside clinical settings, however, raised a myriad of research design questions about appropriate non-clinical settings. I consulted widely with various members and representatives of the gay community and explored various different avenues in which to conduct additional research. Eventually, as will be explained further below under ‘Research Setting’, I chose to do this research in clubs, pubs and saunas at a time when blood testing for syphilis screening was being offered by one of the clinics. I had been involved in earlier research, which explored where MSM with syphilis met their sexual partners. Of these, 70% had met partners in clubs, while 63% had met partners in saunas (Hopkins et al 2002b). Recruiting in saunas meant that people who do not go to other

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<sup>11</sup> Further discussion on the development of the questionnaires will be given in the later section on questionnaire design.

Recommendations during the construction of the questionnaire suggested that MSM may not wish to give their age on a questionnaire in social settings. Instead participant ticked a box indicating an age category to which they belonged.



social venues are more likely to participate. Many participants, but by no means all, reported that they would go to saunas and not to any other venue. Findings from the qualitative research also suggested that many people who go to saunas may not go to any other social venues, and also may not identify to others as being a MSM.

This setting was also only chosen after others were eliminated. Web-based research was considered. I proposed posting a link to a questionnaire on a number of popular websites. I knew from earlier clinic based research, that seven percent of MSM with diagnosed syphilis infection had met some or all of their sexual partners on the internet (Hopkins et al 2002b). The advantage of conducting research from websites would have been to access a population that might not access the STI services. A further advantage is that it would potentially include a population that may not self identify as gay or bisexual. In addition, web based data collection can be time and cost effective. I contacted the webmasters of the two most frequently mentioned websites. I outlined my research proposal and my concerns about privacy and confidentiality. Despite sending two emails to both, I did not get any response. An interesting article by Eysenbach and Till (2001) highlight some of the ethical issues associated with conducting research on Internet communities. Confidentiality and informed consent are key concerns. The research I was proposing to conduct was on a very private subject. As a researcher, I would have been entering into a private sphere of a MSM internet site. I certainly would have identified myself as a researcher at the outset, nonetheless, my presence there would have been as an outsider. As such, my research in that setting could have been seen as intrusive. As a result of these personal reservations, and the non-response from the webmasters, I decided therefore not to pursue the idea of web-based research any further. A gay community centre was another research setting, which was considered. I discussed this with members of staff in the centre, who received the proposal favourably. However, the timing conflicted with a move of the organisation from their old premises to a new building. Considerable refurbishment was required in the new setting and therefore the centre was not operational within my research recruitment timeframe.

#### 4.4 THE SETTING

The research setting was composed of three sites:

1. a large hospital clinic
2. a community clinic
3. community settings i.e. social venues.

There were also *three* different sub populations for this study. These were

1. MSM who were diagnosed with syphilis (**'cases'**). Cases were recruited from either of the two clinics.
2. MSM who attended the clinics as a result of partner notification (**'contacts'**). Contacts were also recruited from either of the two clinics.
3. MSM who were recruited from community venues (**'community'**). This was a 'non-clinical' population and was recruited from MSM social venues.

The study was carried out in Dublin in two sexual health clinics and also in community social settings. The clinical settings were the Department of Genitourinary Medicine and Infectious Diseases (GUIDE) at St James's Hospital and The GMHP. The former is the largest STI and HIV service in Ireland with close to 20,000 attendances each year. Approximately seventy percent of STI cases in the Eastern Region of Ireland are treated at this centre (Hopkins 2004). The GMHP is the only STI service exclusive to MSM in Ireland. Annually, it has approximately 3,500 attendances per year. The non-clinical settings for the study were community venues where MSM meet. These were two clubs, one pub and one sauna. These were conveniently selected on the basis that they represented popular MSM venues and syphilis screening was being offered in these venues on a very occasional basis by one of the major clinics. The syphilis screening team facilitated my access to these sites (as outlined below under Recruitment).

## **4.5. ETHICAL ISSUES:**

### **4.5.1 Ethical Approval**

Ethical approval to conduct the study was sought and obtained from the St James's Hospital and Federated Dublin Voluntary Hospitals joint ethics committee. Ethical Approval was also received from the School of Nursing and Midwifery Studies Research Ethics Committee, University of Dublin, Trinity College. Permission to conduct the study was also received from the clinical director of the GUIDE service at St. James's hospital. In addition, approval from hospital management was obtained after a designated research activity (DRA) hospital approval form was completed. I still continued to do one clinical session each week while conducting the research. This was a condition of access to the main study site as outlined by the legal department of the hospital. It allowed me, as a member of staff, access to the confidential patient information on syphilis cases and contacts. All members of staff at the GUIDE clinic were informed of the research study. The opinions of various members of the multi-disciplinary team were received at both the planning and the piloting stage of the research. The security staff of the hospital was informed that tapes of recorded interviews would be stored in a locked office in the department. The security of computer files (in particular transcribed interviews) was discussed with the Information Management Services (IMS) of the hospital. They arranged to set up a separate secure backed up computer storage area that was accessible only to the researcher and that would not be available to other users on the hospital's computer network.

### **4.5.2 Researching a sensitive topic with MSM**

Sexual health is frequently described as a sensitive topic. But it may be asked: what exactly is a sensitive topic? Lee and Renzetti (1990) suggest that this concept is often used as though self-explanatory. They suggest that any topic can be potentially sensitive, but they outline a number of situations where the research is considered to be more threatening than others. First, it is where research intrudes into the private sphere or delves into some deeply personal experience. Second, it is where the study is concerned with deviance and social control. Third, it is where it impinges on the vested interests of powerful persons or the exercise of coercion or domination. And fourth, it is where the

research deals with things private to those being studied that they do not wish disclosed. They state that the sensitivity of the topic depends on the social context in which it exists, but despite this, they argue that areas of life concerned with financial or sexual matters remain *a priori* shielded from what they describe as ‘the eyes of non-intimates’ (1990: 513).

In nursing research, like all other research involving humans, protecting the rights of participants is of primary importance. Historically, there are many unfortunate examples of research, which failed to achieve this central objective. The Nazi medical experiments of the 1930s and 1940s are possibly the most well known example of discounting the wellbeing of the study population (Polit and Beck, 2004:141). Of relevance to the present study, was the Tuskegee Syphilis Study<sup>12</sup>, which also highlights a disregard for ethical principles. In response to these, and other similar examples of exploitation of research participants, a number of guidelines for good research practice have been set down, including the Nuremberg code and the Declaration of Helsinki (Polit and Beck 2004:143). The work of Beauchamp and Childress (2001 *orig* 1989) on biomedical ethics outlines principles of ethical decision making, which have relevance to conducting research. These are: respect for autonomy; nonmaleficence, beneficence and justice. These principles are critical to carrying out ethical nursing research. In conducting this research study, I was also aware of my need to operate within the guidelines for professional conduct laid down by An Bord Altranais (An Bord Altranais 2000) and also the recommendations for good practice recommended by the Society of Sexual Health Advisers (2004).

The population of interest in the study can, for a number of reasons, be considered to be vulnerable. Firstly, I was recruiting only MSM. As already mentioned, this was a population that has experienced, and continues to experience, profound discrimination

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<sup>12</sup> The Tuskegee Syphilis study was carried out among four hundred Black Americans in a disadvantaged community in Alabama, USA over a period of 40 years (1932-1972). Treatment was deliberately withheld from study participants despite the recognised effectiveness of penicillin. The study was strongly criticised on a number of ethical grounds. There was no review of the study protocol or approval prior to commencing the study (Levine 1986 cited by LoBiondo-Wood and Haber 1998: 278). Furthermore, many participants were not informed about the process and the procedures associated with the research. Others were not aware that they were subjects.

(Glen Nexus 1995, Wasserheit et al., 1999). Secondly, attendees at a sexual health clinic may also be considered vulnerable. Issues of privacy and confidentiality may be to the forefront of their mind. Many attendees at clinics request that their attendance not be revealed to anyone; thirdly, research participants were asked questions about personal and intimate matters. These included topics such as sexual orientation, sexual behaviour, attitudes and relationships. There was a potential for emotional consequences as a result of responding to these questions. Finally, this research was primarily carried out in clinical settings. Similar to nursing research in other clinical settings, there is potential for participants to feel under pressure to *please* members of staff by agreeing to participate in the research. There may also be concern that non-participation in the study may result in a reduction in the quality of care they receive in the future. As Green and Thorogood (2004: 62) point out, in research studies, there needs to be consideration for participants as individuals and not merely 'carriers' of good data. It is important, therefore, that genuine opportunities are given to refuse participation. It is necessary, for the reasons discussed above, that the study be conducted with a heightened sensitivity to ethical concerns. Lee and Renzetti (1990: 525) argue that if researchers are not going to opt out of research on sensitive topics, the problems and issues that these topics pose need to be addressed seriously. In the course of interviews, many people discussed personal, painful and upsetting issues. No one was in such acute personal distress that necessitated me to stop the interview. I frequently gave them opportunities to do so, if they wished. Following the interview, time was spent with participants to debrief on any difficulties they had, and to enquire, when the tape was turned off, about any upset that they might have felt during the course of the interview. I was fortunate that I could offer referrals to all participants, to a team of counsellors in both of the clinics. Although offered, it was not necessary for me to make referrals as a result of any upset caused in the course of the interviews. I gave my contact details to all participants, if they wished to contact me again.

In addition, a further consideration in the planning of the study was the potential that a conflict of interest may occur. Health advisers have a professional duty to protect the sexual health of the community, as well as the health of individuals (Bell, 2004: 216).

While the confidentiality of all participants in the research was considered very important, a necessary exception to this, outlined in the information sheet and explained to participants, would have been in the rare circumstance where information was disclosed by a participant that may be detrimental to the health of another. In such cases, I had a duty of care to inform their sexual health advisor. In practice, during the course of this research, this did not occur.

As already mentioned in relation to access to the study, ethical approval was obtained from the ethics committee of the hospitals and the university. I also met with the medical consultant of the GMHP and the coordinator of the service to discuss some of the ethical considerations about the study. They were particularly concerned that the study was carried out with due respect for the individuals as well as the wider gay community. They expressed concern that if there were any negative effects of this study it would impact on the trust that the service had developed with the community. Furthermore, it would impact on the willingness of the organisation to permit future researchers to conduct research. However, they were reassured that the research proposal contained measures in relation to informed consent and confidentiality and anonymity (as outlined further below) that would ensure respect and protection for participants. I also discussed the research with gay community peer workers. They were an important group as they represented MSM and as such had an insight into the issues from a MSM perspective. This group made no additional recommendations.

#### **4.5.3 Informed consent**

The principle of informed consent was a core principle in my approach to the study. Full verbal and written explanations of the study were provided to all those who were asked to consider participating. It was made clear to all participants (and potential participants) that they were free to refuse to participate. Separate information leaflets were used for participants in the qualitative and quantitative components of the study. The information leaflets outlined clearly the nature of the study and included what was requested of participants; the aim of the study; and the type of data being collected. I was available to answer questions that arose while individuals were considering participation and while

they were participating in the study. My contact details were given to participants should they have any further questions, queries, or complaints after they left the site of the research. It was explained that consent could be withdrawn at any stage and that lack of participation would not affect the quality of service they would receive from health advisors or any other members of the clinical team. Consent was negotiated with participants at many intervals during the study. In the quantitative component, participants signed a consent form and then returned it to the researcher prior to completing the questionnaire. It was explained that this consent form was not linked to the questionnaire that they were completing, which remained anonymous. In the qualitative component, consent forms were also signed before interviews commenced. The nature of semi-structured interviews is such that at the outset, the exact format of the research will not be known. Thus, I explained to participants they could end the interview any time they wished. They were invited to press the stop button on the tape recorder at any time they saw fit.

#### **4.5.4. Anonymity and confidentiality**

Anonymity and confidentiality were also guaranteed to participants. The completed questionnaire was returned to me in a sealed envelope. In the quantitative component, all respondents were told that no link would be made with their anonymous questionnaire and their name or any other details on the clinic charts. A unique identification number was assigned to all participants. All data that might identify an individual was kept in a locked cabinet. This included completed questionnaires, consent forms, tapes and transcriptions. A separate secure file storage area was set up by IMS for this purpose. Access to qualitative data was restricted to those directly involved in the research study; this included one person who transcribed some of the tapes (I did the remainder) and two fellow researchers who reviewed the interviews to enhance the credibility of the research findings, and my primary supervisor who viewed excerpts of the data. Carrying out qualitative research on gay men and lesbians' experience of nursing care, Platzer and James (1997) found participants were worried that their identity or that of their partners would be revealed, especially as partners had not given informed consent to participate in the study. This was a potential issue in this study also, as the central focus was partner

notification, which, for the majority, involved stories of current or previous partnerships, or sexual encounters. At the outset of each interview, I discussed the issues of confidentiality and asked that if possible, they would not use the name of partners or contacts. Many participants still named partners during the dialogue. To ensure anonymity no names were typed on the transcriptions even if the participants named themselves or any partners/contacts in the interview, instead a note was made to that effect (*e.g.* 'names partner'). In the research reports and publications/conference presentations arising from the research, it was decided rather than using a pseudo name which may coincidentally be the name of someone who participated in the study (either qualitative or quantitative components) it was decided to instead number the interviewees. This was based largely on the input from participants and other MSM that suggested that the Gay community in Dublin is considered to be relatively small. For this reason it was critical that all reasonable steps be taken to protect the identity of participants.

#### **4.5.5 Timing of recruitment**

Investigating a sensitive topic requires that attention be paid to the timing of when people are recruited to participate. People were invited to participate after they had been seen by at least one member of the clinic team such as a doctor, nurse, health advisor, or social worker/counsellor. Participants were recruited at a time when they were not considered to be under any undue stress. For many this involved waiting until their return visit to the clinic to invite them to participate, as the first visit, for many, was a time of considerable anxiety which usually involved having tests carried out, receiving treatment and awaiting results. The community setting was different: participants were invited to participate at the same time that blood testing for syphilis was being conducted in social venues. It was not possible in this setting to wait for a return visit to complete a questionnaire. MSM were informed that even if they wished to have a blood test for syphilis, they were under no obligation to complete a questionnaire or give their details for an interview in the future.



## **4.6 DEVELOPMENT OF DATA COLLECTION TOOLS – QUANTITATIVE COMPONENT**

### **4.6.1 The Questionnaire Survey**

The self-administered questionnaire was the approach of choice for all three surveys. The reason this was chosen was because it facilitated anonymity and confidentiality, which is of particular importance when conducting research on sensitive topics. Using a self-completed questionnaire ensured that it could be completed at the respondent's convenience. One of the disadvantages of this approach is that participants may not have the opportunity to ask questions. To address this, I was available during questionnaire administration to answer any queries, but I kept a distance from participants unless they requested my assistance. This was to ensure they had space and time to complete the questionnaires.

### **4.6.2 Questionnaire survey design**

In this section, I will deal with a range of issues, including visual appearance and format of questions, which influenced my decisions in questionnaire design. Design experts hold that questions should be specific and concrete (Denscombe 2003:154). Wording should be unambiguous, language straightforward and jargon should be avoided. The sequencing of questions is important. To ensure that participants are motivated to respond, questionnaires should not be too long in length or require too much time commitments for successful completion (Dillman 2000).

When considering question structure a vital point is whether to use open or closed questions. An open question allows for the respondent to use their own language to respond as they choose. A closed question, as the name suggests, allows for limited, usually predetermined responses. There are advantages and disadvantages for the use of both types of question. Open questions are more likely to present the diversity in participant responses and thereby reap richer data. Closed questions, on the other hand have advantages because they are easier to code, quantify and make comparisons. Questionnaires were designed based on the literature reviewed and previously used

instruments in sexual health research. In particular, these instruments were, the British National Survey of Sexual Attitudes and lifestyles (Johnson *et al.*, 1994) and the questionnaire used in Vital Statistics Ireland, a large study of MSM in Ireland (Carroll *et al.*, 2002). For the survey components of this research closed questions with a tick box option were used. An exception to this was a small number of open questions at the end of each of the questionnaires.

When considering the format of the questionnaire an important consideration was the choice of language used. My aim was to facilitate maximum understanding to ensure standardisation of responses. It was also important to ensure the wording of questions caused no offence. In conducting qualitative research to guide questionnaire design in the national UK sexual health study, the researchers carefully explored the variation in terminology used to describe sexual behaviours. They concluded that sexual health, sexual practices and sexuality are rarely discussed in public discourse, and as a result, the language used to describe it is 'impoverished'. They state that the language used varied from the biblical, to the vernacular; from the euphemistic, to the romantic, and from lay terms to scientific (Johnson *et al.*, 1994:26). They also warned that the use of language, as well as the meaning ascribed to that language, differed between groups and within groups in various social contexts. To ensure as close to a standardised approach as possible they opted to use formal language, with explanations offered for certain words if needed.

For the present study, it was decided to take a similar approach to the use of language. Many of the questions used in the design of the case and contact study were the same as those used in the national UK study. Some words were deemed to cause confusion for people and attempts were made to clarify these where necessary. Examples of this were the terms 'sexual contact' or 'sexual partner'. In the planning of this study, discussions about the meaning of these terms were conducted with members of the study population. For some, the term 'partner' implied a longer commitment rather than a once off sexual encounter, while for others the opposite was true. As a practical solution to this partner/contacts were written together. For the purpose of the quantitative component of the research there was no negative effect on the questionnaire results. The purpose of

those questions, which related to partner or contact, was in relation to contacting those people who were possibly exposed to syphilis infection. For this reason partner/contact was a more appropriate term because some respondents may have had more than one sexual contact/partner applicable to the question(s). The term 'regular partner' is one that is frequently used in clinical practice to differentiate between relationships with sexual encounters of shorter duration. To avoid confusion with the term, the word 'steady' was written in brackets to help clarify. The term 'open relationships,' is another example where potential for confusion existed. For some the term 'open' may refer to the quality of communication within the relationship. In this questionnaire however, it referred to people who were in relationships where both partners consented to having other sexual encounters outside the main relationship. To prevent confusion, the meaning ascribed to this term, in the context of the questionnaire was written in brackets after the question.

Ordering of questions is another important component that may influence the responses received. Denscombe (2003: 154) states that sequencing of questions on a questionnaire is important. Firstly, questions asked at the start can influence the responses later. The ordering may entice or discourage the participant from continuing with the survey, so less sensitive questions should be asked earlier on. While many of the questions in the questionnaires were very sensitive, I decided to start with questions about experiences of sexual health education, as respondents in the pilot said they considered these questions less sensitive than the ones that followed. Filtering was used to ensure participants answered only the questions that were relevant to them.

#### **4.6.3 Reliability and validity of the questionnaire**

Issues of reliability and validity are essential considerations in the design of any questionnaire. Reliability is the consistency with which an instrument measures its target attribute. Validity is the degree to which an instrument measures what it is supposed to measure (Polit and Beck, 2004). In the piloting of the questionnaire a number of steps were taken to enhance quality of the data obtained. Conducting a study on a subject as sensitive as sexual health there is a temptation to give answers that are less than accurate (Lee and Renzetti, 1990). People may give what they consider to be socially desirable

responses to present themselves in a good light. In an attempt to overcome this issue Kinsey et al (1948), in their classic study in the USA used questions that have been described as being 'permissive'. These are questions that by their wording imply acceptance of the behaviour in question. Following Johnson et al (1994), this study uses this technique in a more moderate approach. It asks for example, *when was the last time you went to a gay sauna?* But includes 'never' among the response options. Ordering effect can also be a factor in more reliable responses. For example, the question *how much do you drink at each time?*, presents the responses in declining order of quantity.

Enhancing confidentiality also ensures more reliable responses (Johnson, et al 1994). All participants were given a unique identifier number, which in the clinical questionnaires had no association or reference to their clinical chart or any other health records. To ensure privacy, participants were given time and space to complete the questionnaire away from other people. Large brown envelopes were used to seal the questionnaire before returning it. Following Miles et al (2003), it was hoped that assuring anonymity allowed participants to make unfavourable comments without fear of this affecting future treatment.

Test-retest reliability was conducted in the pilot phase on all three questionnaires, and reliability coefficients obtained. All these achieved reliability coefficient above the 70% acceptability level. To ensure content and face validity, questions used were based on the literature. Members of the study population in the pilot study and experts were asked to review the questionnaire at the various stages of its development and to give their opinion as to whether or not it achieved the desired result. These experts included three health professionals working in genitourinary medicine and two experienced social researchers; one of whom had conducted previous research in sexual health. A number of questions were asked of these members and experts. Amendments made to the questionnaires were based on recommendations by the members and experts.

Face validity explores whether or not the instrument looks sensible to those who will be completing it (Bowling, 1995). To ensure face validity, participants were asked about

layout, structure and ease of completion of the questionnaires. Content validity explores whether the instrument captures all the issues about the concept. In the context of this research, the process involved looking at each item on the questionnaire and asking if this is relevant to the main research interests of the study. In addition, all participants of the pilot study were asked to comment on the appropriateness of the content of the questionnaire. Construct validity is the ability of the questionnaire to converge with other methods related to the same phenomenon (Watson 1999:53). In order to test the construct validity of the case and contact questionnaires a number of questions were used. Those that had responded 'never' to the questions about attending certain venues should have replied zero to the question that asked about number of contacts met at each of these venues within the previous three months. The questions that were examined for the purpose of construct validity related to saunas, cruising grounds, gay pubs, gay clubs, gay social groups, and the Internet. Overall, 100% agreement (158/158) was found on the contact questionnaire, with 99% agreement (329/332) on the case questionnaire. The design of the three questionnaires will now be described.

#### **4.6.4 Case questionnaire survey design**

The questionnaire was divided into five sections (see appendix B). Questions were asked over eight pages of A4 paper, where one side was used only. Section A was concerned with sexual health education, clinic attendance and sexual behaviour, Section B was more concerned with partner notification, Section C was on demographics, Section D asked more general questions about health, Section E explored sexual orientation, relationships and social networks. Most questions were closed questions, requiring a tick box response. The exceptions to this were three open questions on the acceptability of partner notification.

#### **4.6.5 Contact questionnaire survey design**

The contact questionnaire (see appendix C)) was similar in many ways to the case questionnaire. It also contained five sections: (A) Sexual health (B) Partner notification (C) Demographics, (D) Health and (E) Sexual Orientation. In Section A the sexual health questions were the same, with one exception; the question on factors that made attending

clinic difficult, was in the first section on the 'case' questionnaire but was included in the partner notification section of the 'contact' questionnaire. This was following feedback from the pilot study, which suggested it worked better sequentially. Section B asked questions about the process of partner notification. These questions were quite different from those asked in the case questionnaire. The reason for this difference was because in this questionnaire, I was seeking the perspective of people who had attended clinic as a result of partner notification, rather than the perspective of those who had been diagnosed with syphilis and were consequently introduced to partner notification. Participants of this questionnaire were asked about how they were informed that they had possible exposure to infection, how this message was communicated and what their reactions to it were. The same ten questions on sexual health with Likert scale responses were also used in this questionnaire. The remaining three sections on demographics, health and sexual orientation were identical to those that were asked on the case questionnaire. Like the case survey, this also was printed on one side of A4 paper.

#### **4.6.6 Community questionnaire survey design**

The questionnaire for the community section was designed to be administered in social venues. For this reason, it was considered desirable to have a very short questionnaire. The questionnaire asked six questions that aimed to capture views on partner notification and five further questions on demographics and previous STI testing or clinic attendance. The aim of this questionnaire was to explore the attitudes to partner notification in a community population. Because of the sensitive nature of the research, and also the setting in which it was carried out, a short vignette was used on this questionnaire. Finch (1987:105) describes vignettes as short stories about hypothetical characters in specified circumstances, to whose situation the interviewee is invited to respond. Hughes and Huby (2002: 382) expand on this definition, and say it includes, text, images or other form of stimuli to which research participants are asked to respond. The use of vignettes has a number of advantages. They can be conducted quickly and because all respondents respond to the same vignette, they provide for more uniform data (Gould 1996). They also help to describe a potentially complicated scenario in a less complicated way. A particular strength of using vignettes in research is their suitability for research that is

considered to be sensitive (Finch 1987; Hughes 1998; Hughes and Huby 2002; Wilks 2004).

Vignettes were also considered a suitable option because participants may not necessarily fully understand what partner notification is. In particular, the concept might be understood, yet the term 'contact tracing' or 'partner notification' may cause confusion for some people. The vignette provided a plausible 'case scenario' that could illustrate the issues in a straightforward way. Wording of the vignette was kept to short statements that were written in bullet format. The two approaches (patient and provider referral) to partner notification were explained and numbered one and two. Respondents were asked to give their opinion on six questions relating to the vignette. They were given five tick-box options on a Likert scale ranging from 'strongly agree' to 'strongly disagree'. The second part of the questionnaire also required tick box options with the exception of one question, which asked about county of residence.

#### **4.6.7 Pilot studies**

Pilot studies were conducted on all three questionnaires. The aim was to test the feasibility and acceptability as well as the reliability and validity of the research instruments. The pilot studies were conducted using purposive sampling. This is a non-probability sampling method in which the researcher selects participants based on personal judgments about who would be the most representative or informative (Polit and Beck 2004:729). A broad mix of respondents was required in terms of age, background and experiences of clinic attendance and partner notification. The pilot studies provided me with an opportunity to discuss in more depth the study design with MSM. What quickly became clear was the enthusiasm and energy with which they were willing to participate.

##### **4.6.7.1 Pilot study: case questionnaire**

The pilot study commenced in December 2002. Ten people with syphilis completed the questionnaire. The response rate was 90% with the only individual not participating citing lack of time as the reason. I was available to answer any questions and afterwards to obtain feedback on the questionnaire, information leaflet and consent form.

