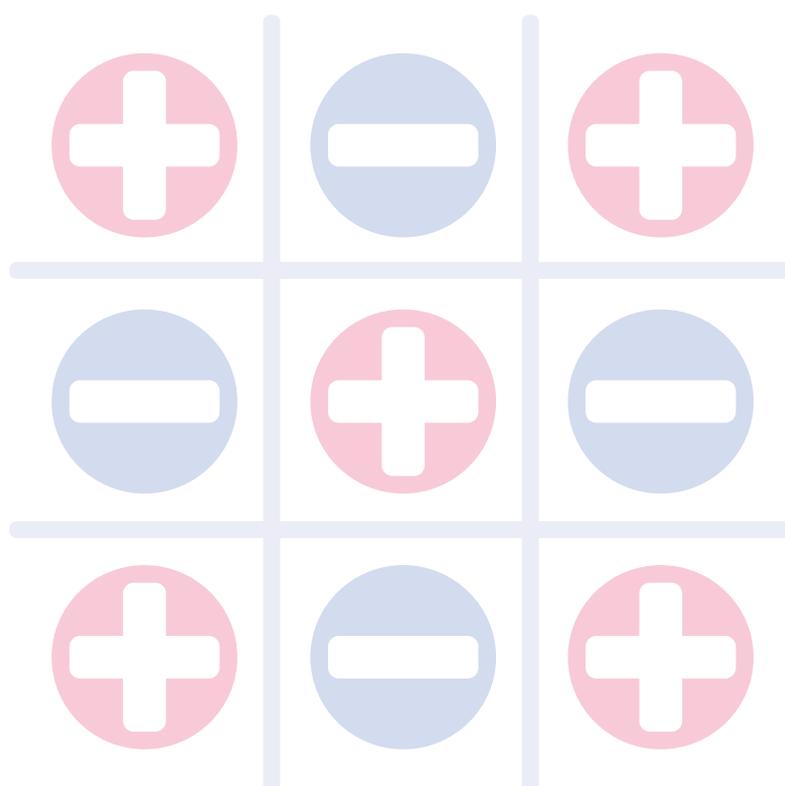


MEN WHO HAVE SEX WITH MEN  
**HIV PREVENTION AMONG THOSE WHO ARE HIV POSITIVE**  
A RESOURCE PAPER





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## **FOREWORD**

Continuing advances in care and treatment of persons with HIV / AIDS require development of new, creative approaches in addressing the needs of persons diagnosed as HIV Positive. It was in acknowledgement of the importance of exploring the broad health and support needs of HIV Positive men and of beginning to proactively develop strategies to respond to these needs in a socially inclusive way that the former Eastern Region Health Authority provided funding towards production of this document.

This resource paper offers a most useful basis for informing further much needed work in the area of secondary prevention of HIV.

I am pleased to endorse the findings of this paper and am wholly supportive of progressing its recommendations.

Alice O'Flynn

*Health Service Executive: National Care Manager: Social Inclusion.*



## EXECUTIVE SUMMARY

HIV prevention among men who are HIV positive may at first seem to be a contradiction in terms, however as this document shows there are a number of issues to be considered if men who are HIV positive are to be supported in having healthy sexual lives while reducing the risks of further HIV infection to themselves or to others.

Men who are HIV positive have broad health needs as members of the general population and particular HIV prevention needs both to prevent the onward transmission of HIV and the potential for re-infection with other strains of HIV. This document identifies strategies and interventions to meet these needs and explores issues for men who have sex with men (MSM) in relation to risk reduction strategies, being included in policy making and acknowledging the levels of prejudice faced by people living with HIV.

The report acknowledges that there is a barrier to working on HIV prevention with people who are HIV positive as it may seem to be contradictory, that an emphasis on onward transmission may be experienced as discriminatory by people with HIV and that generally there seems to be a reluctance to acknowledge that people with HIV have the same rights to a sex life as anyone else.

HIV prevention messages have often failed the needs of people with HIV by assuming an HIV negative status in the audience with an implicit message that HIV positive people have been careless, irresponsible or at best unfortunate. HIV prevention needs to be more inclusive if it is to be more successful. This document reiterates an inclusive system of HIV prevention where:

- Primary prevention includes activities with both infected and uninfected people to reduce primary (i.e. initial or new ) HIV infections;
- Secondary Prevention relates to activities to maintain the well-being of people with HIV and to delay disease progression;
- Tertiary prevention relates to activities to minimise the ill-health of people with HIV who have impaired immune systems, particularly those who have any symptomatic HIV related illness or who have developed AIDS.

As HIV prevalence increases in the MSM population so too does the incidence of sero-discordant sexual encounters. It is recognised that being diagnosed HIV positive does not somehow endow a person with the skills to negotiate safer sex. The factors that make it more likely that someone may engage in sexual practices that are high risk for HIV apply equally to men who are HIV positive, negative or untested. Thus prevention strategies need to take account of biological, social and psychological factors and should aim to ensure that MSM have the skills to negotiate safer sex, recognising that information alone does not lead to behaviour changes.

This document also notes that people with HIV are often not represented in research and the conclusions drawn on their motivations about sexual practice may be based on assumptions rather than their lived experiences.