Participants were asked about any difficulties with completion. They were asked if they considered the questions appropriate and if there was anything they considered offensive or upsetting in any way. Suggestions for improvement were requested. The feedback from the pilot was very positive. Participants said that the questionnaire was clear to read and they did not have any difficulty in understanding it. A number of changes were made as a result of the pilot, however. It was suggested that I leave more space for participants to fill in responses. The ordering of the section entitled 'about you', which included demographic details, including age, was moved from the start of the questionnaire to later in the questionnaire. This was following feedback from some participants that said that asking MSM about their age so early in a questionnaire can be disturbing. Questions that asked about the number of sexual partners that participants met in various settings in the previous six and twelve months were omitted following the pilot study. Many participants said that they found this information too difficult to recall. The questions that asked about numbers of contacts within the previous three months remained. Participants of the pilot said that it took 7-10 minutes to complete and they considered this a reasonable amount of time. For many, the questionnaire was completed while waiting to meet a member of clinic staff and therefore did not add any additional time to that already spent in the clinic. No changes to the information leaflet or consent form were made as a result of the pilot.

#### **4.6.7.2 Pilot study: contact questionnaire**

The 'contact' questionnaire pilot study commenced in December 2002. Ten people who attended clinic as a result of partner notification for syphilis were invited to participate. The response rate for the pilot was 90% (n = 9 people). As a result, similar changes that were made to the case questionnaire were also made to the contact questionnaire following the pilot. All participants said they found the questionnaire easy to complete, with no difficulty in understanding being reported. The time taken to complete the questionnaire ranged from 6-14 minutes. No changes to the information leaflet or consent form were made as a result of the pilot.



### **4.6.7.3 Pilot study: community questionnaire**

The pilot study commenced in November 2003. Participants were recruited from a community-based clinic (GMHP). Ten participants (response rate 100%) agreed to complete the questionnaire. They were asked to comment on any difficulty they had completing the questionnaire. All participants stated that they considered the vignette a useful and clear way to describe the concept of partner notification. Only one question was changed as a result of the pilot. The statement ‘If I had syphilis I would tell all my sexual partners’ was changed to ‘If I had syphilis I would *try* to tell all my sexual partners’. A number of participants acknowledged the practical difficulties people may have contacting their partners. They said many people may not have the names or phone numbers to contact previous sexual contacts. An illustration on the front page of the questionnaire was also removed following recommendations from participants as they felt it did not enhance the layout of the questionnaire. As a result of removing this image it was possible to increase the text font to size sixteen and still keep within the two pages of the questionnaire. Participants suggested that this amendment would improve the visual impact of the questionnaire and make it easier to read in poorly lit social venues. Participants stated that it did not require much time commitment and the majority completed it in less than five minutes.

## **4.7 RECRUITMENT AND SAMPLE**

### **4.7.1 Negotiating research access**

Negotiating research access is a key issue when conducting research in general but in particular in relation to sensitive research such as sexual health. The success in securing research access to the first study site was because I was known to the gatekeepers of the clinical and community services. I had worked for a number of years as a health advisor in the two clinical settings prior to conducting the research. In addition, I had been involved in syphilis outbreak awareness work in the community social venues prior to conducting the present study.

Access to the second clinical site (GMHP) was more difficult to obtain. Formal permission to carry out the study at this site was not obtained until over three months

after recruitment to the GUIDE clinic had commenced. Following negotiations with the coordinator and medical consultant of the service, it was agreed that I could meet with the other members of the multidisciplinary team to discuss my research study. The outcome of this meeting was that they were prepared to allow me to carry out recruitment during two evening clinics. Upon commencement of this phase of the research, nationwide industrial action by public health doctors delayed recruitment for a further month. Although time consuming to obtain access to this site, recruitment from this venue, as well as St James's Hospital, added to the diversity of the study population. Many people said that they would go to one clinic and not the other. In addition, the GMHP is a community-based clinic. It is a more informal environment, where clinics are only conducted in the evenings. These clinics work in conjunction with an active outreach team.

It was anticipated that recruitment in the non-clinical settings would prove to be the most challenging. As mentioned earlier, I decided to recruit for the community component of the research at the same time as community blood testing for syphilis was being carried out in these social venues. Access was secured through the intervention sub-committee of the Dublin syphilis outbreak control team. Onsite testing was carried out, following negotiation with the managers and owners of the various venues (Coleman et al 2004). Outreach workers and nurses explained to those having blood tests, that they were under no obligation to complete a questionnaire even if they wished to test for syphilis. The questionnaires were completed away from the blood testing area. Those agreeing to participate in the follow-up qualitative component of the research were offered one of three locations: a meeting room in the GUIDE clinic, a room in a community setting, or an office in the university at a time convenient to them.

As I have discussed, I had worked in sexual health services for a considerable length of time prior to conducting the study, I had privileged access to the population of interest for this study. I was well known to the gatekeepers of the target population for the research, and this assisted in securing research access. I also had developed skills in the area. Despite these advantages there were potential issues to be considered. My position as a

practitioner doing research gave rise to a possible role conflict. This will be further referred to below under 'Positionality.'

#### **4.8 Data Collection: Quantitative**

Data collection for the quantitative component of the study was carried out from December 2002 to December 2003. The majority of recruitment (91.1%) was done in St James Hospital. The reason for this was not only due to the larger numbers attending this site but also, as discussed earlier, a delay in commencing recruitment at the GMHP occurred. The community questionnaires were administered in four different social venues from November 2003 to December 2003. The main inclusion category for potential participants for the case questionnaire was that they had been diagnosed with syphilis. The main inclusion criterion for recruitment for the contact questionnaire survey was that potential participants had attended clinic as a result of partner notification. Further inclusion criteria for both surveys were that participants were men who had sex with another man in the previous twelve months, over eighteen years of age, were fluent in the English language and were able to give informed consent. The inclusion criteria for the community questionnaire were MSM who were present in the community social venues at the time of onsite testing, were over eighteen years of age, fluent in the English language and able to give informed consent. Exclusion criteria were individuals who did not fit the inclusion criteria, or if they were considered to be under any sort of emotional distress.

##### **4.8.1 Case questionnaire administration.**

The total population for the study period were invited to participate. Potential participants were referred to me from health advisors, social workers or doctors working in the clinic. The majority of participants completed the questionnaire in the clinic although some had a preference to complete the questionnaire over the phone at a time convenient to them. This was an exception to the earlier discussion on privacy and confidentiality. Participants were given the alternative options to complete the questionnaire in the clinic or by post. For those who chose this option their names or clinic reference numbers were

not recorded on the questionnaire. Two hundred and twenty two MSM were invited to participate in the case questionnaire; of these, two hundred agreed to participate (response rate 90%).

#### **4.8.2 Contact questionnaire administration**

The population of interest for this questionnaire survey were all MSM who attended clinical services as a result of partner notification within the twelve-month recruitment timeframe. The entire population of interest was also invited to participate. The sample included those who said they attended due to partner notification. All contacts that were attending the clinic during the study period were invited to participate. As with the case questionnaire, people were referred to me to participate in the questionnaire, by a health advisor, social worker or doctor. The majority were done in the clinic although some had a preference to complete the questionnaire over the phone at a time convenient to them. This was an exception to the earlier discussion on privacy and confidentiality. Participants were given the alternative options to complete the questionnaire in the clinic or by post. For those who chose this option their names or clinic reference numbers were not recorded on the questionnaire. One hundred and nineteen 'contacts' of syphilis were invited to participate in the 'contact' questionnaire, of these 104 agreed to participate (response rate 87.3%).

#### **4.8.3 Community questionnaire administration**

The population of interest for the community questionnaire were MSM recruited from clubs, pubs and saunas. While it would have been preferable to get a sample representative of MSM in Dublin, this was not realistically possible. Any researchers attempting to obtain a representative sample of MSM encounter this problem. One of the reasons for this is that men may choose not to reveal that they are a MSM. The exact number of MSM in Ireland (or Dublin) is unknown. Only 2.6% of people in the latest British national sexual health study reported same sex partnerships (Johnson et al 2001). The results of the Irish Study of Sexual Health and Relationships found 4% of the male population and 1% of the female population have ever had a same-sex genital experience (Layte et al 2006:220). In the present study a representative sample of all MSM was not possible. I sought to obtain as large a number of respondents as possible on the selected

nights in the venues. People in the community setting were recruited in four different commercial venues over eight time periods. Two hundred and fifty people were invited to participate in the community questionnaire; of these two hundred and four agreed to complete questionnaires (response rate: 81.6%). In the context of social settings, it was difficult to ascertain reasons for non-participation; however those that offered reasons included lack of interest in the study in a social setting and time constraints.

#### **4.9 QUANTITATIVE DATA ANALYSIS**

All quantitative data were entered into an excel package and then transferred to the Statistical Package for the Social Sciences (SPSS) version 11<sup>13</sup>. To ensure accuracy of data, they were double entered. The data type was specified in the variable view of SPSS. Data were categorised as being nominal, ordinal or continuous. Codes were attached to each of the variables. Many of the data were nominal. Each variable was given a unique code. Responses that were 'yes' or 'no' were given codes one and two respectively. Ordinal data such as strongly agree, agree, not sure, disagree and strongly disagree were coded 1, 2, 3, 4, and 5 respectively. The values for each variable were entered into the value labels of the SPSS package. Missing data were coded with the number 99. Not applicable was given a code in each of the value labels if appropriate to the question.

As mentioned earlier, three open questions were included in each of the case and contact questionnaires. The text of these quotations were all initially entered into the excel spreadsheet. Later, they were transferred to word and then to N6 student<sup>14</sup>, a software package for sorting and assisting in the analysis of qualitative data. These data were analysed using thematic analysis. The section on qualitative data analysis provides a more detailed discussion on thematic analysis and on the N6 software. The statistical analysis of the study is mainly descriptive; the analysis of the results only refers to the study population and not to a wider population. For continuous variables the mean and

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<sup>13</sup> 11.0.1 release 15 November 2001. SPSS Inc. Headquarters, 233 S. Wacker Drive, 11th floor Chicago, Illinois 60606

standard deviation was found. For nominal data the percentages were calculated. Graphs including bar charts were used to illustrate the results. Cross tabulations were also conducted to compare, age, social class and certain attitudes to sexual health and partner notification. Data from the three questionnaires were only combined where it was meaningful to do so ie. where the same question was asked of all three study populations.

#### **4.10 DEVELOPING THE DATA COLLECTION TOOLS: QUALITATIVE COMPONENT**

The aim of the qualitative component of the research was to explore in further depth the lay perspectives of partner notification. This section of the chapter will outline the methodology used for the qualitative component and the steps to ensure rigour in the process.

Interviewing is the most commonly used data collection method in qualitative research (Darlington and Scott 2002). There are many approaches to interviewing, with advantages and disadvantages associated with each. The first is whether to do group or individual interviews. Focus groups have advantages. They allow for an exchange of information between participants and allow for challenges to another's viewpoint. Amongst the disadvantages for the use of focus groups, is that the views of less vocal members of the group may not be heard. Group interactions require mutual self-disclosure, and because of this it is undeniable that some topics will be unacceptable for discussion among some categories of research participants (Morgan 2004:263). The sensitive nature of the subject under discussion was the primary reason for not choosing to use focus groups to collect data for this study. There was concern that someone may disclose something personal to them or their partners in a heated discussion, and later regret sharing this information. An individual interview was considered more appropriate. Conducting individual interviews meant that there was a significantly greater ability to protect the confidentiality of each research participant. Semi- structured individual interviews were used for this study. The reason for this was because similar topics could

be explored with each participant, but there was greater flexibility to explore topics and issues as they arose. As Power (2002: 88) points out, semi-structured interviews are particularly suited to the study of STI knowledge and behaviour as well as exploring lifestyle and contextual factors. Their aim in this study was to move beyond the rigid structure of the questionnaire, and to explore in more depth the complexity of the issue of partner notification from the perspective of men who have sex with men who were infected with, or affected by, syphilis. Interviewing, therefore, allowed for more expansive answers.

An interview topic guide was devised, based on the key issues raised in the literature review, and discussion with some people who completed the questionnaires (see topic guide appendix D). Interviews commenced in April 2003. The interviews lasted an average of forty-five minutes and were scheduled at a time and place convenient to the participant. The majority of interviews were conducted in a health advisor office in the GUIDE clinic. Other settings were in a meeting room in the GMHP, a health advisor office in the GMHP and an office in the university. One participant requested that the interview be conducted in his own office. For those interviews that were carried out in the sexual health clinics, where possible, interviews were scheduled for the least busy times. A number of participants opted for early morning interviews, which meant that they could have it done before going to work. A number also opted for evening interviews in the GMHP; this was a convenient city centre location. In each of the settings privacy for participants was ensured before commencing the interview.

#### **4.10.1 Sampling and recruitment of participants – Qualitative Component**

The process of sampling in qualitative research differs to that in quantitative research. I was conscious, at the outset, of the sensitive nature of the research subject and the realistic possibility that many may not wish to participate in the study. What came as more of a surprise, was the numbers, and the enthusiasm with which people were willing to participate.

I recruited participants from the clinical sites. Information was given in person to all who attended the clinics about the qualitative component of the study. Selected patients were approached on their return visit and an interview was arranged at a time convenient to them. Participants were selected based on their willingness to be interviewed and their diversity in terms of age and experience of partner notification. The inclusion and exclusion criteria for the qualitative part of the study were the same as the quantitative components. All participants were MSM and were over 18 years of age. Fifteen MSM with syphilis, fifteen MSM who attended clinic as a result of partner notification and ten MSM recruited from community social settings participated in individual face to face interviews. Diversity in terms of experience was sought. Five people who were invited to participate declined to do so. One man reported that he had ended his relationship with his wife, as a result of his diagnosis of syphilis. He said he had mixed feelings about partner notification and, although he felt it had a place in disease control, he also said the consequences of partner notification, for him, were too painful to discuss in an interview. Diversity in terms of ethnicity was something I also sought to achieve, but did not manage to do so. As mentioned above in relation to the profile participating in the quantitative stage, the relative ethnic homogeneity of Ireland at the time meant I was encountering very small numbers of non-Irish nationals. One gay man from Asia initially agreed to participate, but later phoned to cancel his appointment. He said that, on reflection, he was concerned about issues of confidentiality about attending a clinic in general, and therefore did not wish to participate. Another man said that he did not agree with the process of partner notification at all as he considered it to be too intrusive. He said that the process of taking personal sexual histories during medical consultations was, itself, an invasion of privacy. It was my aim to capture a range of views on partner notification including wholly negative views. But, despite trying to ensure this, some respondents may still have felt that I represented a health advisor position. Potential participants with a wholly negative view may have thought it irrelevant to participate. Two participants who had consented to participating did not show up for interviews. Interviews had been scheduled two weeks in advance. However, these dates were scheduled for after Christmas, which meant that they might have simply forgotten. I had given them a wallet size card with a contact mobile number, if they wished to call me. I



chose not to contact them, because of the sensitive nature of the research, recognising their right to change their minds about participation.

#### **4. 10 .2 Interview process and style**

I conducted all interviews. A short amount of time spent on general conversation while having coffee or tea before each interview helped develop rapport, which is considered key to the success of interviews. Establishing trust and familiarity, showing genuine interest and not being judgemental are some important elements of building rapport (Glasser and Loughlin 1987:35) Sufficient amount of time was spent explaining the study and allowing the person time to express any concerns or questions they had about the study. Consent for the interview and to audiotape was granted prior to each interview. A cassette recorder was used, small enough to not be too distracting but with a high quality built in speaker. It was emphasised to all that they were '*in the driving seat*'; therefore, if they wished to stop the tape, and end the interview at any time they were welcome to do so. To emphasise this, I put the small tape-recorder closer to them than to me, and pointed out the red stop button that they could press at any time. Only one interview was not tape-recorded. The participant had initially been hesitant to have his voice recorded, but was still willing to participate in an interview. When I arrived at the interview, he had changed his mind, but by this time I did not have the audiocassette with me. Carrying out the one interview without audio- recording, helped make me realise how much more effective it was to communicate in an interview setting without having to try to write all the key points down. While that one interview had been productive, I felt the communication was hampered by my inability to maintain proper eye contact while also writing notes. For the remaining interviews, a number of notes were made in the interview, but the majority were made immediately afterwards. Sufficient time was allocated to each interview to ensure that participants would not feel rushed. I gave myself adequate time and space to make field and reflective notes after each interview. This ensured that these notes were made while fresh in my mind.

### 4.10.3 Positionality

In qualitative research the position of the researcher is interactive. Researcher and participant are social actors in the research process. Studies carried out on the interviewing process have shown that participants respond differently, depending on how they see the person who is conducting the interview (Denscombe 2003). Influencing factors can be the age, gender, sexual orientation, and many other personal characteristics of the interviewer. As a heterosexual woman, I was aware that I was conducting research on the very sensitive topic of sexual health, and interviewing only men who have sex with men. Some have argued that researchers should be members of the groups that they are researching; there is also what Gatter (1999) describes as a methodological conundrum where the effects of identification with interviewees can be reversed. He offers the example of a gay man finding it easier to open up to someone perceived as less linked to him. He points out that while some identification between researcher and participants is considered a positive thing, over identification can result in a loss of objectivity. Miller and Glassner (2004: 132) argue that interviews can be accomplished in such a way as to make the social differences between the researcher and interviewee work in providing opportunities for individuals to articulate their feelings about their life experiences. 'Matching' interviewers with interviewees, by personal characteristics has been done in a number of studies. Ross (2000) carried out a study of sexual health needs of men who have sex with men, in a Scottish health board area, and used only MSM male interviewers. Spencer et al (1988) conducted qualitative work on sexual health and found only two out of the twenty men in their sample stated they would have a preference for a male interviewer. Among the three gay men in their sample, there was no clear preference for the interviewer to be gay, and all three said they were happy to be interviewed by a woman. Qualitative work carried out in preparation for Natsal II <sup>15</sup> found the communication skills of the interviewer to be the most important factor. Participants preferred interviewers who were warm, friendly, yet detached (Mitchell et al, 1998).

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<sup>15</sup> NATSAL II was the second British National Survey of Sexual Attitudes and Lifestyles.

My social position as a health advisor also influenced how participants and I interacted. When informing participants about the study, I told them all about my background as a sexual health advisor. A potential conflict existed between my role as a researcher and my role as a practitioner. While I could not, even if I wanted to, be divorced from my experiences, it was necessary, for me, to reflect frequently on my personal experiences as a health advisor, and to challenge my own assumptions (See under ‘audit trail’ in Quality mechanisms in Qualitative Research below). My basic position entering this study was that the process of partner notification had important health merits, and this was the reason that I had engaged many professional hours in this activity, as a core part of my role in the previous three years. However, I also had a sense of some disquiet with the process, and this in some respects was driving my research interests. I was keen to explore the lay perspective of partner notification, and sought to capture the complexity of a world, that when viewed from epidemiological public health rationalities could be simply reduced to mere numbers. It was necessary to be aware and reflect on my position at all the stages of planning, conducting and analysis of the interviews. An advantage of my previous experience working in the specialist area, and working as the designated health advisor of the syphilis outbreak team, meant that I was familiar and comfortable with discussing the issues. Some of the participants referred to this:

*I mean... I have no worries ... telling somebody like you... who works in a clinic like this...that I have had sex in a sauna... with somebody whose name I didn't ever know. Not mind have now... or ever... have his number or anything like that... I think a lot of people would find that incredible. (Interviewee 2)*

*No! I don't tell anybody about my sexual activities unless the doctor or a health Advisor (Interviewee 3)*

#### **4. 11. QUALITATIVE DATA ANALYSIS**

All audiotaped interviews were fully transcribed verbatim. I did the first fifteen; the aim of this was to ensure immersion in the data. The transcriptions were typed within twenty four to forty eight hours of the interview, at a time when the interview was still fresh in

my mind. A secretary did the remaining twenty-five. The confidential nature of the material was discussed and respect for confidentiality agreed by this person at the outset. All transcriptions were later read by me whilst also listening once again to the tapes. Six participants, from the three groups, were invited to read their own interviews and make any corrections or comments. The purpose of this was to ensure that the transcriptions were accurate and reflected the totality of the interview experience (Polit and Beck 2004). The majority agreed with this and only very small corrections were made. Many commented on certain expressions that they used frequently, or their use of grammar. Many also engaged in some further discussions about the research and other additional thoughts following interviews. It also provided a further opportunity to debrief on any undesirable effects of conducting the research. Fortunately, all said there were no negative effects and some felt they considered it helpful to talk about their experiences of partner notification.

Thematic analysis was used to analyse the data; this is a process by which the various accounts gathered are compared with each other to classify those themes that recur in the data. It forms the basis of more sophisticated methods of qualitative analysis in which the researcher moves beyond simply categorising and coding the data to thinking about how the codes relate to each other and asking more complicated questions. A good qualitative analysis should provide a thick, rich description of the setting studied, link into theory and provide a satisfying and credible account of what is going on (Green and Thorogood 2004:177).

Once field notes and interviews were transcribed they were read a number of times. Initial analysis was done manually, by coding using a cut and paste approach, with the aim of comparing codes, and starting to build up categories and obtain meaning in the data. Many copies of the transcriptions were printed out. Codes were allocated and then these were sorted into themes. This process was time consuming and labour intensive as well as requiring a lot of space and privacy given the content of the interviews. Following this, the much tidier approach of using a computer software programme to assist in sorting the data, was implemented. While it might seem that there was a duplication of

efforts, it helped to ensure that adequate time was spent immersed in the data. Using computer software alone for analysis can be distracting; sometimes people can become so concerned with developing skills in using and maximising the capabilities of the software, that they become distracted from the main issue of analysing the data. The key advantage of using dedicated software packages is that analysis can be more rigorous and systematic than that done by hand (Green and Thorogood 2004:190). It therefore helps to manage data and retrieve it more efficiently.

NUD\*IST, which stands for Non-numerical Unstructured data\* Indexing Searching and Theorising, Version 6 Student (also called N6 student) was used in this study. Data were prepared from word documents and then imported into N6.<sup>16</sup> The programme offers tools to assist with the analysing of qualitative data. Data were read line by line and coding was carried out<sup>17</sup>. Using the document and node explorer, data could be checked and rechecked with other nodes. All data were coded at least once, initially into 224 codes; this was later reduced to 10 categories.

#### **4.11.1 Quality mechanisms in analysing qualitative data**

Qualitative data is not exempt from the need to be trustworthy. A critic of qualitative research may ask how one can be sure that it is not the researcher's subjective interpretation of events that is presented (Green and Thorogood 2004:192). Four criteria for ensuring the trustworthiness of qualitative data are outlined by Lincoln and Guba (1985). These are: credibility, dependability, confirmability and transferability (Lincoln and Guba 1985). Steps were taken in this present research to ensure that these criteria were achieved. Credibility is considered by Lincoln and Guba (1985) as the most important of all four and is ensured by prolonged engagement, peer debriefing, member checking, negative case analysis, use of simple counts, and credibility of the researcher. To ensure prolonged engagement in the data and in the setting, I was present in the setting of the research for the entire year of data collection; this included being at the main STI clinic for the study Monday to Friday. It also included two evening clinics in

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<sup>17</sup> Codes are called nodes in the N6 Package

the community-based clinic. I also attended all the sessions of 'onsite' blood testing in community social settings for the purpose of the community-based strand of the study. By having prolonged engagement in these settings, it facilitated the development of trust and rapport between me and participants of the research. Peer debriefing is another mechanism for increasing credibility. I was fortunate to have access to a number of experts in STIs and also experts in gay community work willing to discuss my research with me, and the various stages of the process. More formally, I got two social researchers to carry out *blind* analysis on two anonymous interviews each, and to compare their findings with mine. One of these researchers was an experienced qualitative researcher with over twenty years' experience in sexual health. While some differences were found, considerable similarities in main themes emerged. Green and Thorogood (2004) point out that it would not be expected for two researchers to identify the same themes because background, knowledge, and theoretical approach can influence this. Attention to this is still desirable and the exercise helped me consider more critically the analysis I had carried out. Another way of heightening credibility is through member checking, which involves taking the findings back to the participants and checking that they agree with them. Interview transcripts were given to six participants and they were asked to review them. The findings of the analysis were returned to the same six participants and they were asked to check if they agreed with the findings. These people were chosen opportunistically based on their ability to return to meet me and did so at different times during the data collection and analysis period. Agreement was found on most topics with some saying that some of the issues were not applicable to them. In particular, the issue of anonymous sex was contentious, although most agreed that it was a potential barrier to partner notification. The process of searching for disconfirming evidence is also another approach to ensuring credibility. This was carried out in two ways; by purposively selecting participants who were likely to challenge the emerging themes and secondly in the analysis itself by actively looking for evidence to disconfirm the main findings. Simple counting is another approach to ensuring the faith in the validity of findings, recommended by a number of researchers. Green and Thorogood (2004) warn that it is not always appropriate to count in this way. This was done in a very

cautious way in this research as the appropriateness of it was questionable in the context of this study.

Dependability is another important issue for the rigour of research findings and has been described as something similar to reliability in quantitative research (Polit and Hungler 1997:306). To be dependable, the research should be stable and another researcher should be able to follow the steps taken. My primary supervisor assisted me here by reviewing the ways in which my initial codes were sorted into higher order themes and assessing with me the ways in which conclusions were being actively drawn from the data. A number of other measures can be taken to ensure dependability, such as keeping an audit trail, which helps the reader follow the steps of the researcher thus ensuring 'confirmability' (Lincoln and Guba 1985). Audit trail documents include, raw data, data that has been reduced, notes on decisions in method and analysis and reflective notes. Transferability is concerned with the generalisability of the findings (Lincoln and Guba 1985). To achieve this, sufficient detail should be provided in the research report, to help readers consider its application to other settings.

#### **4.12 STRENGTHS AND WEAKNESSES OF THE METHODOLOGICAL APPROACH**

The research approach taken for this study had a number of strengths as well as limitations. The strength of the study is that it researched the subject of partner notification from the perspective of MSM. The lay perspectives of MSM, (as well as the lay perspective on the subject in general) are under-researched. The timing of the study, in the context of an outbreak of syphilis was an advantage, because partner notification was carried out more intensively at this time. As a result of this, there was a heightened awareness of syphilis and partner notification by the Gay community. A combined quantitative and qualitative approach enhanced the study. The former provided for a better understanding of the distribution on attitudes within the research population, while the latter explored in much greater depth the experiences and attitudes to partner notification. As described in the course of this text, the study design changed from a sequential 'qualitative then quantitative' design to a more interactive design. This

resulted in a greater amount of consultation than initially planned. This wide consultation with gay community members and representatives enhanced the study. They offered practical as well as insightful perspectives and were generous with their time and suggestions. Extending the study beyond the clinical settings further added to it. I was unable to find any research study that explored the lay perspective on partner notification for sexually acquired infections conducted outside STI clinics. I attempted to increase the diversity of those participating in sexual health studies by recruiting from community settings.

A number of limitations in the research approach can also be identified. One of the biggest limitations is that I cannot say that this study can be generalisable to other populations of MSM. The population who participated in the case questionnaire represent a considerable majority of MSM with diagnosed syphilis in the Dublin area within the year of data collection. This is based on the fact that approximately 90% of all syphilis cases in the Eastern Region of Ireland (including Dublin) are treated at the site of the current study (Hopkins et al 2004:317). The response rate to the 'case' questionnaire was high at 90% and no significant demographic differences were found between those who agreed and those who declined to participate. Those diagnosed with infectious syphilis and who chose not to disclose the information that they were men who have sex with men were not invited to participate as they did not meet the stated inclusion criteria for the study. The numbers of people falling into this category are likely to be low based on clinical records from the two clinical research sites. Over 84% of all men with infectious syphilis attending these clinics said they were gay or bisexual. In a similar way, men who were contact traced and who did not reveal (i) gay or bisexual (ii) that they were a contact of infection, would also not have been invited to participate in the contact questionnaire.

As discussed earlier in this chapter, the original questionnaires were developed very early on in the study because of ethical committee requirements. The original questionnaires do not solely focus on the issue of acceptability – they focus on effectiveness and acceptability and some ancillary information. As the study progressed, I realised



effectiveness could only be poorly studied in this (retrospective) study design , also such studies are very common. Acceptability was on the other hand, under-researched and this was an original part of the study. Therefore, as the study progressed, acceptability became more important than effectiveness. As a result, I have focused on some aspects of the questionnaire and building a coherent story around that, rather than including all the results which could distract from the main focus.

Limitations also exist in relation to the use of the social venues – the community setting in the research. The participants were likely to be those who usually socialise in clubs and pubs. Extending my data collection to include saunas was an attempt to achieve greater diversity of participants. It was not possible, for the reasons outlined earlier in this chapter, to recruit in all the settings that I approached or considered approaching. The issue of representativeness when sampling MSM is problematic and well documented, therefore this was not my aim. I did seek, however, to achieve diversity in terms of study participants. The discussion of the demographic profile of my study participants highlighted the limitations to this diversity. In particular, clinical participants were a highly educated group and almost all were Irish. Certain minority groups may have different perspectives on the subject of partner notification. The perspective of MSM from ethnic minorities including the travelling community is worthy of further research. This study has been confined to those recruited from an urban centre. The demographic profile of participants showed that the majority were resident in the Greater Dublin Area. Further Irish research beyond Dublin, and in particular focusing on the needs of rural MSM is also needed.

#### **4.13 CONCLUSION**

The methodology of this study may be summarised as a mixed-method study involving survey questionnaires and semi-structured interviews. The setting for the research included two clinical settings – one hospital clinic and one community based GMHP clinic and community settings (social venues). The study had three sub-populations: ‘cases’ and ‘contacts’ populations, which were recruited from the clinical sites and the community population, which was recruited from the community setting (social venues).

Access to the research sites involved long and protracted negotiations, especially in relation to the GMHP clinic and the community settings (social venues). However, as outlined in this study, the broader negotiations and consultations benefited the overall study design. Data collection extended over a period of more than one year. For reasons discussed in relation to ethical requirements, and difficulties in gaining access to all research sites with perfect timing, the qualitative and quantitative data collection occurred iteratively rather than sequentially. The data collection tools were developed from extant questionnaires and previous literature and were extensively piloted. The response rates were very high.. Data analysis for the quantitative component was relatively basic descriptive analysis. The focus of the analysis was on presenting broad distributions of the participants' experiences of sexual health services and especially partner notification. The qualitative analysis followed the principles of thematic analysis and was much more intricate. This chapter has outlined the processes of ensuring that readers could have confidence in the quality of the study as well as outlining its limitations.

## **CHAPTER 5**

### **LIFESTYLE, THE PRACTICE OF SEX AND PARTNER NOTIFICATION**

#### **5.1 Introduction**

In this chapter the findings in relation to lifestyle, the practice of sex, and partner notification among MSM are discussed. Partner notification is not a simple issue. The complex interplay of issues which can pose as barriers to the effectiveness of the practice will be discussed. These include: unprotected sex, alcohol and drug use, the issue of oral sex and the construction of risk difficulties negotiating safer sex, and the impact of HIV/AIDS. The issue of desire and the anonymous nature of sexual exchanges will also be discussed in the course of this chapter. Before moving to these findings, I will turn first to describe the demographic profile of participants to both the quantitative and qualitative components of the study.

#### **5.2 Demographic profile of participants – quantitative component**

This section will outline the demographic profile of participants. I will deal with the three study populations of ‘cases’, ‘contacts’ and ‘community’ participants. To enhance participation, the questionnaires that were administered in the community settings were considerably shorter than those conducted in the clinical settings. More information can be derived from questionnaires administered in the latter rather than the former settings.

##### **5.2.1 Age**

Participants to the clinical component of the study (case and contact questionnaires) ranged in age from 18 to 69 years with a mean age of 36.1 years (SD 9.46). The age range varied between ‘cases’ and ‘contacts’ (see table 5.1). The range for all ‘cases’ was 21-69 years, mean: 37.59 years (SD=9.59) and for ‘contacts’ was 18-65 years, mean: 33.17 years (SD= 8.49). Community participants also had a diverse age profile. The largest percentage (40.7%, n = 83) was in the 20-29 year age group. A quarter of all

participants were aged 30–39 years (26.5%, n = 54), 13.7% (n = 28) were in the 40-49 years age group, 12.3% (n = 25) were over 50 years, and finally only 6.9 % (n = 14) were under 19 years.

This mean age for the clinical component of the study (36.1 years) differs from other studies on MSM, which, as Mc Manus (2003:8) points out, is often biased towards younger respondents. The age in the clinical component of the study is close to the mean age of 35.6 years for the Irish population based on the 2006 census (Central Statistics Office 2007a). The largest study to date of MSM in Ireland (Carroll et al 2002), which involved 1290 people, reported that the mean age of study participants was 29.77 years.

**Table 5.1** Age Profile of Participants: Clinical and Community Questionnaires

	Clinical Questionnaire	Community Questionnaire
19 years and under	0.3% (n = 1 )	6.9% (n = 14)
20-29 years	23.4% (n= 71)	40.7% (n = 83)
30-39 years	44.1% (n= 132)	26.5% (n= 54)
40-49 years	20.9% (n = 63)	13.7 % (n = 28)
50 years and older	10.5% (n = 32)	12.3% (n= 25)
Missing	n=5	n= 0

### 5.2.2 Education

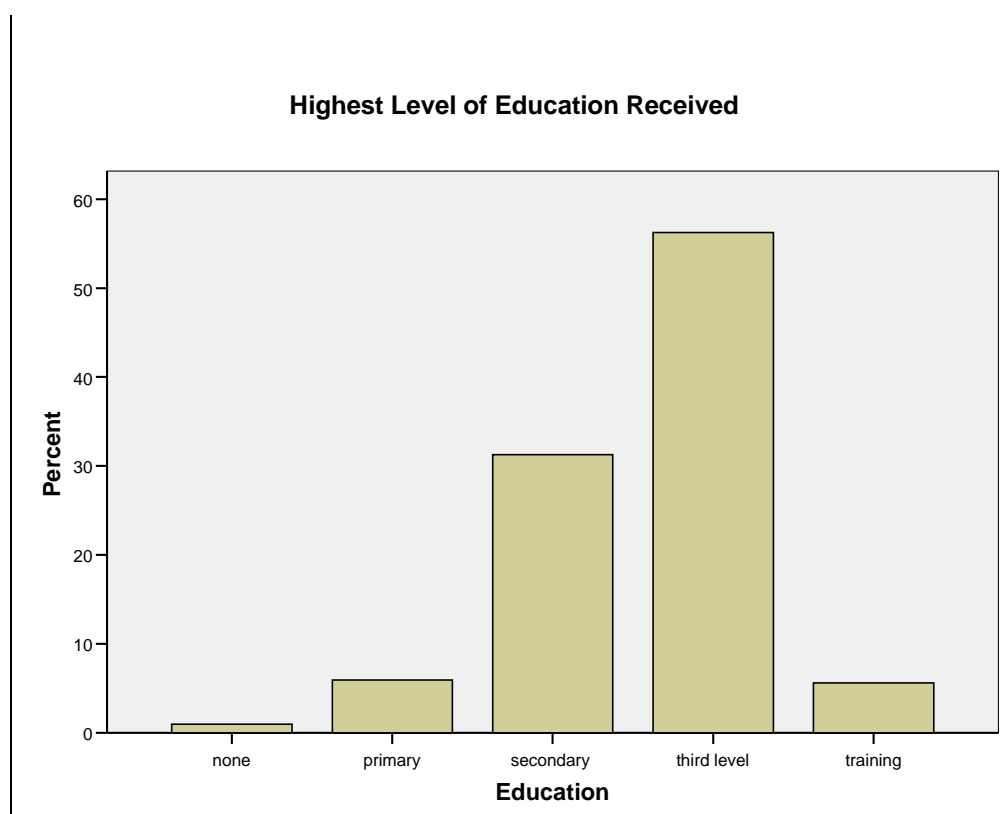
Questions in relation to levels of education were asked in the clinical questionnaires only. Over half (56.3%, n = 171) of participants had completed third level education (see table 5.2 and figure 5.1 highlighted text added). The results for this question are just lower than that found in the all Ireland gay men’s study (Carroll 2002), which found levels of third level education at 60.3% of the total sample of 1290 men. The latest figures from the Irish census (of population of the Republic of Ireland in 2006) found that 32% had completed third level education (Central Statistics Office 2007c). High levels of education among MSM in the present (and vital statistics study, Carroll et al 2002) are

similar to an international profile, which shows that MSM participants in research studies are found to be a highly educated group (Mc Manus 2003:8).

**Table 5.2:** Highest Level of Education Obtained – Clinical Questionnaire

Highest level of education	Number	Percentage
None	n = 3	1%
Primary	n = 18	5.9%
Secondary	n = 95	31.3%
Training Course	n = 17	5.6%
Third Level	n = 171	56.3%
Missing	n =0	0%

**Figure 5.1**



### 5.2.3 Employment Status

The overwhelming majority of participants were employed (79.7%, n = 240) with only 6.6% (n= 20) unemployed (see table 5.3). It is interesting to note that these results are almost identical to that obtained in the Vital Statistics Study (Carroll et al 2002). The findings in that study showed a total employment rate of 79.8% and an unemployment rate of 6.6% of the sample. This figure is lower than the results from the 2006 Irish census, which found unemployment rates to be 8.5% (CSO 2007b).

**Table 5.3:** Employment Status: Clinical Questionnaire

Employment Status	Number	Percentage
Employed	n = 240	79.7%
Unemployed	n =20	6.6%
Full Time Education	n= 19	6.3%
Training	n = 1	0.3%
Disability	n= 9	3.0%
Retired	n= 5	1.7%
Other	n=7	2.3%
missing	n =3	0.1%

### 5.2.4 Nationality and Place of Residence

The vast majority of participants in both the clinic based and community-based questionnaires were resident in the Greater Dublin Area (GDA), 81.1% (n = 245) and 68.6% (n = 140) respectively (see table 5.4). The high percentage, who reported living in Dublin, reflects the approach to recruitment. I did not seek to recruit outside the Greater Dublin Area, primarily because the syphilis outbreak was largely reported from clinics in the Dublin area and the focus of this study was on partner notification in the context of an outbreak of syphilis. Many people may have travelled from more rural areas to Ireland's capital city to attend clinical services (and also to visit social venues). I feel I may have captured a small number of these people who lived outside Dublin (18.8%, n = 57 and 31.4%, n = 64 for the clinical and community questionnaires respectively). I believe that further work on the sexual health needs of rural MSM is required.<sup>18</sup>

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<sup>18</sup> An interesting qualitative study by Anthony Galvin (2002, unpublished thesis) explores the life experiences of rural gay men in Ireland

**Table 5.4** Place of Residence: Clinical and Community Questionnaire

	Yes	No
Resident in Dublin (Clinical Questionnaire) (missing n=2)	n = 245 (81.1%)	n= 57 (18.9%)
Resident in Dublin (Community Questionnaire) (missing n=0)	n= 140 (68.6%)	n= 64 (31.4%)

**Table 5.5** Distance from Dublin: Clinical Questionnaire

Distance from Dublin	Number	Percentage
Less than 50 miles	n = 20	6.7%
50- 100 miles	n = 19	6.3%
100- 150 miles	n = 11	3.7%
Greater than 150 miles	n = 5	1.7%
Not Applicable (living in Dublin)	n = 245	81.7%
Missing	n =4	

In terms of nationality, participants in the clinical components of the study were asked about their nationality or ethnic group (see table 5.6)<sup>19</sup>. The majority (89%, n = 268) were Irish nationals. This figure does not indicate much ethnic diversity in terms of those who participated in the study. This is reflective of a relatively homogenous ethnic population profile in Ireland. The latest Irish Census (2006) showed 88.9% of the population were Irish nationals (CSO 2007a).

<sup>19</sup> While I recognise there is a difference between the meaning ethnicity and nationality, I combined the two of these in the one question following feedback at planning stage of the questionnaire. Participants had an opportunity to describe themselves using either or both terms. The majority described themselves as Irish, while many also described themselves as White Irish. The travelling community are an indigenous ethnic minority within Ireland. According to the 2006 census, there are 22,400 members of the travelling community in Ireland (CSO 2007a)

**Table 5.6** Nationality: Clinical Questionnaire

Nationality	Number	Percentage
Irish	n = 268	89.0%
Rest of Europe	n = 21	7.0%
Africa	n = 5	1.7%
Asia	n = 2	0.6%
America	n = 5	1.7%
Other Nationalities	n = 0	0%
Missing	n=3	

In conclusion, many studies on MSM are biased towards younger, highly educated respondents (Mc Manus 2003:8). The age profile of those participating in the clinical component of this study is older than that of participants in other studies of MSM and is close to the average for the Irish population. Respondents to the clinical component are highly educated, The majority of participants lived in Dublin and were Irish nationals.

### **5.3 Profile of sample: qualitative component**

A purposive sample of 40 MSM were recruited for the qualitative component of the study. Variation was sought by recruiting in different settings: two separate sexual health clinics and also a variety of gay social venues including, clubs, pubs and saunas. Variation was also sought by interviewing men with syphilis, men whose partners had syphilis and men in neither category who were recruited from social venues. Where possible, variation was also sought in terms of age, social class, ethnicity and urban-rural background. Table 5.7 outlines this variation



**Table 5.7:** Characteristics of Participant (qualitative) N=40

<b>Characteristic</b>	<b>Numbers</b>
<b>Age (at Interview)</b>	
20-35 Years	19
36- 50 Years	16
Over 51 Years	5
<b>Employment Type</b>	
Professional/Higher Managerial	12
Other non- manual	10
Skilled Manual	12
Student/Unemployed	6
<b>Type of Client</b>	
Index	15
Contact	15
Non-Patient	10
<b>Source of Recruitment</b>	
Clinical Site	30
Gay Venues	10

#### **5.4 Discussion on partner notification**

Current clinical practice recommends that all potentially infected partners of individuals with syphilis are notified and invited to attend for screening and (if necessary) treatment (Clinical Effectiveness Group 2002). In the present study, the vast majority (95.5 % n = 190) of men with syphilis, who attended clinic, said that partner notification had been discussed with them<sup>20</sup>. Despite this, only 31.1% (n = 50) said that all their partners were

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<sup>20</sup> 4.5% (n =9) said that it had not been discussed and the remaining person (.5%) left this blank on the questionnaire.

informed at the time of the interview (which usually took place 2-3 weeks after diagnosis). Expressed another way, the majority of participants (68.9% n=111) reported that all of their contacts had *not* been informed (note missing for this question=39). Over a fifth (23.8% n = 46) said that none of their partners were informed. This suggests a low level of effectiveness of partner notification among respondents in this study. The UK national guidelines on the management of early syphilis state that at least 60% of all contactable partners of patients with syphilis should attend for screening and/or treatment (Clinical Effectiveness Group 2002). My study results are not unusual. Even lower levels of effectiveness of partner notification have been found in other syphilis outbreaks occurring among MSM. In East London, Hourihan et al (2004) found that of a total of 1279 contacts cited for 103 men with syphilis, only 4% were successfully traced and screened. Similarly in Manchester, Kingston and Higgins (2004) also reported that only 4% of sexual contacts were notified, in their audit of 72 cases of syphilis, (90% of which occurred among MSM).

As proposed previously, to capture a true interpretation of the concept of partner notification, as well as its limitations, it is necessary to look beyond the crude numbers of partners traced and informed. Factors such as the numbers of partners with whom a person has unprotected sex, the use of drugs and alcohol, the anonymous nature of sexual encounters, and the settings in which these encounters occur all have a role to play in the success or failure of partner notification. It is these issues - the lived reality of sex, and how it affects the transmission of syphilis, which I am going to address in this chapter. Central to these issues is the lay interpretation of risk as well as the lay interpretation of pleasure. As discussed earlier, the majority of men who participated in the study were men who had been diagnosed with syphilis, or who had attended a clinic as a result of partner notification. I do not, therefore, seek to be representative of the many MSM who have long term monogamous relationships and who may never come into contact with syphilis.

**Table 5.8:** Contact tracing: Data from Case Questionnaire

	Number	Percentage
<i>Was contact tracing discussed with you?</i> (missing n=1)	Yes: 190	95.5%
	No: 9	4.5%
All contacts informed (missing n=39)	Yes: 50	31.1%
	No: 111	68.9%
No contacts informed (missing n=7)	Yes: 46	23.8%
	No: 147	76.2%

### 5.5 Unprotected sex

The literature supports the finding that unprotected sex is a feature of life for some, but not all, MSM. What are the reasons that men engage in what health professionals might deem to be a ‘risky’ behaviour? Public health professional thinking puts forward the view that a rational person, when made aware of a potential danger, will avoid it. Such a perspective, however, undermines the complexity of personal choice, as well as ignoring issues such as pleasure and desire.

Lack of information is often put forward as a reason for unprotected sex (Ciesielski 2003). This, however, was not found for the majority in this study. Participants were asked to give their opinion on the statement: ‘*I do not think I have enough information on sexual health*’. The majority (65.5% n= 196)<sup>21</sup> disagreed or strongly disagreed with this statement. Access to condoms is also not an issue for most people, with 88.6% (n = 265)<sup>22</sup> disagreeing or strongly disagreeing with the statement ‘*I sometimes have a problem getting condoms*’.

Participants completing questionnaires were asked about condom use. In the clinical setting, this gives an indication as to whether or not partner notification should be conducted. While 56.4% (n=154) of participants in the present study said they always use

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<sup>21</sup> Note: missing n= 5

<sup>22</sup> Note: missing n=5

condoms for anal sex, 4.8% (n= 13) said they never do. The remainder said they usually (32.2%, n= 98) or rarely (2.6%, n=8) wear condoms.

**Table 5.9:** Condom Use for Anal Sex: Clinical Questionnaire

	Always	Usually	Rarely	Never
Condom Use for Anal Sex	n = 154 % =56.4	n = 98 % = 32.2	n = 8 % = 2.6	n = 13 % = 4.3
Missing: n=2				
Do not have anal sex n=9				

**Table 5.10** Sexual Health Questions: Clinical Questionnaire

	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
<i>“I don’t think I have enough information on sexual health” (Missing n=5)</i>	n= 11 %= 3.7	n= 51 %= 17.1	n=41 % = 13.7	n = 126 %= 42.1	n= 70 %= 23.4
<i>“I sometimes have a problem getting condoms” (Missing n=5)</i>	n= 11 %= 3.7	n= 20 %= 6.7	n= 3 %= 1.0	n= 105 %= 35.1	n= 160 %= 53.5

Several participants in the interviews discussed the issue of unprotected sex which many saw as a common occurrence.

I could lose count of the number of people who want to have unprotected sex

(Interview 5, Case)

I try to be as responsible as possible ... even in that situation...but from what I can see going on around me a lot of the sex is very unprotected

(Interview 9, Case)

I mean he did want to have unsafe sex with me...and there was no way I would

(Interview 26, Case)

Both partners being tested before having unprotected sex is sometimes perceived as one way of minimising, if not eliminating, the risk of getting a sexually acquired infection. Limitations of this approach are that it can take up to three months for some infections to be diagnosed, so both partners have to consider this time frame when testing, If one chooses to follow such an approach stringently, a visit to an STI screening service would be required with each new partner. For some, this may not be acceptable, as this example of an interviewee's friend highlights:

I know my friend... I won't mention his name... he was with a boyfriend for 3 months and he wanted to have sex without using protection and...[partner's name]...said yeah no problem, the two of us go... they wanted to get serious, they go ...and get tested... and if it came up clear... or ...the both of them were positive... but he didn't want to... and...he said 'no way' and... he (my friend) broke up over that... and I think he's a very strong person to do that....

(Interview 9, Community)

## **5.6 Alcohol and Drug Use**

Drug and alcohol use is often cited as an explanation for having unprotected sex (Hirshfield et al 2004, Clatts et al 2005). The findings of this study support such a view. In the quantitative component of the study, fifty one percent of participants reported drug use in the last year (n= 155). Only 7.6% (n= 23) report that they never (or no longer) drink alcohol. Two thirds (66.1%, n= 201) said that they would usually drink alcohol before having sex. Drug use was also reported in association with sexual activity. The use

of poppers (amyl nitrate) was the most frequently used drug found in this study. Thirty six percent of participants (n= 109) reporting using this drug within the last month, with 27.6% (n= 84) saying that they would usually use this drug before having sex. Other drugs that participants reported using before having sex were ecstasy (7.9%, n = 24) and cocaine (4.3%, n= 13).

**Table 5.11** Usual drug use before having sex : clinical questionnaire

Missing n= 0

	Yes	No
Alcohol	n = 201 % = 66.1	n = 103 % = 33.9
Cannabis (Hash)	n = 36 % = 11.8	n = 268 % = 88.2
Ecstasy	n = 24 % = 7.9	n = 280 % = 92.1
Cocaine	n = 13 % = 4.3	n = 291 % = 95.7
Poppers (amyl nitrate)	n = 84 % = 27.6	n = 220 % = 72.4

The findings from the individual interviews support the quantitative findings.

Yeah .. it depends like.. I think one of the big factors a lot of times  
... for lots of people and myself also.. It would be alcohol or drugs... heat of the  
moment

(Interview 11, Case)

I wasn't going to do anything ...but I was very drunk... and I think that is my  
problem.. I haven't been out that much ... I put myself at risk again but that doesn't

kick in until the next morning ... and you wake up and go ... what the hell... done the night before...It depends... you can be drunk and then you can be over drunk and I tend to be over drunk!” (Interview 29, Case)

### 5.7 Interpretation of Risk

Unprotected sex cannot be explained by reference to alcohol and drugs alone. How risk is interpreted and negotiated by men is of particular importance. In this next section, I will discuss the issue of oral sex and syphilis transmission, the negotiation of risk between partners and the impact of HIV.

#### *Oral sex*

The promotion of safer sex has primarily focused on condom use and in particular has largely focused on the prevention of HIV rather than any other sexually acquired infections. Using condoms for anal and vaginal sex is considered one of the most important ways of reducing the sexual transmission of HIV and one that has been echoed throughout the world since health education campaigns on the subject began in the mid eighties. The risk of acquiring HIV through unprotected oral sex was considered relatively low. This interpretation of oral sex risk is evident in my study in that 90% of men (n= 263) said that they rarely or never wear condoms for oral sex, while only 3% (n= 9) said they always do.

Table: 5.12 Condom use for oral sex: Clinical Questionnaire

	Number	Percentage
Always	n = 9	3.1%
Usually	n = 21	7.2%
Rarely	n = 57	19.5%
Never	n = 206	70.3%
Don't have oral sex	n= 9	
Missing	n= 2	

This high rate of unprotected oral sex is important, when one considers that unprotected oral sex easily facilitates syphilis transmission. Hourihan et al (2004:509) state that in relation to syphilis, oral sex is a significant risk factor and a distinctly 'unsafe' practice. The main reason for this is that oral lesions are considered to be highly infectious. Raising the issue of oral sex as a route of transmission was a focus of some of the health promotion campaigns that were conducted in Dublin as well as elsewhere, particularly at the time of this study. But nonetheless, as the following interview excerpt shows, not everyone was aware of this as a route of transmission and even if aware, the majority were not prepared to change this practice.

Through oral sex can it? Well you are not going to have ... (laughs)... nobody ever asked me to wear a condom for oral sex nor have I asked them, so it comes down to awareness.

(Interview 23, Case)

### ***The construction of risk***

How men interpreted risk was played out in their sexual encounters. A situation was often viewed as 'risky' based on the encounter rather than use of condoms. A number of participants pointed out that they frequently made judgments about safety based on the physical appearance of sexual partners.

I suppose just going on their visual I would have thought aahm meeting like with like if you could say... I know that doesn't make sense now ...but prior to January (when he was diagnosed with syphilis) I would have said oh if I was in the [*names sauna*] well... he looks healthy...

(Interview 1, Case)



The following participant interprets his personal risk of infection in the context of the sexual relationship.

I remember just mapping it out one time, that my perception of risk was much more related to the tackiness of the sexual experience than the actual risk involved. Then... a more loving...more wholesome sex... I didn't worry as much about HIV. It's quite interesting really.

(Interview 19, Contact)

Some of the men in this study expressed a desire to embrace the risk and ignore worries, rather than be conscious of risk and protect themselves. As Lupton (1994: 107) point outs, engaging in risk not only inspires fear, anxiety and repulsion, it may also be viewed as pleasing, exciting and exhilarating. As Courtenay (2000) points out, embracing health risks can also be away of demonstrating masculinity.

There was one American on talking... and he said I don't want to know if I'm HIV positive... he said it would only make me morose and depressed, just 'to hell with it' attitude... So I don't know?...

(Interview 17, Contact).

Another participant talked about people who sought to get infected. It is interesting to note that participants who made reference to such people described others, rather than themselves, as being involved in the practice.

P: Yeah on the gay scene.. there is what they call bug catchers.. people who actively seek to get infected.

I: These people presumably would have unprotected sex?

P: Yeah.. that would be it..

I: Are these 'bug catchers' common do you think?

P: I don't really think so.. I think some of them begin or start by accidentally getting infected.. and then they think 'well I have HIV so.. let's get everything else' kind of thing... it is bizarre..

(Interview 11, Case)

### *Difficulties negotiating safer sex*

An important issue which was raised was the difficulty that is experienced negotiating safer sex. This extract from this participant explains in great depth the difficulty of his experience and refutes any suggestions that initiating safer sex is as simple as rolling on a condom. This participant describes the ridicule that he experienced when trying to initiate safer sex. Eventually, he had unprotected sex for many months with someone who he later discovered was, and knew himself to be, infected with HIV.

He was the first person ever... that I had unprotected sex with... and literally... I was putting a condom on... and he said to me... 'why are you putting it on?' The first time I ever had sex with him, 'do you think I've AIDS?' and I was like... 'no! not at all'... I'd never had unprotected sex with anyone... I totally thought there's no way on earth this guy is HIV... he laughed at me for putting on the condom... so I took it off... that was the first time I did... what came afterwards I didn't suspect for a minute... for starters I'd end up in a relationship with him... and that somebody could actually do that... could have HIV and literally laugh at someone when they put on a condom.

(Interview 18, Contact)

This participant goes on to say how complex the issues were for him because it was his first time loving someone.

I kind of lost my head, I don't know where, at that stage it was my first time loving somebody and I was... if you are... if I am... the two of us are... kind of thing and I was all over the place really... stupid.

(Interview 18, Contact)

### *Impact of HIV/AIDS*

The suggestion was made by participants that younger men were more likely to engage in 'risk behaviour' as they were a generation that had not experienced the AIDS health education campaigns of the 1980s, or perhaps, more importantly the direct experience of losing friends and loved ones to HIV/AIDS

It is that they are invincible.. I seem to attract younger people and I am not into that (unprotected sex) ...I like people my own age to go out with ...but you know yourself if somebody comes on to you and they are twenty one, twenty two you are, oh my god, it is an ego boost... it really is a major ego boost. And they say oh no condoms... but I say well I have them here in my pocket here so you can use it. And the guy will go off in a huff or else they won't use it...

(Interview 5, Case)

In my experience 35 and older... the condoms are always there the lubrication is always there. It is just assumed that you would use condoms.. 'cos they would have lost people. I would have lost .. not friends.. acquaintances in London. You know you met them once and then you would say the next time 'oh where are they? Where did they go?'... they are DEAD!

(Interview 5, Case)

But the effect of the early HIV campaign, and attitude to sexuality generally, had a negative impact on some participants for a considerable length of time. This participant recalls his experience.

Then I went back and got the results and I didn't have it at all... But he (the doctor) said did you realise you are going to have to change your homosexual lifestyle? And didn't tell me how... (*laughing*)...it was just that you are going to have to change your lifestyle.... So I left... I'll never forget it... I felt so wonderful... But then I broke out in terrible shingles after that.... And I got a strep-throat.... it must have been in my body. It was grand for a week then I was so relieved. But then it brought up a lot of stuff... a terrible anti-gay thing.... Where I almost thought no... I can't be gay... I am going to have to be not gay...

(Interview 19, Contact)

The 'safer sex' message can be interpreted as a negative anti-homosexual message for some people as the previous participant points out. The social context of sex and sexuality in Ireland historically and presently shapes the experience of individuals. The results of Ireland's recent first national study on sexual health and relationships reveals that from 7,441 participants 47% of men and 57% of women believe that homosexual sex is 'never wrong'. Viewed another way, 53% of men, and 43% of women indicated that homosexual sex is viewed at least sometimes as being wrong (Layte et al 2006). This view of homosexuality as negative is also illustrated in the following narrative.

And then there is still that abiding shame about your sexual activity. Maybe that is because I have been involved in HIV prevention, that I feel almost then doubly ashamed if I have been engaged in anything that is risky... I think people would say 'he ought to know better.' So when you are talking about it, I am also reminded of things that help you around that. I remember in the 90s, I know it's silly... but looking at the Madonna film, *In Bed with Madonna*, she is so sex positive. ... I came out of that feeling fine about HIV. Because it was so sex positive. And a more recent one ...I thought was very funny was *Sex in the City* where Samantha goes for the test... because she was sleeping with loads of men...I thought that was

very good....Like the Irish...we are a very anti-sex society... so going to a health professional you don't know where they are coming from.... And you are worried about blame and you being blamed.... or a whole range of things. I think it is a problem, I think anyone would find it very difficult to talk about their sexual activities.... It is very... very private.

(Interview 19, Contact)

### **5.8 Desire**

As discussed earlier the concept of pleasure and desire underlies most of the themes emerging from the discussion on the lived reality of sex for participants. It is of course, an issue that is often ignored in much epidemiological research. These respondents illustrate this point that for a full understanding of the context in which unprotected sex occurs it is necessary to acknowledge the value men place on what Sheon and Crosby (2004) describe as spontaneity, risk-taking and intimacy:

I mean sex is a very strong driving force isn't it?

(Interview 17, Contact)

I have been highly irresponsible... and I don't need to be told that because I know it.... But... I am gay. And I like sex.. and what am I supposed to do? I am not a nun ...I am not a priest... I am not celibate and I never will be...

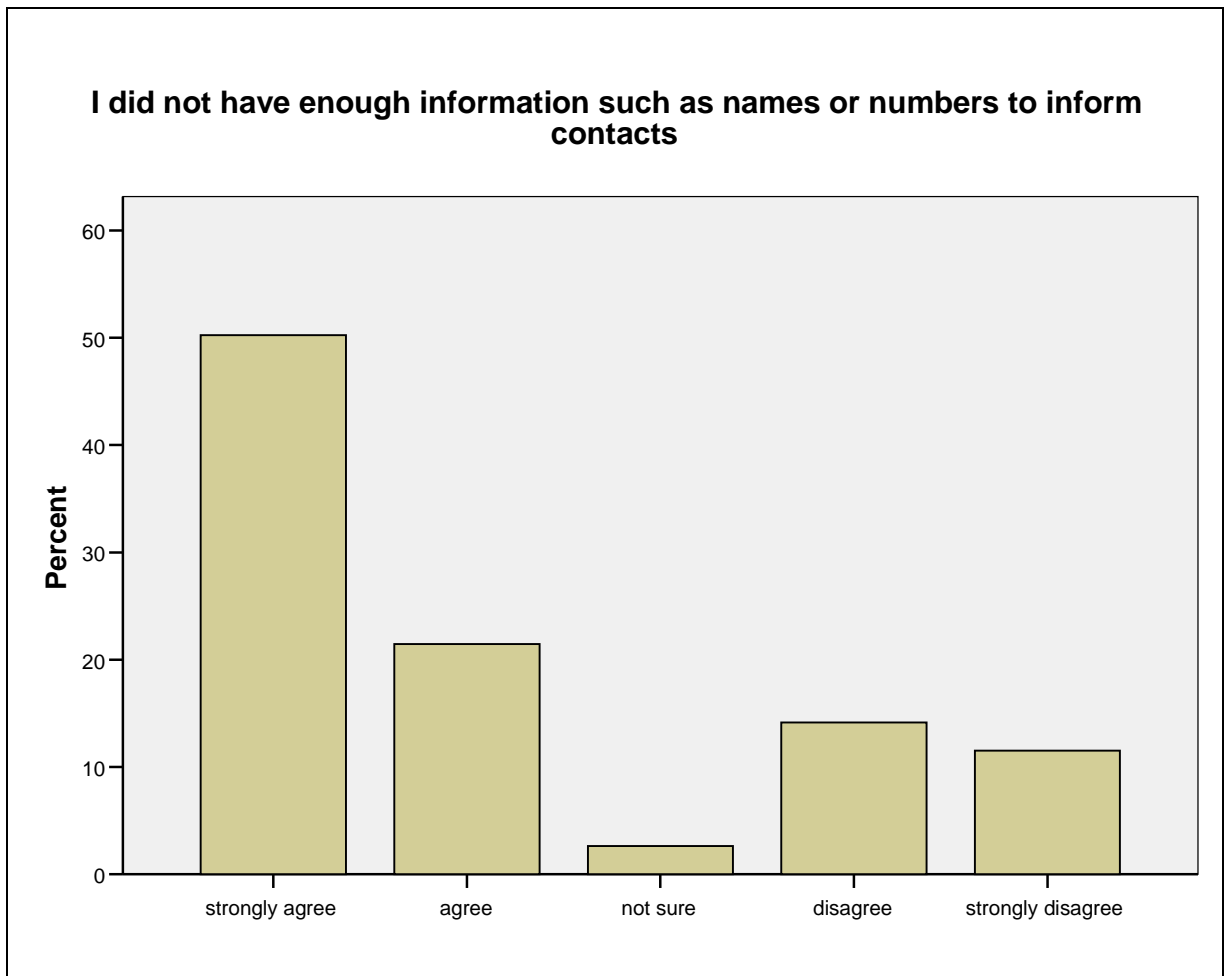
(Interview 3, Contact)

### **5.9 Anonymous Sex**

As previously mentioned, only 31% (n = 50) of cases in this study ensured that all their contacts were informed when they had syphilis. In addition, both cases and contacts were asked about contactable partners within the previous three months. Just under half (49.3% n= 136) of cases and contacts combined, said that all their partners from the last three

months were contactable. A fifth (20.9% n=58) said none of their partners were contactable from the last three months. In the case questionnaire a number of questions were asked, which explored the reasons why people did not inform their sexual contacts when they had syphilis. The most common reason found in this section of the research was that many participants did not know the names or phone numbers to contact sexual partners. Half of all participants strongly agreed with the statement, 'I did not have enough information such as names or phone numbers to inform sexual contacts' (see figure 5.2). A further fifth (21.5%) were in agreement with this statement.

**Figure 5.2**



**Table 5.13** Partner notification: case questionnaires

	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
<i>“I didn’t have enough information (such as name or phone number) to inform my sexual contacts/partners” (missing n=9)</i>	n = 96 % = 50.3	n = 41 % = 21.5	n = 5 % = 2.6	n = 27 % = 14.1	n = 22 % = 11.5
<i>“I was too embarrassed to inform some of my contacts/partners” (missing n=8)</i>	n = 28 % = 14.6	n = 31 % = 16.1	n = 19 % = 9.9	n = 66 % = 34.4	n = 48 % = 25
<i>I was too worried about confidentiality to give the names of some of my contacts/partners” (missing n=9)</i>	n = 18 % = 9.4	n = 36 % = 18.8	n = 18 % = 9.4	n = 74 % = 38.7	n = 45 % = 23.6
<i>“I didn’t have enough time to contact some of my contacts/partners” (missing n=9)</i>	n = 3 % = 1.6	n = 7 % = 3.7	n = 17 % = 8.9	n = 84 % = 44	n = 80 % = 41.9
<i>“I didn’t contact some of my contacts/partners because I worried about verbal abuse” (missing n=10)</i>	n = 7 % = 3.7	n = 15 % = 7.9	n = 13 % = 6.8	n = 80 % = 42.1	n = 75 % = 39.5
<i>“I didn’t contact some of my contacts/partners because I was too worried about physical abuse” (missing n=9)</i>	n = 6 % = 3.1	n = 3 % = 1.6	n = 11 % = 5.8	n = 81 % = 42.4	n = 90 % = 47.1

The qualitative data further supported the view that anonymous sex is an important issue. Some participants said that anonymous sex was a choice that people make for a number of reasons: firstly again, the issue of pleasure was central.

I think some people get a buzz from it [anonymous sex]

(Interview 13, Contact)

It is easier for me to have anonymous sex... because I can control the situation... .. whereas in a more intimate situation, where you really like someone, and then things are happening and you get into a relationship and you are going to have intimate sex and that is a more difficult situation to negotiate ...

(Interview 19, Contact)

This participant goes on to say how frustrated he was when he was notified by a sexual health nurse by the provider referral route that he had been exposed to infection. He believed that the sexual encounters were anonymous. Therefore, receiving a call suggesting that he was a contact of syphilis was, as he saw it, an invasion of his right to remain anonymous:

Part of the frustration was ...I had slept with others... over a while at that time... I am in a relationship now... but at the time... I didn't know their names. And... that was kind of a surprise to me. Someone actually had my name.

(Interview 19, Contact)

Being asked the questions in relation to partners, and in some circumstances, being under some degree of pressure to inform partners may be counterproductive because it is time consuming and not effective if people do not have any contact details. It may also serve as a barrier to people who wish to attend the clinical service. Only two participants suggested that people might state they had only anonymous sex as 'an excuse' to avoid engaging in a discussion about partner notification.

I would say that they know them but they just don't want to say...

They don't want to give the name... they know in their heart and soul who they are.... and they don't.. it might be through a friend of a friend that they have met this person .. so they don't want to say.



(Interview 4, Case)

This suggests that sexual contacts are not as anonymous as the term implies- there may be some identifying features and there is the possibility of future encounters. But the issue of safety, both social and physical, may be a reason for not breaking the ‘silence’.

*Faces and places*

When discussing anonymous sex, frequently a natural progression by participants in the interview dialogue was to move on to the issue of commercial sex venues, in particular, saunas. Concern about saunas was raised in Dublin, at the peak of the syphilis outbreak; and the question of whether saunas should be closed was raised in public (health) discourse. This did not happen, but attempts were made to increase the health promotion work conducted in these settings. Saunas were very frequently discussed in the interviews, as a potential barrier to partner notification effectiveness. The majority of participants (recruited from clinics) reported that they had been to a sauna in the last year (58%, n = 173), only 18% (n = 53) said they had never been to a sauna.

**Table 5.14: Last time in a gay sauna – clinical questionnaire**

		In the last month	In the last year	Over a year ago	Never
Last time in a gay sauna (missing n=6)	n	84	89	72	53
	%	28.2	29.9	24.2	17.8

Saunas come under the umbrella of public sex venues and Frankis and Flowers (2005:274) describe them as private indoor spaces specifically (though sometimes unofficially) marketed as 'sex on the premises' venues that require entrance fees and cover charges. The term used can vary between countries. For example they are called 'bathhouses' in the USA and saunas in Ireland and the UK. The mean number of partners that respondents met in saunas in the previous three months was 2 (SD 7), in gay pubs it was 1 (SD 2), on the internet was 1 (SD 3) and cruising ground was 1 (SD 3). The qualitative data also support this: The following participants explain in their opinion why people might go to a sauna.

I suppose a lot of people are into that very erotic thing of having sex in a group.

(Interview 21, Contact)

They'd stay there all night 'till they had enough... and they'd go from one to the other...

(Interview 27, Case)

Many respondents talked about saunas as being associated with drug and alcohol use.

normally when I go the sauna is when I have fallen out of the pub.. and I have few drinks on me or dutch courage.. or some sort of night when you are out partying and you have probably taken something and whatever and you end up there..

(Interview 9, Case)

A number of participants reported going to saunas precisely because sexual encounters are anonymous as this participant reports.

...was only at that stage [after the end of a long term relationship] that I started being promiscuous as such.. going to the sauna.. am.... and ... it would be just for the sake of anonymous sex.

(Interview 9, Case)

### *Darkness*

A number of factors present in the saunas contributed to the possibility and desirability of anonymous sex. This participant illustrates vividly the progression of physical darkness as one goes through the sauna.

Well initially there are changing rooms and lockers, then you'll go up then and there's cubicles and showers and there's a steam room and sauna, the sauna you can see people, you can see what they look like, the steam room that's a bit darker, there's a glass door and there's a small hall way and then you go into the right and it's dark there, but also up on the top floor there's what's called the dark room and now that's pitch black, so people are having sex and they don't even know what the other person looks like.

(Interview 17, Contact)

Absolutely, you don't know their names, you don't know anything about them, you don't even know what their face looks like, so it's quite scary actually

(Interview 18, Contact)

### **Silence**

Silence was reported as an unwritten rule in the settings of saunas. In particular, in the areas of the sauna where people engaged in sexual activities. Silence served to protect individuals physically and socially as well as adding to the sexual 'frisson'.

because you daren't talk, they mightn't like the sound of your voice...but this is ..just part of the illusion or whatever, it's just another world... like you wouldn't understand anything about it... a normal girl likes you ...

(Interview 26, Case)

I: Is there a reason for the silence that you can think of?

P: For the silence between the guys? well they may not like the sound of your voice and if you do find people talking too much in that environment, in the actual sauna or something like that ...it kind of breaks whatever kind of sexual frisson there is in it,.. if you get a blabber mouth it does have an effect. But like I was talking out in the changing room which is the most obvious place to talk ...so it's permissible there apparently.

(Interview 26, Case)

The view that silence is an important feature of saunas has been supported by other researchers (De wit et al 1997, Keogh and Weatherburn 2000, Elwood, Green and Carter, Frankis and Flowers 2005). Keogh and Weatherburn (2000) point out that communication of intention happens but is carefully conducted using non-verbal cues. Eroticism, they point out is generated by this total anonymity. Non-verbal communication in these settings preclude an ability to discuss condom use verbally and Elwood et al (2003) argue that it is this silence norm, which contributes to lack of condom use. As this participant points out, the 'silence' of saunas also contributes to the inability to inform sexual contacts when syphilis is diagnosed.

P: I have had sex in a sauna with somebody whose name I didn't ever know..not [to] mind have [it] now.. or have his number... or anything like that... I think a lot of people would find that incredible...

(Interview 2, Case)

### *Dangers of saunas*

A small number of participants had adopted the discourse of public health medicine and suggested that saunas should be closed down: This person had worked in a sauna and his argument for sauna closure was based on what he had seen there

P: They're not healthy, I worked there for 3 weeks and it's just not healthy, I don't know how anybody can go in there, there's drugs and then alcohol and unprotected sex, ...the counter for condoms there but them don't be used.

I: People just don't use them?

P: They couldn't be bothered running down the stairs and getting a condom and running back up.

I: So it's in a different area?

P: Yeah they don't have them up stairs in the container on the wall, you've to run all the way down and get them and run all the way back up.

I: So that's a disincentive for people is it?

P: Yeah and there's no cautions, there's no signs up, well there is but not up around...it's just not... it's just ....disgusting

(Interview 27, Case)

Many participants did not agree with such a view and argued that there were a number of advantages to using saunas. Saunas provided an outlet for people especially as this participant suggests, those that have no other social supports:

P: ..... like it's a wonderful amenity to have there if you've no outlet

(Interview 26, Case)

Another interviewee identified some benefit of saunas because it provides a setting for health promotion interventions such as health information campaigns and offering screening services for sexually acquired infections.

I think testing in the [names sauna] is a bloody good idea.... When they came in...it's an expensive thing to do I suppose... you can talk to people and show them leaflets... I think that's a good idea... you're in there where the harm is being done...

## **5. 10 Conclusion**

What I have explored in this chapter is the lived practice of sexuality in the context of a syphilis outbreak. This helps to explain the gulf between implicit expectations of how partner notification is supposed to work in theory and how it occurs in practice. Health professionals assume that they know what MSM desire, namely the avoidance of infection. Yet as Holmes and Warner (2005) state, the level of ‘forbidden’ desire can have a deep psychic meaning- it is not, they point out, an incorrigible act that can be educated away. This chapter has explored the complexity of the issue of sex and sexuality from the perspective of MSM.. Negotiating and practising safer sex is a challenge, as outlined by the men who participated in this study. A tension existed for many men between a desire for pleasure and protecting health. In some cases, engaging in a practice that was deemed by professionals as ‘risky’ added rather than took from the element of enjoyment. Yet, many participants sought to reconcile the balance, believing that they ‘should care’ (Robertson 2006). Good sexual citizenship may be seen to prevent infection to self and others. To reconcile this apparently contradictory position, men went for ‘check ups’ to overcome the limitations of their ability to control the potential to acquire infection. In exploring the lived practice of sex from the perspective of MSM, anonymous sex is frequently raised. As outlined in Chapter 2, it is widely held, in particular in the epidemiological literature, as being the biggest barrier to partner notification amongst MSM. The findings of this study have shown that ‘anonymous’ sex is itself complex. Rituals govern the setting in which men meet for anonymous sex. The unwritten rules of these sexual exchanges mean that the encounter ends with no commitment or obligation (Haubrich *et al* 2004). The practice of partner notification puts an expectation on people that they should inform partners but communication is in conflict with an unwritten code of contact for such exchanges. Having set out the context of men’s experiences of sexuality in this chapter, I turn in the next chapter to explore the participants’ specific experiences of partner notification.

## CHAPTER 6

### LAY PERSPECTIVES OF THE PROCESS OF PARTNER NOTIFICATION

#### 6.1 INTRODUCTION

This chapter is concerned with the findings in relation to the lay perspective of partner notification. It offers a previously untold story of the attitudes, experiences and perceptions of men who have sex with men on the subject of partner notification. There are three stages to the partner notification process from the perspective of men in this study. I have named these stages: ‘coming forward’, ‘finding out’ and ‘telling others’. Each of these stages will be addressed in sequence. As described in Chapter 1, this research took place in the context of an outbreak of syphilis in Dublin. A large information campaign encouraged people (MSM in particular) to come forward for testing.

#### 6.2 COMING FORWARD

In the Irish ‘vital statistics’ gay men’s study (Carroll et al 2002), 28% of men had attended for a check up for sexually acquired infections in the last year, with only 66% saying they had a ‘check up’ for sexually acquired infections at some point in the past. Equally, in this study the majority of my population sample had come forward for testing previously. In the community component of the study (the men recruited from social venues), 57% had previously attended a clinic.

**Table 6.1** Previous sexual health clinic attendance: community questionnaire

Missing n= 0

	Yes	No
Have you ever attended a sexual health clinic	n = 117	n = 87
	% = 57.4	% = 42.6

What I want to explore in this part of the thesis is how MSM, rationalise about when to come forward (or not to come forward) for testing. In describing below men's decision making about coming forward to clinic for testing, I will show that the men in this study did not necessarily conform to hegemonic masculine ideas of health and health care. As outlined in Chapter 2, men are traditionally seen as being reluctant to seek help in relation to health issues. The men in the study also did not conform to classical health promotion ideas of health. Rather, the study supports a view that other life priorities may interfere with a desire or an ability to seek health advice. The sample can crudely be divided into two groups: which I have named the 'vigilant testers' and the 'reluctant testers'. The 'vigilant testers' reported a willingness to attend for screening proactively, while the 'reluctant tester' were slow to attend even when symptomatic.

*'The vigilant testers'*

There were two overriding factors for the vigilant testers: a sense of duty for their own health and sense of duty to others. A quarter of those who completed the clinical questionnaires had attended for a proactive 'check up'. This group of people fall into the 'vigilant testers' category. These participants demonstrated a more feminised approach to health seeking that is more typically associated with women and assumed to be associated also with MSM (Robertson 2006). Many of those I interviewed also spoke about their belief in the value of attending proactively. There was a suggestion that it was good sexual citizenship to attend. Frequently the men in this study suggested that there was a moral imperative for MSM to attend for sexual health screening, seeing it perhaps as much a duty as a right.

Certainly... every gay man should be coming here.... once a year at least... if they are not in a monogamous relationship.

(Interview 13, Case)

Some participants talked about attending for a sexual health screening when a relationship became more serious or when they wanted to improve their relationship(s).



As such, coming forward for testing was an act conducted out of concern for others as well as oneself.

My first time was the clinic on (*names street*)...no worries at the time... just decided to amend my life at the time ...and decided the first thing to do would be to get checked out...make sure everything was okay...so I could improve my relationship with my wife...more or less....

(Interview 14, Case)

*'The reluctant testers'*

Not all participants indicated a willingness to attend clinic. Three quarters of all clinical participants (those that did attend) reported that they had difficulty attending clinic. Not all participants indicated a willingness to attend sexual health screening services either for a proactive 'check up' or even when they recognised some possible symptoms. This was particularly relevant to men recruited from the Gay community venues (clubs, pubs and saunas), where just over half had ever been to a clinic for STI testing. It becomes clear that more participants fit into the 'reluctant testers' than the 'vigilant testers' category. The description from the participant below is one such example of a reluctant tester.

P: I hadn't been [to clinic]

I: Ever?

P: Well I had... but not since... Jesus ...1985...which is crazy.... but I hadn't been... So that was the reason... I would be very involved in gay stuff and gay politics... and I would have a huge amount of social support... but I find it very difficult to go to clinics... I just find it very challenging to go.

(Interview 19, Contact)

Non-attendance at clinic was described as ‘doing the macho thing’ by a forty year old man (Interview 9 case), who had not visited a doctor for 20 years. Even on recognition of symptoms a number of men conformed to a hegemonic construction of masculinity indicating reluctance to attend even on recognition of symptoms.

I think with guys... men are notoriously bad...they won't even go to the doctor for stomach ache ... so they think 'I've just a strained muscle'...if the lymph nodes....just strained muscle, just carry on...

(Interview 5, Community)

A number of factors made attending clinic difficult. A third of all participants in the quantitative component of the study (29.6%, n=90) described embarrassment as a factor that made attending clinic difficult. Concerns about confidentiality were reported by fifteen percent of all participants (n=46).

**Table 6.2** What (if any) made attending clinic difficult? (Clinical Questionnaire)

	Number	Percentage
Fear	n = 81	31.6%
Embarrassment	n = 90	29.6%
Time constraints	n = 89	29.3%
Concerns about confidentiality	n = 46	15.1%
Other	n = 16	5.3%
None	n = 62	20.4%

Perhaps not surprisingly then, a similar number reported that they did not tell anyone that they had attended a sexual health clinic. A concern about being seen in the clinic waiting room was frequently reported.

I don't think ...If ...say... I was given the choice ...and I think I was at the beginning... of having it closer to home... or here... I would have it here...and probably if I was given the opportunity of having it in America... (laughs)... I would have to take America...

(Interview 10, Case)

The stigma of sexually acquired infections was the biggest reason why some participants reported a reluctance to discuss their sexual health clinic attendance.

**Table: 6.3:** Have you told any of your friends or family that you attended a clinic? (Clinical Questionnaire)

	Yes	No
Have you told any of your friends/ family that you have attended a sexual health clinic (missing n=1)	n = 235 % = 77.6	n = 68 % = 22.4

It was also the reason that many others guarded closely the knowledge of their diagnosis and divulged it only to a select few. The stigma was contributed to by the 'dirty' label attached frequently to sexually acquired disease and extended beyond those who had infection to also include those who might be suspected of having one. In addition, the stigma related also to having a sexual orientation which deviated from what might be perceived by society as 'normal'. Many participants referred to a double stigma, which was due to being gay and having a sexually acquired infection.

P: I don't know... treatment for STDs... people going for treatment is... it's going to be an uphill struggle I think.

I: And you used the word hatred?

P: Well to be honest I haven't encountered but it is there.

I: Hatred towards gay people?

P: Yeah... but maybe that's a perception I have of... maybe if you hear of someone getting mugged... or something like that.

I And you feel that it's because they're gay?

P Yeah... I don't know how you would go about getting people relaxed into the idea of going to be tested in an STD clinic... I really don't...`

(Interview 17, Contact)

Fear was another major reason why men found attending clinic difficult. One third of all participants reported experiencing fear. The interviews revealed the complexity of the issue of fear for many participants. The fear was due to a range of issues: such as their personal health, fear of the unknown and fear of treatment.

I: When you saw the sore... what did you think?

P ....oh God I am going to die? (laughs)

I: Did you really?

P: Yeah... I have never had any kind of STD... or anything like that...I have never even been for a screening.....so...it was a major shock...

(Interview 9, Case)

Practical difficulties were an issue for many participants as they struggled with the challenges of a busy personal and work schedule and the niggling awareness that they might benefit from a sexual health screening. This was particularly true when they had reason to believe that they may have been exposed to an infection. A third of all participants (30%, n=89) reported time constraints as a factor that made attending clinic difficult. Taking time off work was a concern for many, not least because it was often coupled with a concern that the information that they had attended a clinic might be leaked to employers. This participant describes the refusal of his previous sexual partner to attend as he feared the negative impact it may have on his employment.

I: What do you think would be the main reason?

P: He's afraid that it might get back to his employer... because if he had anything...and he's working with food... even though they do wear gloves... and all this stuff... he's afraid that he would lose his job... but I was explaining to him it's completely confidential and his employer or that wouldn't be notified ...

(Interview 26 case)

It becomes clear that the 'reluctant testers' had very genuine concerns which make attending clinic difficult and in some cases impossible. Considering that the 'reluctant testers' were a sizeable proportion of the sample, it might be asked then, what actually prompted the attendance of those who did come forward for testing. Participants in this group largely attended because they had symptoms, or were informed by a sexual partner that they should attend. As mentioned previously this research was conducted against a background of an intensive syphilis awareness information campaign which acted as a trigger to prompt attendance. In many cases, it was a combination of factors that resulted in men in this study attending. For example, some men may have been informed by a partner that they should go for a check up, but this alone was not sufficient for them to attend. Many reported that they also waited for symptoms. This was despite the fact that a person can be infected with syphilis and be asymptomatic. The participant below describes the difficulty he had attending clinic even when he had symptoms.

But then I just got the courage... and just went up... because I knew I had something then... so then I had to go... because I knew it was kind of serious and I went and they took it from there ...

(Interview 27, Case)

A key informant, usually a previous sexual partner, put 'the ball in motion' for some of the reluctant testers.

- P: My partner had told me... prior to me noticing ...that he had picked up syphilis and he also had gonorrhoea. My partner and I... like... he lives in Manchester and I live here in Dublin so I had been watching out for signs... then I did [get signs].
- I: What signs did you have?
- P: Mm...spots on my tongue, then they came out later around my groin area.
- I: So then you came to clinic?
- P: Yes.
- I: How much later after he had told you that, did you go to the clinic?
- P: About 3 ½ weeks.

(Interview 20, Contact)

In this section, the complex issues that help or hinder someone in coming forward for sexual health screening have been described. It is commonly assumed that men who have sex with men adopt more feminised approaches to a wide range of life events including health seeking. This study has highlighted the complex relationship MSM have with notions of masculinity. The first group of men I have identified as the vigilant testers did indeed present a more feminised approach to health seeking, but they formed only a quarter of the group. The second group, the reluctant testers, demonstrated a hegemonic masculine approach. Therefore, the men in this study cannot be said to easily fit into a hegemonically feminine *or* hegemonically masculine approach to health seeking behaviour. Instead, the findings demonstrate the complex interplay of real life issues that may act as barrier to attendance. In the next section, the experience of ‘finding out’ about syphilis results will be discussed.

### **6.3 FINDING OUT**

In this section, I will concentrate on the reactions of men in the study who received positive syphilis test results. The reactions, not surprisingly, varied between men. Yet, the major reactions experienced by many included shock, fear, relief, and shame. I will

discuss each of these issues separately. In this section, I will draw mostly from the qualitative interviews which reaped rich data on the experience of a syphilis diagnosis on the individual lives of the men who participated.

The word 'shock' was frequently voiced to describe initial reactions to a syphilis diagnosis, as this participant described.

I: How did you feel when you were told that you had syphilis?

P: Gob smacked, shock and horror... and then to be told that it was probably quite old syphilis ...that it wasn't something new or current.

(Interview 1, Case)

Many other participants also echoed these words of shock:

I got a bit of a land.... To put it mildly...

(Interview 10, Case)

Co-existing with this reaction of shock reaction was a searching for meaning. For some, the shock was because participants believed they had been 'careful'. However, some participants had considered that being 'careful' included having unprotected oral sex. It came as a surprise to many that being 'safe' for HIV was not the same thing as being 'safe' for syphilis. Being 'careful' often also meant that there was an assumption of monogamy on both sides of relationships, although, in practice, this was not always the case. This participant describes vividly his deep search for explanations to his own syphilis diagnosis.

I remember then they phoned me... and said I had to come in... that they discovered that I had syphilis ....and all that.... and then for me I couldn't understand how ...because I was also so careful... and saying that... I wasn't perfect either...I know that... but I always sort of felt that I was very careful and cautious and all that... and I wasn't a person who went

out and was with everybody... involved with everybody... So of course I was there trying to think ...and being honest I wasn't too sure how I actually got it...well I know how I got it... but I wasn't too sure who was I with that I had got it off.... And then you sort of think back now and say ok... there probably was a couple of people that I sort of was with and obviously I caught it off one of those... and then the guy that I was with... we were sort of going out with each other too... and I said well ok I wonder if he has it because myself and him we were having unprotected sex... so I wasn't really too sure... and knowing the gay scene the way it is too... you have to be very careful... I realise now that you wouldn't...I wouldn't trust a man as far as I'd throw him anyway... So I sort of look at my own life and sort of see how did it happen... where was it and all that and being honest I can't say that I can pin point it down and say ok this is exactly... that's probably the hardest thing...

(Interview 25, Case)

Fear was another major reaction for most men who were diagnosed with syphilis. The fear varied between individuals and differed depending on their previous knowledge and experiences. The connection with HIV was a concern for some. Symptoms were interpreted by some as symptoms of HIV rather than those of syphilis infection. The fear of HIV, which already existed was not helped by the fact that some information awareness leaflets pointed to the fact that syphilis can facilitate the transmission of the HIV virus.

... At first it was oh my God what is this? Is this it... have I got the big A?... and all those kind of questions..... it was just that feeling.... Is this down the line... is this down the slippery road now?... is this going to lead to my end?.... when I just relaxed and said..... right .... just deal with this now....you know.... But .... It wasn't a definite doom.... But it was upstairs [points to his head] ...at the same time....

(Interview 9, Case)



Relief was a subsequent reaction for most of the participants. For some, this relief was a result of knowing that they were negative for HIV. For others it was relief at knowing that there was an effective, (if inconvenient and often painful) treatment. A small number of the participants reported that prior to attending the clinic, they had perceived syphilis to be a disease of the dark ages. For which there was little hope or cure.

Yeah, I was obviously a bit shocked... I was glad it wasn't anything worse. It could have been... it could have been HIV... or that. Obviously I felt a bit weak at the time... but it was a short-term effect. When it was explained that it was easily treated and you will be cured in a fairly quick period of time I was happy enough to get on with it.

(Interview 14, Case)

Many participants talked about an abiding sense of shame, that they carried a disease which was associated with stigma and transgression.

In a way you see it... you feel bad... you feel more negative towards yourself in a way.

(Interview 12, Contact)

The association with dirt was reported by a number of the men. While most reported that that feeling disappeared quite quickly, others said it lasted a little longer. This participant chose to cut himself off from social interactions for the duration of his treatment.

No... I suppose in my head I knew... .. but... I just felt.. I felt dirty... do you know what I mean.. and I just didn't want to be around other people ... 'cos I felt dirty.

(Interview 9, Case)

The sense of shame and dirt was related to the way in which the infection was acquired. Some participants communicated a sense of self-blame that they in some ways got what they deserved. This participant described why he chose to keep his syphilis diagnosis to himself and not tell even his closest friends to whom he would ordinarily tell most things.

There was a sense of... this is what you get 'cos you screw around...  
(Interview 2, Case)

In this section the experiences of men who were diagnosed with syphilis have been explored. It has been seen that the experiences varied between individuals but nonetheless the four reactions of shock, relief, fear and shame were reported by many. In the final section of this chapter, I will focus on the issue of telling others: an action that is requested by health professionals when individuals are diagnosed with sexually acquired infections.

#### **6.4 TELLING OTHERS**

The experience of MSM dealing with partner notification will be described in this section. I will look at how partner notification was conducted and experienced. The overwhelming sense from both the qualitative and quantitative data was that men were in principle in favour of partner notification. It was seen by most as the 'right thing to do' and was frequently framed in such moral language. However, men still found it a difficult thing to do.

##### *Approaches to partner notification*

As discussed in earlier chapters, partner notification can be conducted in a number of ways. Sixty nine percent of participants who had syphilis (n= 138) said they informed some of their sexual partners themselves ('patient referral'). Twenty four percent (n=46)

said they did not inform any partners themselves or arrange for a clinic to do so on their behalf. Provider referral was used very often with 42 % (83 participants) reporting that they gave details to a health advisor to inform some (or all) of their ‘contacts’. This figure is much higher than usually reported (Dehne et al (2002)). The most common approach, however, was to tell ‘contacts’/partners ‘face to face’. This was used by 70% (n= 97) of index ‘cases’ at least once. Notifying over the phone was used by 46% (n= 63) of index ‘cases’. Other possible approaches to informing were used much less frequently: Only 7 % (n= 10) informed a possible sexual contact through email, even less (4% n= 5) sent a text message and finally only 2.2 % / n=3 informed by letter, one person ticked the ‘other’ option and stated that he informed via another person.

**Table: 6.4** Approaches to partner notification: case questionnaires

	Yes	No
Informed over the phone	n = 63 % = 45.7	n = 75 % = 54.3
Informed face to face	n = 97 % = 70.3	n = 41 % = 29.7
Informed by text message	n = 5 % = 3.6	n = 133 % = 96.4
Informed by email	n = 10 % = 7.2	n = 128 % = 92.8
Informed by letter	n = 3 % = 2.2	n = 135 % = 97.8
Informed by other means	n = 1 % = 0,7	n = 137 % = 99.3

Of those who did inform partners themselves, the most usual approach was to meet them and tell them ‘face to face’. This approach was used by 70% of ‘cases’ at least once. The ‘matter of fact’ way in which this is communicated is highlighted in this example although this relatively relaxed approach is not necessarily typical of all those who informed their sexual contacts face to face.

I just rang him at work and I said I’ll meet you for a jar. And I met him in [*names bar*] that evening... which is where we normally go. I just said I was up in [*names clinic*] today for a check up ... and I said I have a dose of syphilis... I said you better go and get yourself checked out. And he says “ah shite...that is all I need!” and then we had a drink...

(Interview 4, Case)

As mentioned earlier, partner notification was an immediate concern for many when a syphilis diagnosis was made.

I: Your first reaction... You said was who am I going to tell?

P: Well who am I going to tell.. my first reaction was.. well... who have I been with sexually?... and the second one... am I going to tell my friends?... no I not going to tell my friends... again, It wasn’t anything.. There was a sense of (pause..) this is what you get cos you screw around... but I wasn’t sort of... if this had happened to me 10 years ago I would have been devastated...

(Interview 2, Case)

People with syphilis engaged in ‘information management’. Disclosure of a syphilis diagnosis was done on a ‘need to know basis’ as this participant highlights. The public health imperative to control disease was seen as a reasonable justification for disclosing

the information to those who had been exposed to infection. For other people, however, such as friends or social acquaintances, many were not prepared to disclose this personal information. There is a complex issue of trust in telling sexual contacts about the diagnosis. The stigmatising effect of having a sexually acquired infection, or being identified as gay or bisexual was a considerable concern for many and the possibility exists that they may reveal this private information to other acquaintances. One participant makes this point:

Yeah... I spoke with [*names health advisor*] at the time and she gave me some slips that I could pass on if I ever did come across anyone ... but ... I thought about it.. I thought about it lots and even still.. I still can't .. I couldn't imagine walking up to myself and saying .. there is a chance that you could have contracted something cos I picked up something.. you know... some parts of me would... NO.. I can't imagine myself doing that.. I think it is a very hard thing to do.. and I think I would be .. especially... in the gay community ... in the gay scene.. it would be very easy for somebody to point the finger.. and say.. oh my gawd.. he said this.. or he is kind of like... he is the one with the big infection.. and he is the one that started it and he told me and blah blah blah...So .. ... I.. I couldn't see myself doing that..

(Interview 9, Case)

Many participants talked about a strong sense of responsibility to tell sexual contacts and partners. Although not confined to those in a relationship, it was most noticeable within this group. The various relationship contexts among MSM added to the complexity of partner notification. Some participants had long-term monogamous relationships, others had open relationships, others had casual encounters with the same people on an infrequent basis, others engaged only in sex where they never exchanged names or any other contact details. In general those who were in regular relationships had the greatest difficulty with partner notification and the impact for some was the ending of a long term relationship.

The choice of referral method was closely related to the type of relationships. A consideration in making this decision was based on how men with syphilis anticipated the person receiving the message would react. The following participant gave details for a health advisor to inform a number of his contacts. These were people who he felt were 'au fait' with the syphilis information campaign and who, therefore, would not be overly alarmed to receive a call indicating that they had been possibly exposed. By contrast, he then outlines his reason for telling one partner himself.

I decided to tell him face to face as I didn't know what his level of knowledge would be ...and he wouldn't be somebody who would be on the scene... I didn't know how scary a thing it would be for him, where I knew that I could talk to him... if he was going to give me the impression he wasn't going to go for a test... than I could talk to him... and tell him it was not that bad and blah... the two guys whose names I gave you for the syphilis... were people that I knew were as knowledgeable about syphilis as I was... So that it wouldn't be a huge ordeal for them... They knew the story with it and so on...

(Interview 2, Case)

Some participants chose not to tell in person. Telling someone over the phone is the next most usual approach to patient referral. This approach was taken by 46% of cases (63 men). Below is an example where phone contact is anticipated to be less acceptable to contacts than meeting them face to face. It was used when contact was difficult to make or when relations were strained and face to face contact was not usual. This point is illustrated when he says 'just a phone call'. However, it is not always desirable or practical to inform face to face such an approach to partner notification as this example also highlights.

I was finished with him that April... the same year and

We didn't finish on very good terms... so he was going to be just a phone call...I wasn't going to visit, the others were phone calls because they live down the country and there was no way I could find them... so I just had mobile phone numbers.

(Interview 16, Case)

### *Ease and Difficulties of Telling Others*

Men preferred patient referral as a means of notifying sexual partners of a syphilis diagnosis. However, patient referral was not an 'easy option'. At the very least it was considered embarrassing, for many it was very stressful. The unpredictability of the situation may have resulted in the end of a relationship and in some cases abuse or fear of abuse. The stigma of having a sexually acquired infection coupled with the stigma of being identified as gay or bisexual was also a difficulty identified by many participants.

Frequently participants reported that the response to the notification was a positive one where the partner communicated gratitude for being informed:

He was grand... he was more relieved that I told him that I had contacted...that everything was out in the open... he's actually in a partnership... he's with somebody else but he was delighted...he went straight up and got tested for it.

(Interview 29, Case)

However, not everyone got such a reaction. This participant had a more negative experience.

Yes, I had all their numbers on my mobile. I phoned them up and it was quite difficult... (nervous laughing)...to do it, some people, one guy in particular I could hear the disgust.

(Interview 22, Case)

Men who were diagnosed with syphilis ('cases') reported a mix of feelings as they communicated with partners about their syphilis diagnoses. Embarrassment was frequently reported:

I was more embarrassed than anything else. I think embarrassed was the main thing... mm...but I mean... he was very...you know... calm about it all. I was pretty embarrassed that was the greatest thing about it...

(Interview 13, Case)

It was more embarrassing 'cos I knew him.

(Interview 4, Case)

Notifying partners was intensely stressful for many participants, with many suggesting that anticipating the 'telling' was often worse than actually doing it.

Driving home, I had to go through all the possible scenarios...not knowing how he would react.

(Interview 1, Case)

I thought about it on my way home and I said: 'No, I am just going to confront him and tell him out straight'.

(Interview 15, Case)

The issue of blame was damaging to relationships and was also raised in interviews. The effect for some was the end of relationships.

...and even with the syphilis... a lot of the stuff was sort of thrown at me which made it very... very difficult... I think that's probably the reason



that we split up so many times and yet each time we split up we got back together... and we didn't really sort of sit down and clarify... work everything out...

(Interview 25, Case)

Abuse or potential abuse can be a factor that prevents individuals from notifying their sexual 'contacts'. For the vast majority this was not an issue; However for a number it was. Sixteen individuals said that they experienced verbal abuse after telling sexual 'contacts' or partners. Two individuals strongly agreed with the statement that they experienced physical abuse as a result of informing sexual partners. A small number of other participants also raised the issue of personal safety as an important issue in relation to partner notification and as a potential barrier to approaching contacts themselves:

I: And you would be worried about yourself?

P: I wouldn't want to approach him myself... because ...I wouldn't want him...fair enough... he knows I'm around Dublin... but he doesn't drink in the pubs that I drink in ...and he doesn't... know where I live and he doesn't know where I go to college...I prefer that...to keep it that way ...

(Interview 5, Case)

Public health policy operating through health advisors recommends the tracing of all sexual partners (within the 'infectious period') of a person with sexual acquired infection. The men in this study who were index patients (cases) were also duly asked to inform partners. This is a unique health care situation because it involves asking patients to break bad news to other patients. Telling someone that there is a possibility that they may have a sexually acquired infection is bad news. Breaking bad news is recognised in practice and research as a challenging area of health care and health professionals such as nurses and doctors receive training to carry out this work (Cooke et al 2003, Wakefield et al 2003). But people diagnosed with sexually acquired infections are always asked to break this bad news to their sexual partners. This is a very challenging for them to do for the following reasons: Firstly, this comes at a time of considerable stress as they seek

treatment and make sense of their own personal diagnosis and treatment; secondly, individuals with infection, unlike health professionals, do not receive training in how to communicate bad news effectively; Thirdly, unlike health workers who keep a professional distance from their patients, those with sexually acquired infections have (or had) intimate relationships with the person to whom they are breaking bad news; Finally, the disclosure of the bad news, involves potentially serious negative consequences for the individual person with syphilis: relationships may end, knowledge of their syphilis diagnosis will no longer be private, many others may hear about their syphilis diagnosis, their character and reputation may be damaged. Relationship contexts also have a role to play in how easy or difficult the process may be. The intensity of the difficulty will depend on the relationship situation. Those in relationships may experience greater difficulty as a result of the impact on their personal relationship. Without doubt, breaking the bad news of syphilis diagnosis to a sexual partner involves significantly more repercussions to the patient communicating the message, than the breaking of bad news by health professionals in other situations. In the section that follows the experience of MSM who were notified as a result of partner notification will be explored.

## **6.5 PARTNERS REACTIONS**

Those completing 'contact' questionnaires were asked to give their opinion on the statement: 'the way I was told was ok with me'. Almost two thirds (61%), n = 63) strongly agreed with this statement. A further 31% (32 people) agreed with this statement. Four people strongly disagreed with the statement and a further two disagreed. The dissatisfaction with method of partner notification did not appear to be related to any one particular relationship context or method of partner notification used. Of those that strongly disagreed, two had been informed by 'casual' 'contacts' and two had been informed by partners. One of these had been informed by text message, two over the phone and one by 'face to face' contact.

**Table 6.5** Contact reactions to partner notification : contact questionnaire

	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
<i>“The way I was told was ok with me”</i> (Missing n=0)	n = 63 % = 60.6	n = 32 % = 30.8	n = 3 % = 2.9	n = 2 % = 1.9	n = 4 % = 3.8
<i>“I would rather be informed than not, that I had come into contact with an infection”</i> (Missing n=0)	n = 97 % = 93.3	n = 6 % = 5.8	n = 0 % = 0	n = 0 % = 0	n = 1 % = 1
<i>“If I came into contact with an infection in the future, I would like to be informed”</i> (Missing n=0)	n = 93 % = 89.4	n = 11 % = 10.6	n = 0 % = 0	n = 0 % = 0	n = 0 % = 0

Provider referral is considered by some to be controversial and potentially unacceptable to ‘contacts’. It is interesting to note that of the sample of 104 ‘contacts’ that filled out questionnaires, 21 had been informed by a health advisor. Of these 21, thirteen strongly agreed and a further seven agreed with the statement ‘The way I was told was ok with me, only one person disagreed with this statement and no one strongly disagreed. Nonetheless, the interview data which explored the experience of provider referral presented a more fulsome and negative view of this process of provider referral.

Provider referral for cases was often characterised by an initial reaction of panic which was perhaps intensified because a ‘third party’ was identifying them and contacting them essentially ‘out of the blue’. Participants reported a sense of powerlessness as a result of receiving a call to say their health may potentially be ‘at risk’. The personal and intimate nature of the subject contributed to this sense of powerlessness. This narrative highlights the initial sense of panic. Of note also, this participant communicates that he has nobody with whom he can share this information.

I was a little bit stunned initially to be honest with you I was awake

for about four hours... And I literally went back thinking about all the casual partners I had...not throwing the blame on anybody... cos it could easily be me... but somebody might be making the phone call about and then I just dismissed that idea that it could be ... Name 1 . or Name 2 or whatever the case was. But I got the shivers when I got the phone call. Panic..... for a little while maybe. And nowhere to turn I thought about calling up a friend and said look because I had a friend who had a similar scenario and he was tested clear as well... but I just decided not to tell anybody.. and I kept calm.... as best as I could...

(Interview 3, Contact)

I What was your reaction when you got a call?

P: Aaahm,, ... Panic... probably initially, ... but then ...after a couple of days you accept it and you come along to the clinic.

I: Sure... When you say panic- what was the panic about?

P: The initial panic is that you have got some disease.. or whatever... not necessarily AIDS. Or even syphilis. Am... And I guess that was what the initial panic was ...

(Interview 7, Case)

The multitude of questions and lack of answers to those questions characterised the response of men who received anonymous provider notifications. The anonymous nature of the approach is such that the identity of the index patient (person with initial infection) is not revealed. This can be a source of confusion and anger for many people. In addition, the sense of an invasion of privacy is heightened.

I: Did you find yourself thinking who has given my number to the clinic?

P: Yeah, that was annoying me then... who? Why? how long ago was this? It wasn't really making sense because she was just saying come in and we will talk about it and it mightn't show now and you will have to come back again and get tested again to make sure you really don't have it...I was trying to think that person might have been with somebody after he met me how long ago was that person with me, I don't know. So there was all these questions initially.

(Interview 12, Contact)

That is the worst part.... Not being told who got your number

(Interview 8, Contact)

Common among MSM, who received a call from a clinic, was a feeling that someone may be carrying out a practical joke. People who are notified in this way are given the opportunity to contact the clinic or attend to confirm that it is an authentic call. Some men, for example the following participant, reported that it took some time to 'digest' the news and to then act upon it.

...me head started running around trying to think ... who would have given it [his phone number] out ...or is somebody winding me up Yeah.. like there is nothing stopping me giving my mates' numbers and names.... And saying... yeah give them a ring... That what I thought... first of all that someone had given my name and number as a joke...

(Interview 8, Contact)

The powerlessness associated with provider referral was evocatively communicated by a number of participants. The anonymous nature of the communication contributed to this.

There was a sense of, yeah like intrusion and of... I think this feeling of powerlessness.... Someone is ringing you with this bit of news and they have power of you or something.

(Interview 19, Contact)

This participant talks about the paradox of power, while he talks about the sense of powerlessness with the process of partner notification. On another note he also talks about the sense that he wanted this power to be taken from him. For someone to 'look after him' and tell him that everything was going to be ok

But at the time you want someone to be there, it's almost like catching you if you fall, we are not going to let you fall, don't worry, this is just protecting health, we are not here to make problems, contacting is just part of helping you and others to protect your health.

(Interview 19, Contact)

and it's just ...you are so aware of your vulnerability

(Interview 19, Contact)

The 'big brother' effect of receiving a call from somebody who potentially knows a great deal about perhaps the most intimate details of another person's life is disturbing for many.

P: I was... maybe thinking... Jesus... who is keeping tabs on me or whatever?

(Interview 19, Contact)

One participant suggested that people may choose not to access the service as a protest to the fact that they were not given the name of the person who had given their personal

details to a health advisor. While he attended himself, he communicated considerable annoyance at the approach and suggested that many may choose not to attend.

P: but the fact that you are told.... No... we can't tell you... you could easily... I would say there is probably one in ten... that would say they didn't tell me so I am not going to bother going in.... do you know what I mean?

(Interview 8, Contact).

In this section the difficulties with provider referral have been highlighted. Participants' dialogue has been used to illustrate the complexity of this approach and the additional challenges that this approach presented to people who were on the receiving end of such a phone call (or letter). Nonetheless, many of those who were informed by a provider referral approach communicated that they were happy with the method of notification, and this has been found by the quantitative results as well as the interview data.

(Long pause....) I am glad ... cos I would never have come in otherwise..... I would have just continued on... this was the last place that I would have come into. I ever even... I never even heard of it [the clinic].... To tell you the truth...

(Interview 8, Contact)

In this section the experience of being told has been explored, the perspective of those telling the news has also been described. It has been pointed out that partner notification is a unique area of health care where individuals with diagnosed infection are asked to break bad or (potentially bad) news to others. The consequences of this action were often serious for the individuals concerned and their relationships. The narratives which have been presented highlight the complexity of the practice of partner notification. Public health perspectives were evident in the narratives of many participants. However the difficulty for those breaking the news and those receiving the message was also evident.

## **6. 6 CONCLUSION**

This chapter has explored the lay perspective of partner notification. It commenced with a discussion on coming forward, the process whereby men who have sex with men contemplate attending (or not) attending STI services. Traditional notions of masculinity suggest that men are reluctant to seek health care (Moynihan 1998, Courtenay 2000, O'Brien et al 2005). By contrast, health seeking behaviour is often associated with notions of femininity. However the results of this study show that MSM do not fit neatly into stereotypical ideas of masculine or feminine. Instead, MSM in this study, showed both a traditional feminine and traditional masculine approach to health seeking. The complexity of the ideas of gender ideology and health were evident in the various attitudes to attending clinic. The section that followed described the lay perspective of finding out positive test results when an infection was diagnosed. Often in research relating to sexually acquired infections the focus is on the epidemiology of infections, ignoring frequently the impact of the diagnosis on individuals and their lives. The focus of this study was on the experience of a syphilis diagnosis for MSM as well as the perceptions of partner notification. The perception that syphilis was an incurable disease of the dark ages was present in some of the narratives. Initial reactions of shock were replaced later with relief that an effective treatment was available. However for many, the stigmatising effect of having an STI remained a significant factor in how MSM dealt with a diagnosis. In addition partner notification is made difficult in the context of stigmatising homosexual identities. In the final section of this chapter, the experience of 'telling others' was explored. Partner notification is a unique area of health care, where the individuals experiencing the stress and uncertainty of a diagnosis of a sexually acquired infection are asked to break this bad news to their partners. The breaking of such bad news is associated with potential for public and private humiliation. In other areas of health care the onus is on the professional rather than the patient to break bad news. The difficulties with such a task are intensified by the complex variances in MSM relationships, with the impact being worse for those in long term relationships.



## **CHAPTER 7**

### **DISCUSSION AND RECOMMENDATIONS**

#### **7.1 Introduction**

The aim of this study has been to explore the lay perspective of partner notification in the context of an outbreak of syphilis among MSM. The perspectives of this group are important for a number of reasons; firstly, this is a unique population who are identified throughout the literature as being particularly ‘difficult’ in terms of the effectiveness of partner notification; secondly, MSM are often a targeted group in the sexual health arena, thirdly, this is not a homogenous group – this group did not so easily split along social lines, but on lines of types of relationships. The present study sought to explore diversity of the participants’ opinions and experiences and used mixed methodology incorporating qualitative and quantitative components to achieve this aim.

As discussed in depth previously, partner notification is a public health activity, conducted under the direction of health professionals. The ‘expert’ perspective dominates the epidemiological literature, with an implicit assumption presented that the practice is always good because it can be justified on public health grounds. Missing from epidemiology literature, and research to date, has been the non-professional perspective on the practice. This omission of the lay voice has occurred despite the fact that partner notification is a voluntary activity, which can only occur when a lay person is willing (and able) to comply with the requests of the relevant health professionals. In the second chapter, a range of social theories were used to offer possible explanations as to why the lay voice has been neglected in sexual health policy and practice in general, and in partner notification in particular. Theoretical perspectives offer new ways of viewing the world, and offer much to epidemiological research, which has been criticised for its lack of a theoretical base (Inhorn and Whittle 2001). The question of why partner notification has been conducted for over six decades, without consideration of the lay perspective is not a simple one. The use of multiple theoretical perspectives is put forward by Turner (1995) as a useful means of exploring complex situations where answers are far from simple or straightforward. For this reason, the theoretical perspectives of Talcott Parsons,

Michel Foucault, and Jürgen Habermas were used. In this current chapter the findings of the study will be discussed in the light of the original aims of the thesis and its theoretical perspectives.

The findings of the study provide an insight into the perspective of MSM on partner notification. In addition, it explores the views of a non-clinical sample of men recruited from social venues. It explores the lived experience of the practice for individuals who were diagnosed with a syphilis infection or attended clinic as a result of a partner notification process. This perspective is significantly different to that of a health professional perspective which (as already discussed) dominates much of the literature. In many cases, participants presented viewpoints which were consistent with that of health professionals, but frequently other life priorities co-existed with these viewpoints. Health professionals have a professional distance from their patients. Patients on the other hand cannot, even if they wish, remove themselves from their situation and categorise it as 'just another case'. The findings of this study strongly support the view that patients cared deeply about their own health and the health of those close to them. The process of partner notification, as currently practised, places a responsibility on people diagnosed with infection to inform partners, or to give details for a health professional to do so, on their behalf. Asking individuals to inform partners is a tall order: as discussed in Chapter 6, health professionals have training in breaking bad news, while patients with diagnosed sexually acquired infections do not. Asking a person who is attempting to cope with their own diagnosis to disclose this information to another person involves great personal cost, not least because the information they are exchanging with another is 'bad news' also for the recipient. It becomes clear then that the experiences for the lay person are different to that of a health professional.

In Chapter 5, the lived reality of sexual encounters from the lay perspective of MSM was described. This chapter was particularly important as it illuminated the private and personal realities for the men who participated in the study. It highlighted other life

priorities which co-existed with a concern for health: concern also with sexual pleasure, sexual expression, relationships, and freedom from rules about what constituted 'healthy' behaviour. Unprotected sex was an important aspect of this lived reality. There were a number of reasons why the men in the study reported not always engaging in what health professionals describe as 'safer sex'. Sexual pleasure was a core explanation as to why men engaged in unprotected sex; the use of alcohol and drugs was also discussed as a relevant consideration; how risk is constructed and played out in the lives of men; the impact of HIV on how risk is perceived; and individual difficulties negotiating safer sex. Anonymous sex was discussed in some detail. The anonymous nature of sexual exchanges between MSM is often reported in the literature as a reason why partner notification is less effective with MSM. The men in this study described their perception of the anonymous nature of sexual encounters and the settings in which they occur. Pleasure was once again an underlying explanation for this. Many participants described the 'buzz' of the anonymous encounter. Some saw it as a way to offer greater control of the situation. But the term 'anonymous sex' was not a straightforward one. The difficulty with partner notification extends beyond naming partners to actually being willing to approach a sexual partner about an infection if they have a chance meeting again. As one participant points out it is difficult to make a disclosure:

How do you? Are you going to walk up to them?

Particularly if they are in company or whatever?

(Interview 2, Case)

The settings where men meet were also a subject of much discussion. Saunas in particular were discussed. Many participants took a similar view to popular medical science discourse in which saunas are constructed as dangerous places and sites for infection. Some echoed the sentiments of health authorities, calling for their closure. Many others talked also (and sometimes simultaneously) about the benefits of saunas and their place in the Gay community, or more importantly a place to go for those who did not openly express themselves as gay or bisexual.

Exploring the lived reality of sex and sexuality from the perspective of MSM, opens up a whole new world of explanations to inform partner notification practice. It helps to explain the gulf between implicit explanations of how partner notification is supposed to work and the reality of the challenges that it faces in practice. Health professionals assume that the avoidance of infection is the number one priority for MSM, but in reality other life desires might take priority.

In Chapter 6, the lay perspective of the process of partner notification was explored. The three stages of 'coming forward', 'finding out' and 'telling others' were described. In the first section: 'coming forward', I explored the process of contemplation and action (for cases) which resulted in attendance at a clinic. The population were crudely divided into what I described as the 'vigilant testers' and the 'reluctant testers'. 'Vigilant testers' were largely driven by a concern for their own health and the health of others. The reluctant testers, were a more sizeable group, and reported difficulty attending clinic. Embarrassment, concerns about confidentiality, the stigma of STIs and fear were all factors making attending clinic difficult and in some cases not possible. 'Finding out' syphilis test results was the next section which was explored. Reactions included shock, fear, relief and shame. Shock was frequently reported, but many said it was short lived – particularly if the news of their diagnosis was swiftly followed with information on available effective treatment. Fear was also a very common reaction of the men who participated. Fear was frequently due to concern about the health implications of the infection itself and its connection with HIV. Some men in this study also reported an embodied sense of shame due to the diagnosis of syphilis. Following on from this feeling of shame was a sense of blame that they got what they deserved, a feeling that it was a result of their 'deviant' sexual actions.

Finally, the experience of 'telling others'- a pivotal part of the partner notification process was explored. A contrast was made with the practice of health professionals breaking bad news, and lay people doing so. Firstly, health professionals receive training, professional

support and supervision. Secondly, health professionals do not have a personal relationship with the person to whom they are breaking bad news. Health professionals ask patients with syphilis and other sexually acquired infections, to break the ‘bad news of their diagnosis’ to another person, a previous or current sexual partner, at a time of considerable personal stress as they attempt to come to terms with their own personal diagnosis. Receiving information of a personal exposure was not easy either. But the greatest dissatisfaction was reported by those who were notified by a health professional through the provider referral route. A number of participants described a sense of powerlessness – in cases where they were called out of the blue and experienced a sense of intrusion into their personal lives.

## **7.2 Theoretical perspectives**

I will now address the theoretical perspectives used in the second chapter in relation to the findings of the study. In turn, I will discuss, Parsons, Foucault and Habermas. The first theoretical perspective I considered was the functionalist perspective of healthcare associated with Talcott Parsons, in particular his work entitled ‘the social system’ (Parsons 1951). Whilst this is now an old piece of work, it still holds relevance in modern health care services. According to Parsons, there are rules and responsibilities on both side of the patient-doctor relationship. A doctor is expected to conduct his or her practice in a professional manner. The patient, on the other hand, is expected to accept the sick role; these conditions included that patients are deemed to have a desire to get well as quickly as possible and that they have a responsibility to seek and comply with medical advice (Parsons 1951:437).

The results of this study correspond with a Parsonian model in the way that the majority of participants reported that they voluntarily attended clinics and underwent treatment when they were diagnosed with syphilis. They adhered to the rules of the ‘sick role’ in that they came forward on recognition of symptoms, sought help from professionals and complied with medical procedures. Many reported relief that treatment was available. The potential sick role was also relevant for many others who did not have syphilis diagnosed. Many men subscribed to the notion that proactive check ups were a sensible

thing to do. In so doing, many renounced hegemonic notions of masculinity associated with reluctance to attend proactively for check ups. Many participants talked in terms of being 'due a check up'. Of interest, a number of men spoke in very strong terms about promoting the message to attend for testing, suggesting that clinics and health professionals 'should be shouting it from the roof tops'. The men in the study reported being, in principle, in favour with the practice of partner notification and justified practice on public health grounds. The men associated this with a sense of moral responsibility, frequently using concepts and language associated with the new public health (Crawford 2000).

The results of the study also conflicted with a Parsonian model; an assumption in Parson's work is that the views of the patient and professional concur. The study findings indicate that while there may be some agreement on certain things, such as a broad agreement on the value of partner notification, the position of patient and professional may mean that their value systems and priorities differ. MSM are informed consumers of health care and the findings of this study indicate that they are not prepared to accept a professional perspective passively or comply with instructions if those instructions are unacceptable to them as individuals. For some, this meant not complying with requests for partner notification in some or all cases, or for others not attending clinic in the first place.

The second theoretical perspective of Michel Foucault and in particular his work on surveillance<sup>23</sup> shall next be addressed. The theoretical perspective of Foucault provides a refreshing contrast to the perspective of Parsons; it highlights the complexity of the power relationships inherent in health care services. Foucault suggests that people have power and the ability to resist medical surveillance. However, the majority of participants in this study still supported the practice, even though they acknowledged the medical surveillance of their bodies and sexual behaviour implicit in the service. Foucault

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<sup>23</sup> Included in this discussion in chapter 2 is reference to the works of other Foucauldian scholars such as Armstrong and Lupton.

accounts for a lack of resistance by referring to the social processes through which expert discourses become hegemonic – or pervasive – discourses. A Foucauldian analysis highlights the ways in which lay people adopt expert discourses of health, cooperating with surveillance by attending clinics and furthering surveillance by surveying their own bodies for signs of infection. The dominance of the medical discourse mitigates resistance and alternative ways of being, although resistance is still possible. In particular, Foucault talks about the ways in which ‘targeted groups’ can become centres of resistance.

In relation to the present study, elements of Foucauldian perspectives were present. Some men in the study were critical of the surveillant nature of the sexual services. This was apparent in many ways. Participants talked about the intrusiveness of the examination, physically and psychologically. The practice of onsite testing was seen by some participants as a form of surveillance by the health care service. While considered by some a novel and innovative response to the problem of a syphilis outbreak in the greater Dublin area, a small number of respondents saw it as an extension of the surveillance carried out. As Pryce (2001) points out, the questioning nature of the lay professional interaction in the sexual health clinical encounter moves the boundaries, from the clinic walls through stories of sexual encounters. In so doing, the private becomes public and is documented as part of the clinical encounter. Taking testing kits and public health staff to the private spaces where MSM socialise may be viewed as an extension of the surveillance of the sexual health clinics. While one or two men were critical of this action, the majority of participants supported it on public health grounds, i.e. the dominant medical discourse. Partner notification itself was viewed by participants as another form of surveillance. This was particularly true for men who were on the receiving end of a provider referral notification. Some described it as a ‘call out of the blue’ and an invasion of privacy. Foucauldian thinking provides an interesting and useful way to consider the practice of partner notification for sexually acquired infections.

The final theoretical perspective to be considered is Habermas (1987). While the men in the study supported broadly the practice of partner notification, this study also provided an insight into the inherent difficulties for individuals. These challenges are frequently overlooked in health care practice and research, demonstrating what Habermas would describe as a colonisation of the lifeworld by the systems world. For health professionals to respond sensitively and genuinely to the needs of the people they claim to serve, it is necessary in the first instance to have an understanding of the difficulties and other life priorities which make partner notification difficult or in some cases impossible.

The most frequently cited reason for the lack of success of partner notification reported in the professional literature is the casual and anonymous nature of sexual health encounters between MSM. Support for this view was found in this study, but the professional bias in the literature means that the difficulties for MSM to disclose to long term partners is overlooked. Reasons why men engage in unsafe sex has also been overlooked in the literature and practice – the use of drugs, alcohol and the importance of pleasure and desire are neglected subjects. The difficulty and lack of training that individuals have in disclosing bad news to partners was also discussed. Once again this is an area overlooked in the literature to date. The literature makes reference to the fact that health advisors perform a delicate balancing act between counselling individuals and advising patients on partner notification. For patients with a diagnosed sexually acquired infection, the struggle to balance the challenges of dealing with the personal situation and disclosing is all the greater. Throughout the study of the lay perspectives, stigma was often at the fore. Sometimes this was explicitly stated or often implied when referring to a considerable fear about being seen in a clinic. Stigma was generally two fold; it was due to the stigma of sexually acquired infections, and it was fear of being identified as gay or bisexual. Frequently, both forms of stigma prevailed.

Habermas's theory, like Foucault's, questions the taken for granted nature of many social structures such as medicine and public health, but goes further because of his interest in emancipation. Habermas' theory of communicative action (1984, 1987) is concerned with liberation through communication. He describes society as consisting of the system and



the lifeworld. The system is composed of the economy and the state, which are concerned with money and power. The lifeworld on the other hand is a symbolic space where culture, social integration and personality are sustained and produced (Thompson 1984). The lifeworld is concerned with communication that seeks understanding. This contrasts with the system world which is concerned with strategic action and success. What concerned Habermas was the imbalance between the system and lifeworld in modern societies. When applied to health care settings it is the bureaucratic nature of organisations, where the system encroaches on the values of the lifeworld which is of concern. In such a setting, expert technical knowledge can take over from the life experiences and values of individuals. While denying suggestions to be utopian, Habermas held out hope that the imbalance between system and lifeworld could be reconciled through communicative action. This involves real communication with an interest in humanely responding to individuals. How relevant then is such a perspective to the present study? The justification for the practice of partner notification is based on system rationalities and technical knowledge driven by public health experts. The primary concern with partner notification in the professional literature is with effectiveness in the reduction of sexually acquired infections. This study, by contrast has been about bringing the system world perspective (literature review) together with the lay perspectives (empirical study). A study such as this can enable communicative action.

### **7.3 Recommendations for Practice**

My intention is to be non-complacent in my daily work in the settings of sexual health care services. My intention is to discuss these findings on lay perspectives to the health professional community. As such the study may serve to make health professionals aware of some of the lay concerns regarding partner notification. The difficulties that individuals encounter in tracing partners, informing contacts and attending clinics pose a challenge to the practice of partner notification and as such need to be highlighted. There is a need for health professionals to support index patients in ‘breaking bad news’ to partners. To this end, there is a need for health professionals to provide training- even short teaching sessions in ‘breaking of bad news’ to partners. There are limitations to partner notification effectiveness and therefore there is further need for proactive

screening to be promoted. In order for partner notification to be effective and acceptable, health professionals, including nurses, have a responsibility to challenge the stigma of sexually acquired infections and homosexuality. Policy makers in both the Health Service Executive and the Department of Health and Children, have a responsibility to put sexual health and sexually acquired infections on the public health agenda. In so doing, consideration should be given to lay perspectives, including lay perspectives of partner notification to inform policy. Health professional educators are ideally placed to encourage the appreciation of lay voices in health care in general and sexual health services in particular. Further research is required to assess the generalisability of this study's finding. In addition, there is a need to explore further diversity of MSM's experiences of partner notification, in particular in more rural settings.

The overall lesson from this thesis is that health professionals must seek to understand lay perspectives in order to improve the effectiveness and quality of health care delivery.

The following points stand out for me in terms of understanding lay perspectives of MSM from this study. The desire for good health cannot be separated from other life desires. Following Parsons, there is a desire for individuals to co-operate with health care workers and to trust them to provide practical solutions. Following Foucault, there is understanding that sexual health is also a form of surveillance. Whilst some clients may accept this surveillance, others do not. So it is important to understand this factor as being a barrier to treatment and healthcare. Following Habermas, we gain an understanding of the differences that health care systems might prioritise compared to lay people, but also following Habermas, there is hope that these two worlds can be bridged if a genuine dialogue can be opened up between them. The participants in this study have begun to articulate some of their concerns in relation to partner notification that need to be brought to the attention of healthcare providers in this area. Sexual infections are regarded as a physical health burden, but also, they are a psychological health burden because of the stigma they contain. Furthermore, the context in which sex happens is not straightforward. Sex sometimes happens when people are high on drugs or alcohol. Anonymous sex is a significant part of sexual pleasure for MSM. Partner notification is not a simple practice or an exact science. Health professionals have always blamed

MSM for the lack of effectiveness of partner notification whilst neglecting the difficulties which index patients face in telling partners. Patient referral is the preferred choice but it is wrong to assume it is the easy choice. For health practice to be delivered in a humanistic way, health professionals need to focus on ways of listening to patients, to understand their life world perspective and to support them to notify partners.

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## Appendix A: Ethical Approval

Dan Lynch, Joint Research Ethics Committee Secretariat.

Telephone: 4142860. Fax : 4142371. Email: [dan.lynch@amnch.ie](mailto:dan.lynch@amnch.ie)

Ms. Claire Coleman,  
Health Advisor,  
Department of Genitourinary Medicine and  
Infectious Diseases,  
St. James's Hospital,  
James's Street, Dublin 8.

6th December, 2002

**RE : An exploration on the acceptability and effectiveness of contact tracing**  
in the context of an outbreak of syphilis

*Please quote this reference in any follow-up to this letter : 020502 / 7602 / 2002 / 11 / 5*

Dear Ms. Coleman,

Thank you for your letter dated 8<sup>th</sup> August 2002 in which you respond to the conditions attached to the initial ethical approval of the above study. This response has been approved by the Chairman on behalf of the Joint Research Ethics Committee. Ethical approval for this study is, therefore, complete.

I apologise for the long delay in sending this letter to you.

Yours sincerely,

---

**Daniel R. Lynch,**  
Senior Executive Officer.

**Appendix B**  
**Questionnaire (Case)**

STUDY: AN EXPLORATION OF THE ACCEPTABILITY  
AND

EFFECTIVENESS OF CONTACT TRACING

*Thank you for completing this anonymous questionnaire. The questions are mostly personal and will be treated confidentially.*

When completed please place it in the envelope provided. Please do not hesitate to ask for assistance.

No.878787\_\_



**SEXUAL HEALTH**

**1. While you were growing up, from which of the following did you learn about sexual health matters? (Tick the 3 most relevant)**

- Mother      \_\_\_1    Friends      \_\_\_5    Books      \_\_\_9  
Father      \_\_\_2    School      \_\_\_6    Magazines    \_\_\_10  
Sister(s)    \_\_\_3    Television    \_\_\_7    Internet      \_\_\_11  
Brother(s)   \_\_\_4    Radio      \_\_\_8    None      \_\_\_12    Other    \_\_\_\_\_

**2. Do you feel the sexual health education you received while growing up was appropriate?**

- Yes \_\_\_1                      No \_\_\_2                      Other \_\_\_\_\_ (please specify)

**3. Nowadays, where do you get information about sexual health matters?**

(Tick all that apply)

- Clinic (sexual health) \_\_\_1    Internet      \_\_\_4    Outreach workers    \_\_\_7  
Daily Newspapers    \_\_\_2    Radio      \_\_\_5    GP/ Practice Nurse    \_\_\_8  
Gay community news \_\_\_3    Friends      \_\_\_6    Don't get information \_\_\_9  
Other \_\_\_\_\_ (please specify)

**4. When was the FIRST time you attended a sexual health clinic?**

- Less than one year ago      \_\_\_1                      6-10 Years ago      \_\_\_4  
1-2 years ago                      \_\_\_2                      Over 11 years ago      \_\_\_5  
3-5 years ago                      \_\_\_3

**5. Have you told any of your friends/family that you have attended a sexual health clinic?**

Yes \_\_\_1                      No \_\_\_2                      Other \_\_\_\_\_ (please specify)

**6. Where did you first hear about this clinic?**

Sexual contact/partner            \_\_\_1                      Internet                      \_\_\_5  
Health advisor                      \_\_\_2                      Newspaper/Magazine \_\_\_6  
G.P.                                      \_\_\_3                      Leaflet                      \_\_\_7  
Outreach worker                    \_\_\_4                      Friend                      \_\_\_8  
Other \_\_\_\_\_ (please specify)

**7. What was the main reason you attended clinic?**

“Check-up”                      \_\_\_1                      Symptoms                      \_\_\_2  
I was told I had come into contact with an infection                      \_\_\_3  
Other reason \_\_\_\_\_ (please specify)

**8. What (if any) of the following made attending clinic difficult. (Tick all relevant)**

Fear                                      \_\_\_1                      Concerns about confidentiality \_\_\_4  
Embarrassment                      \_\_\_2                      None                      \_\_\_5  
Time constraints                      \_\_\_3                      Other \_\_\_\_\_ (specify)

**9. How many people have you had sex (oral, anal, or vaginal) with in the...?**

Last 3 months \_\_\_\_\_ Last year \_\_\_\_\_

**10. How many sexual contacts did you meet at the following venues?**

	Within the last 3 months
Outdoor cruising ground	
Gay sauna	
Gay pub	
Gay club	
Gay social group	
Internet	
Phone line	
Private party	
Other- Please specify	

**11 How many sexual contacts in the last 3 months, would you be able to contact again should you so wish?**

All \_\_\_\_ None\_\_\_\_  
Some (give percent or number) \_\_\_\_

**12. How would you contact these people? (Tick all that apply)**

- Phone (mobile) \_\_\_\_\_
- Text (mobile) \_\_\_\_\_
- Phone (Landline) \_\_\_\_\_
- E-mail \_\_\_\_\_
- Visit their home \_\_\_\_\_
- Meet them at a venue \_\_\_\_\_
- Contact them through friend/mutual acquaintance \_\_\_\_\_

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**13. Do you use condoms for oral sex?**

Always\_\_\_1 Usually \_\_\_2 Rarely\_\_\_3 Never\_\_\_4 Don't have oral sex \_\_\_5

**14 Do you use condoms for anal sex?**

Always\_\_\_1 Usually \_\_\_2 Rarely\_\_\_3 Never\_\_\_4 Don't have anal sex \_\_\_5

**15 Do you use condoms for vaginal sex?**

Always\_\_\_1 Usually \_\_\_2 Rarely\_\_\_3 Never\_\_\_4 Don't have vaginal sex\_\_\_5

**16 Which of the following would you usually take before having sex?**

*(Tick all that apply)*

Alcohol \_\_\_ Cocaine \_\_\_ Ecstasy \_\_\_

Hash \_\_\_ Poppers \_\_\_ None \_\_\_

**17 Have you received a hepatitis B vaccination?**

Yes \_\_\_1 No\_\_\_2 Have immunity\_\_\_3 Other\_\_\_\_\_ (please specify) \_

**18. (a.) Have you ever tested for HIV?**

Yes \_\_\_1 No \_\_\_2 *(if you answered no, please move to question 14)*

**18(b) When was the most recent time you tested?**

\_\_\_\_\_

**18. (c). What was the result?**

Positive \_\_\_1 Negative \_\_\_2 Other \_\_\_\_\_ (please specify)

**19. (a) How long has it been since you were diagnosed with syphilis?**

\_\_\_\_\_

<b><i>CONTACT TRACING</i></b>
-------------------------------

**1. Was your diagnosis of syphilis adequately explained to you?**

Yes \_\_\_1                      No \_\_\_2                      Other \_\_\_\_\_ (specify) \_

**2. Did someone discuss informing partners or sexual contacts with you?**

Yes \_\_\_1                      No \_\_\_2                      Other \_\_\_\_\_ (specify)

**3. (a) How many of your contacts were informed (By you or a health advisor)?**

All \_\_\_1              None \_\_\_2              Some \_\_\_3 (give percentage or proportion)

**3(b). Did you inform some of your contacts/partners yourself?**

Yes \_\_\_1                      ⇒ How many? \_\_\_\_\_

No \_\_\_2                      (if no go to Q.4)

**3 (c). How did you inform them? (Tick all that apply)**

Over the phone              \_\_\_1                      e-mail     \_\_\_4

Face to face            \_\_\_2                      Letter \_\_\_5  
 By text message       \_\_\_3                      Other \_\_\_\_\_ (specify)

**3. (d).** Please give your opinion on the following statements, about the reactions you received after informing people they had come into contact with an infection.

	<b>Strongly Agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
Telling my partner/contact was easier than I had anticipated.					
I was accused of giving them an infection					
They said they didn't believe me					
They were verbally abusive					
They were physically abusive					
If I had an infection in the future I would inform my partner/contact					

**4. (a) Did you give details for a health advisor to inform some of your contacts?**

Yes \_\_\_1                      ⇒ How many?\_\_\_\_\_

No\_\_\_2

**Contact tracing is the process by which people who come into contact with a sexually transmitted infection are notified and invited to come to clinic.**

**5. (a) Do you consider contact tracing an acceptable practice? (Please comment)**

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**5 (b) Do you think that other people would consider this practice acceptable?**

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**5 (c) Do you think there are any suitable alternative to contact tracing?**

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**6. Please give your opinion on the following statements**

<b>Contact Tracing</b>	<b>Strongly Agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
I was too embarrassed to inform some of my contacts/partners					
I was too worried about confidentiality to give the names of some of my contacts/partners					
I didn't have enough time to contact some of my contacts/partners					
I didn't have enough information (such as name or phone number) to contact some of my contacts/partners					
I didn't contact some of my contacts/partners because I worried about verbal abuse					
I didn't contact some of my contacts/partners because I worried about physical abuse					
Having syphilis has created difficulty in my relationship(s)					

If I came into contact with an infection in the future I would like to know so that I could receive treatment or care.					
<b>Sexual Health</b>	<b>Strongly Agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
<i>“ HIV is the only serious infection”</i>					
<i>“I don’t feel comfortable talking about sex”</i>					
<i>“I don’t like talking to partners about infections”</i>					
<i>“When I have casual sex the less I know about the person the better”</i>					
<i>“I sometimes have a problem getting condoms”</i>					
<i>“I would encourage a friend to attend a sexual health clinic”</i>					
<i>“I am more likely to have sex without a condom in my home”</i>					
<i>“I plan to have a sexual health ‘check-up’ every year”</i>					
<i>“I would take a risk rather than ask someone to use a condom”</i>					
<i>“I don’t think I have enough knowledge about sexual health”</i>					

**ABOUT YOU**

1. What age are you? \_\_\_\_\_



**2. What is your nationality or ethnic group?** \_\_\_\_\_

**3. (a) Do you live in Dublin?**

Yes \_\_\_<sup>1</sup> (if yes please go to Q4)

No \_\_\_<sup>2</sup>

**3. (b) If you answered no, to the last question, how far do you live from Dublin?**

Under 50 miles \_\_\_<sup>1</sup>

100-150 miles \_\_\_<sup>3</sup>

50-100 miles \_\_\_<sup>2</sup>

Over 150 miles \_\_\_<sup>4</sup>

**4 What is your highest level of education?**

No formal education \_\_\_<sup>1</sup>

Third Level \_\_\_<sup>4</sup>

Primary \_\_\_<sup>2</sup>

Training scheme \_\_\_<sup>5</sup>

Secondary \_\_\_<sup>3</sup>

Other \_\_\_<sup>6</sup>

**5. Are you?**

In full-time education \_\_\_<sup>1</sup>

Sick/disabled \_\_\_<sup>5</sup>

On training scheme \_\_\_<sup>2</sup>

Retired \_\_\_<sup>6</sup>

Employed \_\_\_<sup>3</sup>

Full time homemaker \_\_\_<sup>7</sup>

Unemployed \_\_\_<sup>4</sup>

other \_\_\_\_\_

**6. If employed what is your occupation?** \_\_\_\_\_

## HEALTH

### 1. How would you describe your state of health? (*Choose one*)

Excellent \_\_\_1 Good \_\_\_2 Fair \_\_\_3 Poor \_\_\_4 Very Poor \_\_\_5

### 2. Please give your opinion on the following statement

*“There is a lot that people can do to keep themselves healthy”.*

Strongly Agree \_\_\_1 Agree \_\_\_2 Not sure \_\_\_3 Disagree \_\_\_4 Strongly Disagree \_\_\_5

### 3. (a) How often do you drink alcohol?

Every day \_\_\_1 Less than once a week \_\_\_4

Several days a week \_\_\_2 Never \_\_\_5 (⇒move to Q4)

At least once a week \_\_\_3 Other \_\_\_\_\_ (please specify)

### 3. (b). How much do you drink at each time?

*(Consider a drink to be a half pint of beer/ lager or one measure of spirits / wine)*

10 or more drinks \_\_\_1 2-4 drinks \_\_\_3

5-9 drinks \_\_\_2 1-2 drinks \_\_\_4

### 4. Do you smoke cigarettes?

Yes \_\_\_1 No \_\_\_2

### 5. Have you in the last month used any of the following drugs?

Cocaine \_\_\_1 Heroin (smoked) \_\_\_5

Cannabis (Hash) \_\_\_2 Heroin (injected) \_\_\_6

Poppers                    \_\_\_3                    None \_\_\_\_\_  
Ecstasy                    \_\_\_4

<b>SEXUAL ORIENTATION</b>
---------------------------

**1. How would you describe yourself?**

Homosexual/gay        \_\_\_1                    Heterosexual    \_\_\_3  
Bisexual                    \_\_\_2                    Other                    \_\_\_4 \_\_\_\_\_(specify)

**2.(a) Are these people aware of your sexual orientation?**

*(Tick all relevant)*

Friends                \_\_\_1                    Partner                \_\_\_4  
Family                    \_\_\_2                    Colleagues            \_\_\_5                    None                    \_\_\_\_\_  
G.P. (doctor)        \_\_\_3                    Other \_\_\_\_\_(specify)

**2(b) Are there people you would have wanted to tell about your sexual orientation, who you did not?**

Yes \_\_\_1                    No \_\_\_2

(Comments) \_\_\_\_\_

**3. (a) Are you in a regular (steady) relationship at present?**

Yes \_\_\_1                    No \_\_\_2                    Other \_\_\_\_\_ (please specify)

**3. (b.)Do you have an open relationship?**

(i.e. partners consent to have other sexual partners/contacts out of the relationship)

Yes \_\_\_1

No \_\_\_2

Other \_\_\_\_\_ (specify)

**4. When was the last time you?** (*Put one tick on each line*)

	4	1	2	3
	<b>Never</b>	<b>In the last Month</b>	<b>In the last year</b>	<b>Over a year ago</b>
Went to an outdoor cruising ground				
Went to a gay sauna				
Went to a gay Pride event				
Looked at the gay press (GCN,GI,)				
Went to a gay pub				
Went to a gay club				
Went to a gay social group				
Went to a gay community centre				
Used the internet				
Went to a G.P.				
Phoned a gay help line (e.g. switchboard)				
Phoned an HIV/AIDS organisation				
Volunteered for a gay or HIV/AIDS organisation				
Paid for sex				
Received payment for sex (money/accommodation/drugs or other payment)				
Replied to Advert in personal pages				

**Please make any comments you wish about this questionnaire**

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**Thank you.**

**Your participation is very much appreciated.**

Please place this questionnaire in the envelope provided  
and return it to the person who gave it to you.

**Appendix C**  
**Questionnaire (Contact)**

STUDY: AN EXPLORATION OF THE ACCEPTABILITY  
AND  
EFFECTIVENESS OF CONTACT TRACING

*Thank you for completing this anonymous questionnaire. The questions are mostly personal and will be treated confidentially.*

When completed please place it in the envelope provided. Please do not hesitate to ask for assistance.

No.878787\_\_\_

(Contact)

**SEXUAL HEALTH**

**1. While you were growing up, from which of the following did you learn about sexual health matters? (Tick the 3 most relevant)**

- Mother \_\_\_1 Friends \_\_\_5 Books \_\_\_9  
Father \_\_\_2 School \_\_\_6 Magazines \_\_\_10  
Sister(s) \_\_\_3 Television \_\_\_7 Internet \_\_\_11  
Brother(s) \_\_\_4 Radio \_\_\_8 None \_\_\_12

Other \_\_\_\_\_ (please specify)

**2. Do you feel the sexual health education you received while growing up was appropriate?**

- Yes \_\_\_1 No \_\_\_2 Other \_\_\_\_\_ (please specify)

**3. Nowadays, where do you get information about sexual health matters?**

*(Tick all that apply)*

- Clinic (sexual health) \_\_\_1 Internet \_\_\_4 Outreach workers \_\_\_7  
Daily Newspapers \_\_\_2 Radio \_\_\_5 GP/ Practice Nurse \_\_\_8  
Gay community news \_\_\_3 Friends \_\_\_6 Don't get information \_\_\_9

Other \_\_\_\_\_ (please specify)

**4. When was the FIRST time you attended a sexual health clinic?**

- Less than one year ago \_\_\_1 6-10 Years ago \_\_\_4  
1-2 years ago \_\_\_2 Over 11 years ago \_\_\_5  
3-5 years ago \_\_\_3

**5. Have you told any of your friends/family that you have attended a sexual health clinic?**

Yes \_\_\_1                      No \_\_\_2                      Other \_\_\_\_\_(please specify)

**6. Where did you first hear about this clinic?**

Sexual contact/partner            \_\_\_1                      Internet                      \_\_\_5  
Health advisor                      \_\_\_2                      Newspaper/Magazine \_\_\_6  
G.P.                                      \_\_\_3                      Leaflet                      \_\_\_7  
Outreach worker                    \_\_\_4                      Friend                      \_\_\_8  
Other \_\_\_\_\_(please specify)

**7. What was the main reason you attended clinic?**

“Check-up”            \_\_\_1                      Symptoms                      \_\_\_2  
I was told I had come into contact with an infection                      \_\_\_3  
Other reason \_\_\_\_\_(please specify)

**8. How many people have you had sex (oral, anal, or vaginal) with in the...?**

Last 3 months \_\_\_\_\_  
Last year                      \_\_\_\_\_

**9. How many sexual contacts did you meet at the following venues?**



	Within the last 3 months
Outdoor cruising ground	
Gay sauna	
Gay pub	
Gay club	
Gay social group	
Internet	
Phone line	
Private Party	
Other (specify)	

**10 How many sexual contacts in the last 3 months, would you be able to contact again should you so wish? \_\_\_\_\_**

**11. How would you contact these people?**

*(If you had no sexual contacts in the last 3 months please indicate with 0)*

- Phone (mobile) \_\_\_\_\_
- Text (mobile) \_\_\_\_\_
- Phone (Land line) \_\_\_\_\_
- Email \_\_\_\_\_
- Visit their home \_\_\_\_\_
- Meet them at a venue \_\_\_\_\_
- Contact them through friend/mutual acquaintance \_\_\_\_\_

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**12. Do you use condoms for oral sex?**

Always \_\_\_1 Usually \_\_\_2 Rarely \_\_\_3 Never \_\_\_4 Don't have oral sex \_\_\_5

**13 Do you use condoms for anal sex?**

Always\_\_\_1 Usually \_\_\_2 Rarely\_\_\_3 Never\_\_\_4 Don't have anal sex \_\_\_5

**14 Do you use condoms for vaginal sex?**

Always\_\_\_1 Usually \_\_\_2 Rarely\_\_\_3 Never\_\_\_4 Don't have vaginal sex\_\_\_5

**15 Which of the following would you usually take before having sex?**

*(Tick all that apply)*

Alcohol \_\_\_ Cocaine \_\_\_ Ecstasy \_\_\_

Hash \_\_\_ Poppers \_\_\_ None \_\_\_

**16 Have you received a hepatitis B vaccination?**

Yes \_\_\_1 No\_\_\_2 Have immunity\_\_\_3 Other\_\_\_\_\_ (please specify)

**17. (a.) Have you ever tested for HIV?**

Yes \_\_\_1 No \_\_\_2 *(if you answered no, please move to question 18)*

**17 (b) When was the most recent time you tested?**

\_\_\_\_\_

**17. C. What was the result?**

Positive 1 Negative 2 Other\_\_\_\_\_

**18. (a) Have you ever tested POSITIVE for syphilis?**

Yes \_\_\_1 No \_\_\_2 Other\_\_\_\_\_

**18 (b) If you tested positive for syphilis, how long ago was it since you were treated?**

\_\_\_\_\_

**19. Have you had a sexually transmitted infection in the last year?**

Yes \_\_\_1      No \_\_\_2      Other\_\_\_\_\_

<b>CONTACT TRACING</b>
------------------------

**1. Did you attend clinic because you were told that you had come into contact with an infection?**

Yes \_\_\_1      No \_\_\_2

**2. Who told you that you had come into contact with an infection?**

Partner \_\_\_\_\_1

Friend \_\_\_\_\_2

Someone I had sexual contact with (not a regular partner) \_\_\_\_\_3

A Health Advisor (or someone from a sexual health clinic) \_\_\_\_\_4

Other\_\_\_\_\_ (specify)

**3. How was this message communicated?**

Over the phone \_\_\_\_\_1      e-mail \_\_\_\_\_4

Face to face \_\_\_\_\_2      Letter \_\_\_\_\_5

By text message \_\_\_\_\_3      Other \_\_\_\_\_ (specify)

**4. How long after you were informed, did you attend clinic? \_\_\_\_\_**

**5. What (if any) of the following made attending clinic difficult**

*(Tick all that apply).*

Fear \_\_\_\_\_1                      Concerns about confidentiality                      \_\_\_\_\_4

Embarrassment                      \_\_\_\_\_2                      None                      \_\_\_\_\_5

Time constraints                      \_\_\_\_\_3                      Other \_\_\_\_\_(specify)

**6. Please give your opinion on each of the following statements. *(Tick each line)***

<b>Contact Tracing</b>	<b>Strongly Agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
<i>“I would rather be informed than not” (That I had come into contact with an infection)</i>					
<i>“The way I was told was OK for me”</i>					
<i>“If I came in contact with an infection in the future I would like to be informed ”</i>					
<i>“I would like to be informed in a similar manner”</i>					
<i>“I felt like I was been blamed for passing on an infection”</i>					
<i>“Coming to clinic has caused difficulties for my relationships”</i>					

<b>Sexual Health</b>	<b>Strongly Agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
<i>“ HIV is the only serious infection”</i>					
<i>“I don’t feel comfortable talking about sex”</i>					
<i>“I don’t like talking to partners about infections”</i>					
<i>“When I have casual sex the less I know about the person the better”</i>					
<i>“I sometimes have a problem getting condoms”</i>					
<i>“I would encourage a friend to attend a sexual health clinic”</i>					
<i>“I am more likely to have sex without a Condom in my home”</i>					
<i>“I plan to have a sexual health ‘check-up’ every year”</i>					
<i>“I would take a risk rather than ask someone to use a condom”</i>					
<i>“I don’t think I have enough knowledge about sexual health”</i>					

**Contact tracing is the process by which people who come into contact with a sexually transmitted infection are notified and invited to come to clinic.**

**5. (a) Do you consider contact tracing an acceptable practice? (Please comment)**

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**5 (b) Do you think that other people would consider this practice acceptable?**

---

---

**5 (c) Do you think there are any suitable alternative to contact tracing?**

---

<b>ABOUT YOU</b>
------------------

**1. What age are you? \_\_\_\_\_**

**2. What is your nationality or ethnic group? \_\_\_\_\_**

**3. (a) Do you live in Dublin?**

Yes \_\_\_\_\_<sup>1</sup> (go to Q4.)                      No \_\_\_\_\_<sup>2</sup>

**3. (b) If you answered no, to the last question, how far do you live from Dublin?**

Under 50 miles            \_\_\_\_\_<sup>1</sup>                      100-150 miles            \_\_\_\_\_<sup>3</sup>

50-100 miles            \_\_\_\_\_<sup>2</sup>                      Over 150 miles            \_\_\_\_\_<sup>4</sup>

**4 What is your highest level of education?**

No formal education    \_\_\_\_\_<sup>1</sup>                      Third Level                      \_\_\_\_\_<sup>4</sup>

Primary \_\_\_\_\_<sup>2</sup>                      Training Scheme \_\_\_\_\_<sup>5</sup>  
Secondary \_\_\_\_\_<sup>3</sup>                      Other (please specify)\_\_\_\_\_

**5. Are you?**

In full-time education \_\_\_\_\_<sup>1</sup>                      Sick/disabled \_\_\_\_\_<sup>5</sup>  
On training scheme \_\_\_\_\_<sup>2</sup>                      Retired \_\_\_\_\_<sup>6</sup>  
Employed \_\_\_\_\_<sup>3</sup>                      Full time homemaker \_\_\_\_\_<sup>7</sup>  
Unemployed \_\_\_\_\_<sup>4</sup>                      Other\_\_\_\_\_

**6. If employed, what is your occupation?** \_\_\_\_\_

<b>HEALTH</b>
---------------

**1. How would you describe your state of health? (Choose one)**

Excellent\_\_\_\_<sup>1</sup> Good\_\_\_\_<sup>2</sup> Fair\_\_\_\_<sup>3</sup> Poor \_\_\_\_<sup>4</sup> Very Poor \_\_\_\_<sup>5</sup>

**2. Please give your opinion on the following statement**

*“There is a lot that people can do to keep themselves healthy”.*

Strongly Agree \_\_\_\_<sup>1</sup> Agree \_\_\_\_<sup>2</sup> Not sure \_\_\_\_<sup>3</sup> Disagree \_\_\_\_<sup>4</sup> Strongly Disagree \_\_\_\_<sup>5</sup>

**3. (a) How often do you drink alcohol?**

Every day \_\_\_\_\_<sup>1</sup>                      Less than once a week \_\_\_\_\_<sup>4</sup>

Several days a week \_\_\_2                      Never \_\_\_\_\_5  
At least once a week \_\_\_3                      Other \_\_\_\_\_

**3. (b). How much do you drink at each time?**

*(Consider a drink to be a half pint of beer/ lager or one measure of spirits /wine)*

10 or more drinks \_\_\_1                      2-4 drinks \_\_\_\_\_3  
5-9 drinks \_\_\_\_\_2                      1-2 drinks \_\_\_\_\_4

**4. Do you smoke cigarettes?**

Yes \_\_\_\_\_1                      No \_\_\_\_\_2

**5. Have you in the last month used any of the following drugs?**

Cocaine \_\_\_\_\_1                      Heroin (smoked) \_\_\_\_\_5  
Cannabis (Hash) \_\_\_\_\_2                      Heroin (injected) \_\_\_\_\_6  
Poppers \_\_\_\_\_3                      None \_\_\_\_\_7  
Ecstasy \_\_\_\_\_4

**SEXUAL ORIENTATION**

**1. How would you describe yourself?**

Homosexual/gay \_\_\_\_\_1                      Heterosexual \_\_\_\_\_3  
Bisexual \_\_\_\_\_2                      Other \_\_\_\_\_



**2. Are these people aware of your sexual orientation? (Tick all relevant)**

Friends      \_\_\_                      Partner      \_\_\_                      None      \_\_\_

Family      \_\_\_                      Colleagues      \_\_\_

G.P. (doctor)      \_\_\_                      Other\_\_\_\_\_

**3. Are there people you would have wanted to tell about your sexual orientation, who you did not?**

Yes\_\_\_1                      No\_\_\_2

(Do you wish to comment?)\_\_\_\_\_

**3. (a) Are you in a regular relationship at present?**

Yes 1                      No 2                      Other \_\_\_\_\_

**3. (b.)Do you have an open relationship?**

(i.e. partners consent to have other sexual partners/contacts out of the relationship)

Yes 1                      No 2                      Other \_\_\_\_\_

**4. When was the last time you? (Please tick each line)**

	4	1	2	3
	<b>Never</b>	<b>In the last Month</b>	<b>In the last year</b>	<b>Over a year ago</b>
Went to an outdoor cruising ground				
Went to a gay sauna				
Went to a gay Pride event				
Looked at the gay press (GCN,GI)				

Went to a gay pub				
Went to a gay club				
Went to a gay social group				
Went to a gay community centre				
Used the internet				
Went to a G.P.				
Phoned a gay help line (e.g. switchboard)				
Phoned an HIV/AIDS organisation				
Volunteered for a gay or HIV/AIDS organisation				
Paid for sex				
Received payment for sex (money/accommodation/drugs or other payment)				
Replied to Advert in personal pages				

**Please make any comments you wish about this questionnaire**

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**Thank you.**

**Your participation is very much appreciated.**

Please place this questionnaire in the envelope  
provided and return it to the health advisor who gave it to you.

## Appendix D

### Questionnaire (Community)

<b>SYPHILIS Questionnaire - Attitudes to Contact Tracing</b>
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**Syphilis is a sexually transmitted infection. The story below explains what contact tracing is. This questionnaire asks you about your attitudes to contact tracing**

- There is an increase in syphilis in Dublin.
- Joe Bloggs finds out he has syphilis and comes to the clinic for treatment.
- There are 2 types of contact tracing that are used:
  1. He tells some of his regular sexual partners that he has syphilis
  2. He gives permission to health workers at the clinic to tell some of his sexual partners that he is no longer in touch with  
*(The clinic guarantees that they won't reveal his name to the contacts)*

**Please give your opinion on the following statements by ticking the appropriate box.**

	<b>Strongly Agree</b>	<b>Agree</b>	<b>Not sure</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
I feel Joe should tell his recent sexual partners					
I feel it is ok for the clinic to tell Joe's sexual partners (With Joe's permission)					
Joe may not know the names or phone numbers to contact some of his partners					
If I had sex with someone who had syphilis I would like to be told by them.					
If I had sex with someone who had syphilis I would like to be told by them.					
If I had sex with someone who had syphilis I would like to be told by a clinic.					
If I had syphilis I would try to tell all my recent sexual partners					

Age Range: <19  20-29  30-39  40-49  50+

What county do you live in? \_\_\_\_\_

(If you live outside Ireland- please state country)\_\_\_\_\_

Have you ever attended a sexual health clinic? Yes  No

When was your last syphilis test?

Less than 6 months  6months to 1 year ago  Over 1 year ago   
Never  (*If never please skip last question*)

Where did you have this test done?

Gay Men's Health Project  St. James's Hospital (GUIDE)

Clubs, Pubs, Saunas

Other  Please state \_\_\_\_\_

**MANY THANKS FOR YOUR PARTICIPATION**

## **Appendix E**

### **Participant Information Leaflet: Questionnaire**

#### **Participant Information Leaflet-Questionnaire**

**Study: An exploration on the acceptability and effectiveness of contact tracing in the context of an outbreak of syphilis**

A syphilis outbreak has been reported in Dublin at the GUIDE clinic (Department of Genitourinary Medicine and Infectious Diseases) St James's Hospital and The Gay Men's Health Project (a community based clinic attached

to St James's Hospital service.). There has been a 30 fold increase in the number of cases of early infectious syphilis in 2000 with a further 5 fold increase in 2001. Similar outbreaks have been reported in other European and US cities

Contact tracing is the process by which sexual contacts (or partners) of persons with sexually transmitted infections are notified, counselled on their exposure and offered services.

You are being invited to participate in a study exploring the acceptability and effectiveness of contact tracing. You have been selected if you attended clinic as a result of contact tracing or if you have been diagnosed

with syphilis. If this is not the case for you, you can discuss your participation with the researcher.

**What does this involve?** You will be asked to complete an anonymous questionnaire. The questions asked will relate to contact tracing and sexual health

**How long will it take?** Approximately 20 minutes

**Will the research benefit me?**

Although the research may not benefit you directly it is hoped that it will result in improvements in care of those persons diagnosed with or coming in contact with sexually transmitted infections.

**Are there any risks?** There are no physical risks of participating. If at any time you feel upset or distressed by any of the issues discussed you are welcome to speak with a counsellor or health advisor in relation to this.

**Do I have to agree to partake?**

You do not have to join this, or any other research study. This decision will not affect the care you, your partner, or any sexual contacts will receive from health advisors or any other members of the clinic team.

**Can I change my mind?**

If you do join and later change your mind, you can quit at any time.

**How confidential is the information?**

Your identity (and that of your partner or any contacts) will be kept anonymous from those other than those directly involved in the research.

The study data will be coded so it will not be linked to your name.

Research data will be kept confidential.

Your identity will remain anonymous in reports and publications arising from the research

All study data will be stored in a secure place and will only be shared with those persons involved in the research

The Health Research Board has funded this study. Participation in this study is covered by an approved policy of insurance in the name of St James's Hospital. In addition the medical practitioners involved in this study have current medical malpractice insurance cover. The sponsor will comply with ABPI guidelines and Irish law in the unlikely event of you becoming ill or injured as a result of participation in this study.

The study has approval from ethics committees of St James's hospital and the School of Nursing and Midwifery Trinity College Dublin.

### **Any Further Questions?**

If you have questions, comments, or complaints relating to this research you can contact:

Claire Coleman

Research Student

Telephone 01-4162315/



## **Appendix F**

### **Participant Information Leaflet: Interview**

#### **Participant Information Leaflet- Interview**

**Study: An exploration on the acceptability and effectiveness of contact tracing in the context of an outbreak of syphilis**

A syphilis outbreak has been reported in Dublin at the *GUIDE* clinic (Department of Genitourinary Medicine and Infectious Diseases) St James's Hospital and The Gay Men's Health Project (a community based clinic attached

to St James's Hospital service.). There has been a 30 fold increase in the number of cases of early infectious syphilis in 2000 with a further 5 fold increase in 2001. Similar outbreaks have been reported in other European and US cities

Contact tracing is the process by which sexual contacts (or partners) of persons with sexually transmitted infections are notified, counselled on their exposure and offered services.

You are being invited to participate in a study exploring the acceptability and effectiveness of contact tracing. You have been selected if you attended clinic as a result of contact tracing or if you have been diagnosed

with syphilis. If this is not the case for you, you can discuss your participation with the researcher.

**What does this involve?** A health advisor (researcher) will interview you. The process of contact tracing will be discussed. You will be asked questions in relation to your experience of contact tracing. Factors that helped or acted as barriers for you will be discussed.

If you attended clinic as a result of contact tracing you will be questioned in relation to the process by which you were informed that you had come into contact with an infection, any difficulties you experienced with this process and your recommendations will be discussed

In addition you will be asked questions about your sexual health,

**How Long will the interview last?** The time of this "once off" interview will be approximately 45 minutes

**Will the research benefit me?**

Although the research may not benefit you directly it is hoped that it will result in improvements in care of those persons diagnosed with or coming in contact with sexually transmitted infections.

**Are there any risks?** There are no physical risks of participating. If at any time you feel upset or distressed by any of the issues discussed you are welcome to speak with a counsellor or health advisor in relation to this.

**Do I have to agree to partake?**

You do not have to join this, or any other research study. This decision will not affect the care you, your partner, or any sexual contacts will receive from health advisors or any other members of the clinic team.

**Can I change my mind?**

If you do join and later change your mind, you can quit at any time.

**How confidential is the information?**

Your identity (and that of your partner or any contacts) will be kept anonymous from those other than those directly involved in the research. The study data will be coded so it will not be linked to your name.

Research data will be kept confidential. The only necessary exception to this right to confidentiality would be in the event of a participant disclosing information that is considered detrimental to the health or wellbeing of another person.

Your identity will remain anonymous in reports and publications arising from the research

All study data including audio-tapes will be stored in a secure place and will only be shared with those persons involved in the research

The Health Research Board has funded this study. Participation in this study is covered by an approved policy of insurance in the name of St James's Hospital .In addition the medical practitioners involved in this study have current medical malpractice insurance cover. The sponsor will comply with ABPI guidelines and Irish law in the unlikely event of you becoming ill or injured as a result of participation in this study.

The study has approval from ethics committees of St James's hospital and the School of Nursing and Midwifery Trinity College Dublin.

**Any Further Questions?**

If you have questions, comments, or complaints relating to this research you can contact

Claire Coleman

Research Student

Telephone:01-4162315/6

**Appendix G**  
**Consent Form**

**Consent Form**

**Study: an exploration on the acceptability and effectiveness of contact tracing in the context of an outbreak of syphilis**

I *(name)* \_\_\_\_\_ have received written and verbal information in relation to the above study.

I have had the opportunity to ask questions and all my questions have been answered to my satisfaction.

I have read (or had read to me) the information leaflet and consent form and voluntarily consent to participate in this study though without prejudice to my legal and ethical rights.

Participants Name \_\_\_\_\_ Date \_\_\_\_\_

Participants Signature \_\_\_\_\_

I have explained this study to the person named above and have sought his understanding for informed consent.

Name \_\_\_\_\_ Date \_\_\_\_\_

Signature \_\_\_\_\_

## **Appendix H**

### **Interview Transcript**

#### **Tape 15 –Interview Transcript**

Q Thanks a million for agreeing to do the interview. Can I ask you first of all what was the reason you came to the clinic the first time.

A The very first time I came here I came for a check up.

Q Okay.

A I was clear then. So then about 6 months down the road I had been with someone else so I thought I had better come and have a check up so when I came for the check up that is when I found out I had caught syphilis.

Q Were you surprised.

A Mm...yes, because I didn't think that something like that would happen in this country at the time. I was surprised.

Q What was your reaction.

A My first reaction was shock but then I just said to myself okay I have it so I had better go and have something done about it.

Q Yeah.

A So the guy that I was with I met him on the way out.

Q Right.

A When I was coming in, so then I knew that he had been checked out so everything was okay.

Q Was that the only person you had been with

A No, I have a partner for 4 year.

Q Okay.

A When I found out that I had what I had and got it treated, I asked him to come to the clinic and he started giving me every excuse under the sun so I phoned him up

and told him and he said O I have nothing, I have been to me doctor and all this. And I have been taking antibiotics for a cold, he said to me. So one thing led to another and I slept with him again.

Q Did you believe him.

A I got re-infected again. I did believe him in a way, you start to trust someone when you know them that long. So now I am having a hell of hard time getting him to come here. he is making every excuse, because he is bisexual and he has a girlfriend and a baby.

Q Okay.

A He is saying people will see me down there and what will they think of me. I said nobody will think anything, so that is why I agreed to give you his number and let you contact him. Maybe you will get more authority than what I can get with him. So it's best that I give you the number.

Q Okay.

A I am getting no satisfaction from him.

Q Right. what do you think is the reason.

A I think the reason is here, I don't think he has been to a clinic like this before. Where I have. I lived abroad so therefore I used to go and have regular checks. But I don't think the ordinary individual in this country goes and has check ups.

Q Yeah.

A I don't think there is enough maybe advise given to them. Gay bars take their money but we don't get no advise from them.

Q Yeah.

A I have a friend that works for gay alliance, so he helps me a lot and we talk about different things and everything like that and if you come round and give out condoms and everything like that which is good. But I think they should give out leaflets saying you should have regular check ups. But there is nothing that goes around stating that you should have check ups. I know your friends should tell you but some people don't do it. They are scared, they would want to be reassured about something like that, that they could come and talk to someone. Like what you are doing, like have them come in. I think it's real intimidating

when you come into a room and you are sitting out there with the people around. But that is the way it is and that is the way you have to think, everybody in that room doesn't have a problem they are just coming for a check up.

Q Yeah, yeah.

A I think it's just in their heads.

Q Do you think his relationship with his girlfriend is an issue.

A Yeah I would say so. I would say so. He was pretty close so therefore I would say he is afraid that someone would see him coming to this clinic and maybe go back and tell her.

Q Yeah.

A So maybe that is his reason.

Q How many times have you been treated now.

A I have been treated, this is my third time now.

Q How much injections have you been getting.

A The first time I had the one every week for 3 weeks. And the second time I had one every day for 21 days. This is my third time now and I come here every 3 days.

Q How often then have you been for blood tests.

A Every month I come here for blood tests.

Q That has been going on for how long.

A Nearly a year. Over a year.

Q How do you feel at this stage after been through all that.

A I am not with him anymore and I will not be with him, because if he can't protect himself then I am not going to suffer the consequences again.

Q Yeah.

A I would be brainless if I went out there and done it again. Where he won't take a half an hour of his time to come in here and be treated.

Q Is this the only partner you have had for the last 4 years.

A Yeah, for 4 years.

Q Would this have been the most difficult time.



A Yes, yeah. Because you know he won't come in. I find it really difficult, I have asked him, phoned him, I have text him.

Q What is his response.

A I have seen a doctor, I am okay. I have nothing. If he has nothing how am I after getting re-infected again when he is the only person I have been with.

Q Is he still wanting to have sexual relations with you.

A Yes, he rings me up but I am not allowing him. I say no, go to the clinic.

Q What does he say.

A I can't go there. He could, his child could have it. I didn't get it off the road, I got it off someone and he was the only one I have been with. So therefore I got it off him.

Q Yeah, yeah.

A Maybe he had it before his girlfriend got pregnant. The child could be born with it, he doesn't care, he doesn't know. But she would be tested wouldn't she.

Q She would be tested in pregnancy.

A So therefore.

Q But it can take up to 3 months to be detected in the blood so there is a bit of a window period there.

A Mm...

Q Do you think contract tracing is something that is not necessarily acceptable to everybody.

A Well, I find it really, really difficult. I am with him 4 year. There are people out there that go to the saunas, they go to a bar, they meet someone, they go home, and all of a sudden they have it. How can they contact that person. It's difficult. Even if you were in a new relationship and suddenly you had something I would find that it would be difficult to talk to someone about it. I don't know what it is, in Ireland people are narrow-minded and they think that as soon as you mention venereal disease or anything like that they back off. They say no, it's not me.

Q Yeah.

A Then they are gone, instead of listening to you and doing something about it.

Q Is that because it's sexually related.

- A Yeah. They think they can close the door after they have been with someone. Forget about it, it didn't happen.
- Q Yeah. Is confidentiality a concern.
- A I see that as one of the main reasons, I suppose it's that they come into the open and be with people in that room out there. They are afraid in case they meet someone they know. I walked in there last week and a friend of mine, a girl that I know and we just talked about it in the car going home. And we dealt with it, she knew I was here for the same reason she was. So we dealt with the situation. And it wasn't difficult at all. She is open-minded and I am open-minded, she knows I am gay but it wasn't a problem with it. But I think I have seen people come in and they are cowering and trying to turn their head away as if to say I don't know you, or you don't know me. But why, the disease came from somewhere and we have to face up to it. If we all just turned our heads away it's not going to go away. Where if everybody was responsible and came in and had their check ups you would have the facility to get rid of it. Whereas if you stay outside the door you are not going to get rid of it. You are just going to keep on spreading it around to people. I think that is totally selfish and irresponsible. If you do something like that.
- Q What do you think is the biggest issue, say for someone who is bisexual is that more difficult.
- A I would say so, especially coming in here when you are bisexual but still even if they are bisexual like that friend of mine, she is a girl, so therefore it's not all gay people that come in here.
- Q Exactly.
- A You could be only coming in for a check up.
- Q Yeah.
- A I think seeing you are doing what you are doing, I think that you should draw up a leaflet and hand it out to inform people that it's necessary for them to come and have a check up.
- Q Yeah. Who should get that leaflet.

- A I think everybody. I think that it should be like either on the news or something like this, but it's all pushed away and it's not brought out. We didn't have this kind of thing years ago, it's all only after happening in the last 3 years or 4 years but now that it's here we should do something about it and say okay, everybody go and have a test.
- Q What do you think would be the biggest barrier for people going.
- A I think they are worried about what other people might think of them.
- Q Yeah.
- A Over here, like in London they deal with it much, much better. We talk about it and it's more open and you talk about even in the job where I worked even with girls they say I am bringing him to the clinic to ensure that if he wants a relationship with me we are both going to the clinic and if he doesn't go to the clinic then I am not having a relationship with him. This is the way they are. They are out straight with each other and up front. Where no one would ever, if you met someone say, you wouldn't say if you want me to have sex with you, you have to go and get checked. In London they do.
- Q So what needs to change.
- A I think people should be more aware of what is out there and drill it into them. To go and get checked, see their doctor or see their health advisor and be treated, whether they have it or not they should come and have the check ups.
- Q Yeah, what was the most difficult part of coming to clinic for you.
- A No, I didn't find it difficult at all. I came every 6 months. When I was away I used to go every 6 months. Me flat mates would say have you been for your check up. I would say no, I am going such a time. And we all even push each other to make us go.
- Q Right, and do you think, would you talk to friends in Ireland about going for check ups.
- A Not really, no, you see because over there its, you know with some people I have. That I know, that I care about I have said have you gone and had check ups.
- Q But over here you wouldn't.

- A No, not necessarily.
- Q Have you told any friends that you have syphilis.
- A Yeah, I have seen friends of mine in here. And they said to me don't worry about it. At least you have done something about it. You have gone and you had it treated. No, I have seen, with all my comings and goings in the last year I have seen about 20 people I know. And I am not ashamed I think it's a good thing that I am here, at least they seen me come in here and they know and they will treat it. I am not embarrassed or ashamed, I spoke to them while I was sitting outside on the chairs. I didn't feel bad, just I am aware of what is out there and I am doing something about it. Anybody can catch it.
- Q Absolutely, do you think other people think the way you think.
- A I doubt it, I doubt it.
- Q Would you have always been quite open minded about these types of things.
- A I got syphilis when I was about 16 years old, and ever since then I have always gone and had a check up every 6 months. I went to Sir Patrick Dunnes hospital years ago. And I was treated there and ever since then I have always gone every 6 months. Gone and had the test.
- Q So because that happened at such a young age.
- A Yeah, it made me aware.
- Q Anything else you think would make contract tracing easier.
- A I don't know.
- Q Do you think one approach would be where the person tells their partner themselves. And the other one is where a health advisor does the informing and sometimes they don't disclose the identify of the person with the infection. What do you think of health advisors doing the informing.
- A Well the health advisors have enough to do without having to do that. If someone is responsible for their own body and if they go to bed with someone else then they should be able to go to that person and say. speak to them. And show them the consequences. But then as in my case if the person is not coming forward well then I think the person should inform the health advisor.
- Q Okay.

- A And let the health advisor take it up then. But I think the person that made contact with them should tell them the consequences.
- Q Do you think it would be difficult with a shorter term, maybe a casual encounter.
- A I think even worse, because how would you, you might never see that person again.
- Q If you had their phone number and you had a casual encounter would you ring them up.
- A Yeah, you should ring them and tell them.
- Q The person rather than the health advisor.
- A Yeah. Yeah, you should do it yourself because you should take responsibility over your own doings.
- Q If you were to receive a phone call saying you had been in contact with syphilis what would you think.
- A I would find it strange, it would knock me back for a bit, but I think I would handle it and I would go definitely to the clinic.
- Q But you prefer the person to tell you.
- A I would prefer the person that I had been with to tell me. To have the decency to come and tell me
- Q Okay, yeah.
- A It's not a big thing, a few injections and it's gone. If everybody did that then it wouldn't be out there. It's people that are not coming in, not having been tested or anything. They are irresponsible people.
- Q Yeah.
- A I think it should be put in people's face more. Like the way condoms is advertised in public toilets and things like that and in bathrooms, everywhere. They should be put in that place and let them know that syphilis is out there big time. I think a billboard or something put in some place. Like they are saying Aids is coming back in this country because it was put in their face and now it's kind of gone away. They think it's gone away and now they are going to do another big publicity about it because it's on the up, it's increasing. So think that it should be just left in people's faces all the time. And let them be aware of it, I

think that is what it is. That is put in your face, it's there. Making you aware that things like that are out there and take care of yourself.

Q Yeah. Do you think that people feel their privacy is being invaded by going to a clinic or even by a name been given over to the health advisor.

A When you go to ...you are not private, so therefore we should take responsibility. They really should. I think that people that run the saunas should take responsibility for their actions.

Q What could they do.

A They have that bathroom up there, and it's casual sex all the time. I have not been in one in a year and a half, when I seen what was going on I said no. I said no, that is it.

Q What is it like there.

A Casual sex, you could have 2 or 3 partners in the one night. So that is why it's rampant in this country.

Q What do you think the saunas should do.

A I think they should put signs up. And in gay bars signs up.

Q What do you think signs would do.

A Put it in people's faces and make them aware of what is out there.

Q So they would go.

A Yeah, I think in Ireland everything is put behind the door. Where it should be put in people's faces.

Q Would it be possible that people who go to saunas and never see a poster at all.

A That is it, you would never see a poster. There is nothing like that put up in front of them. I heard that you have gone down there and even tested people and you went to the (names club) and opened up a clinic upstairs. And unfortunately when I got there I was going to go up only for you were gone.

Q What did you think of that idea.

A I thought it was a good idea. an excellent idea. because when they don't come to you you went to them. And you put it in their face and I thought it was an excellent idea. that is what needs to happen. It's not just do it once off, do it again. Just to let people know, make them aware of what is out here. I think

people don't take responsibility for their actions. They really don't. Not to the degree they should, they should look after their health a lot more in Ireland than they do. Because if you meet the average person on the street say between 18 and 25, and say to them have you ever had a check up, how many of them are going to say yes.

Q Mm...

A I don't know, it was a person in London that brought me totally out of myself and taught me a different way to think, that I don't think like an Irish person anymore. I am Irish and proud to be Irish but I don't think like Irish people. I think they have broadened my horizons. I used to go to St. Thomas's, just run in give my blood, run back out, it was done.

Q How long were you over there.

A 10 years. And people talk about it much more. When you hear a girl coming to you and saying, then there is a discussion, I worked in a bar at nighttime and it was the discussion that she brought up, that she said to him okay we have to go to the clinic and get tested. She just said it, that is the way. She was a dancer in the show and I would say there was about 30 of us just sitting around having a drink or coffee after a show and it was just the conversation and everybody was just natural about it. Talking about it. I have never had that conversation with anybody in Ireland. Even the one person I get something from I confront him and it's not me. The barriers are up straight away whereas I have done something about it and he hasn't. I must have got it from him and why won't he do something about it. At least I had the decency to go and tell him. And you know, I feel responsible that he won't come. I even said to him I will meet you and I will go with you, O no, he just stopped me. I said you can drive, you can walk down the road, it's 10 minutes away. What is to stop you, that is a year ago and he still hasn't been.

Q Were you anticipating that reaction.

A No, I thought about it on my way home and I said no I am just going to confront him and tell him out straight. I thought maybe he might hit me a box, but I had to do it. It's up to me to sort it out.

Q Even though you were a bit afraid.

A Yeah, I was a bit apprehensive but I had to do it. I am taking full responsibility and I am handling it. So I handled it.

Q Even though you were quite nervous.

A Yeah, I was a bit nervous but I said to myself it has to be dealt with and I am dealing with it. Even I spoke to a friend of mine and I said ring me in about 2 hours time just in case I am dead....laughing. I said I am going to tell him, he is on his way here and I am going to sit him down and tell him. So I said ring me in 2 hours to make sure I am alive....laughing, joking like.

Q So you were quite concerned.

A I was a bit concerned.

Q Did you feel he would be aggressive.

A Of course, you don't know what way someone is going to react when you tell them. Immediately they are going to throw the blame on you.

Q Is that what happened.

A No, he was annoyed, he said there is nothing wrong with me. Go away sort of thing. (interruption). I was a bit apprehensive about telling him. I know him 4 years, God help someone that meets someone and maybe only knows them a week or a month, for them to tell someone it's harder. It's a bit difficult because it's not open about it. The people I met in the bar, I told them, I told them out straight, I said I caught syphilis.

Q Would these people you had sex with.

A No, they were just friends of mine and I said look I caught syphilis that is why I was up in the clinic. The people I met when I came in here. I spoke about it to them.

Q What did they say.

A They said well thank god you are looking after yourself, are you okay, I said yeah. They had been here. I would say it's the people that are bisexual and are not out. They are the ones that find it more difficult. They are the ones that are sleeping around, because when their wife is away or whatever. They are coming into town. They are spreading it, so they should be responsible for their actions. I



don't know, I have never spoken to anybody and said do you go and have a check up. Because I don't think that they do. I think maybe if you say when did you last have your check up, are you aware of all these diseases out there, go to your GP or clinic and put it in their face and make them aware of it.

Q Okay.

A I don't think there is enough out there, it's not in the faces enough to make them really aware. They need a bell ringing that there are things happening out there and they should be responsible. Even in the locker rooms where they give them their towels I think that is where they should have the posters and leaflets.

Q And saying go for check ups.

A Yeah, when did you last have your check up or something like that. Put them where they will see them. As I said if you meet someone on the street and you ask 10 people when were they last in for their check up, they wouldn't even know what you were talking about. People don't take care of their actions. They don't take enough responsibility. Sex is there, it's a word that shouldn't be used sort of thing yet they do it but don't want to talk about it. This is why you are doing this because people don't care and they don't take responsibility for what they are doing. It's needs to be put in their faces.

Q Okay, anything else you want to say.

A No.

Q Yeah, okay, thank you again.

## Appendix I

### Semi- structured Interviews: Interview Topic Guide

#### Outline of Questions (case)

Age: Sexual orientation: Live in Dublin? Time since diagnosis: Occupation:
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#### Health Seeking Behaviour- clinic issues

- What was the reason you attended clinic?
- Had you heard about the syphilis outbreak, before you came to clinic?
- Where did you hear about it?
- How did you feel about attending clinic?
- Had you ever clinic attended before?

#### Syphilis-

- How did you feel when you were told that you had syphilis?
- How long ago was it since you were diagnosed with syphilis?

#### Contact tracing

- Did someone in the clinic talk with you about telling your partners/ sexual contacts?
- Are you in a relationship at the moment?
- Do you have an open relationship?
- How did you feel when you were asked questions about your sexual partners/contacts?
- Did you inform any contacts yourself?      ⇒(if yes) How did you tell them?

- ⇒ What type of reaction did you receive?

- Were there any negative effects of telling your partner/contact to come to clinic?
- Do you think anything could have made it easier?
- Did you give details for the clinic to inform some of your contacts anonymously?

#### **Attitudes to contact tracing**

- If the 'tables were turned' and you were a contact of syphilis would you like to be informed?
- How would you like to be informed?
- Do you think that contact tracing, where the person with infection informs his partner, is an acceptable practice?
- Do you think that contact tracing, where the person with the infection gives details to a health advisor to inform the contacts, is an acceptable practice?
- Which is best?
- Can you think of any times it might not be acceptable?
- Are there approaches to contact tracing that should be different, in your opinion
- If you were the health minister faced with the problem of an outbreak of syphilis and certain budgetary constraints – what would you do?
- Should we consider the health of the broader MSM community over individual rights?

### **Outline of Questions ( contacts)**

Age:

Sexual orientation:

Live in Dublin?

Time since notified of possible exposure:

Occupation:

- What age are you?
- Do you live in Dublin?
- How would you describe your health?
- Are you in a relationship at present?
- Is it regular (steady) or casual?
- Do you have an open relationship?
- Did you attend clinic because you were told that you were a contact of syphilis?
- Who told you that?
- How long ago was it since you were told?
- Where were you when you were told?
- How did you feel when you were told?
- Do you think the person who told you that you had been in contact with infection did the right thing informing you?
- How much later did you attend clinic?
- How did you feel attending clinic?
- Had you ever attended clinic before?
- Do you think that contact tracing is an acceptable practice?
- Are there approaches to contact tracing that should be different, in your opinion?