The impact of Highly Active Antiretroviral Treatment (HAART) may have created a sense of complacency about HIV infection, while the challenge of adherence and the physical and psychological effects of HAART may be underestimated. People with HIV are often expected to bear the responsibility for disclosure of their status with the potential for rejection and discrimination. Anecdotal evidence from HIV positive people suggests that Ireland is less accepting, even on the gay scene, than other countries, most notably parts of the UK and US.

HIV positive people in Ireland can also face significant prejudice in employment. It would seem reasonable to accept that social and work related discrimination will impact on the individual's self-esteem and ability to negotiate safer sex. Studies show that gay men who are unemployed or who have lower educational qualifications are at greater risk for HIV. Therefore HIV prevention needs to take account of a range of social processes that influence the factors leading to HIV exposure.

A key recommendation of the report is that clinical services incorporate prevention interventions, while recognising the challenge it would pose for clinicians. Programmes should include harm reduction approaches, maintain a balance between peer support and professional support and include outreach.

The report also recognises that further research on the needs of MSM who are HIV positive is needed and should be commissioned by the Health Service Executive. This should include treatment issues and sexual health but also the broader socio-economic issues related to well-being.

People with HIV have expressed concern that there are few mechanisms for MSM with HIV to contribute to policy development, clinical management or HIV prevention strategies. Developing targeted interventions for MSM with HIV should ensure that this population has been included in their planning, delivery and evaluation.

Gay HIV Strategies (GHS) secured funds from the Eastern Region Health Authority to address the issue of secondary prevention in a strategic manner. GHS is one of the key policy and development areas of GLEN (Gay Lesbian Equality Network).

Ciarán McKinney

*Director of Gay HIV Strategies*

## 1. INTRODUCTION

Although HIV is less common in Ireland than in many parts of the world, diagnoses of new infections are increasing annually. Men who have sex with men (henceforth referred to as MSM) have been and remain one of the main risk groups for new infections. There have, in particular, been significant increases in new infections from 2000 onwards. The 2000 figure of 72 cases of MSM was an 80% increase on the figure for 1999 with figures rising to 73 new cases in 2001, dropping somewhat in 2002 but rising again to 75 new cases in 2003, the highest figure yet recorded in Ireland for this group.

This increase, according to the Health Protection Surveillance Centre (HPSC) is "likely to reflect an increase in risky behaviour in this group. Increases in risky sexual behaviour, HIV and other sexually transmitted infections have been reported from Western Europe" (HPSC, 2004).

Various reasons have been put forward for the increase in risk taking sex, including, it has been suggested some degree of complacency around the apparent efficacy of highly active anti-retroviral therapies (HAART). However, the most recent and comprehensive study on sexual behaviour between MSM - Vital Statistics Ireland: Findings from the All-Ireland Sex Survey, 2000 (2002) - has highlighted considerable "unmet prevention needs" among this group. These unmet needs relate to knowledge about HIV and its transmission, access to condoms (and the skills to use them), exclusion from supportive social networks and social exclusion more generally<sup>1</sup>. Prevention needs, the report notes, were also more commonly unmet among those who lived outside Dublin, among younger men and among men with lower levels of formal education (2002: 59).

Vital Statistics also noted the importance of focusing on the needs of MSM who are HIV positive in HIV prevention work. Men who are HIV positive, it is emphasised, have HIV prevention needs also and these needs are often compounded rather than alleviated by a HIV diagnosis. Promoting the general and sexual health of HIV positive men is not only important for positive men themselves, especially given the potential for more virulent re-infection, but should also have a very significant impact on the general incidence of HIV among MSM's.

Just what the prevention needs of HIV positive men might be and how these needs can be met is the subject of this report and the research on which it is based. In particular, the report seeks to:

- Outline the rationale for a stronger focus on the prevention needs of MSM who are HIV positive;
- Identify the broad health needs of MSM who are HIV positive and in particular, the needs particularly related to HIV prevention (in terms of both onward transmission and the sexual health of men who are HIV positive themselves);
- Identify potential new strategies and interventions through which the broad needs of HIV positive MSM men can be met, with a particular focus on needs linked to HIV prevention and sexual health more generally, which can then inform the development of more detailed plans and strategies in an Irish context.

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1. In the context of HIV Prevention and sexual health promotion, social networks have historically been a central source of knowledge and awareness about both sexual hazards and health services (Vital Statistics, 2002).

## 1.1 METHODS

The research is based on the following methods;

1. An extensive review of Irish and international literature was conducted, based on Internet search and on literature identified by key informants.
2. Interviews with a range of informants internationally including researchers and those working in prevention services. Informants interviewed in this respect are outlined in Appendix 1.
3. Interviews with a range of service providers in Ireland from both the statutory and NGO sectors. These include those representative of the perspectives of people who are HIV positive. A list of those contacted in this respect is again outlined in Appendix 1.

## 1.2 STRUCTURE OF THE REPORT

Chapter 2 of this report briefly outlines the rationale for a greater focus on the needs of people who are HIV positive in prevention work and the changing concepts of primary and secondary prevention associated with this shift in focus.

Chapter 3 examines the information available on prevalence of HIV among MSM, the risk factors associated with HIV transmission and the associated prevention needs of MSM who are HIV positive. The next two chapters then go on to outline some of the strategies that have been developed for meeting the prevention needs identified, including developments in an Irish context. The final chapter summarise the main conclusions of the research and outlines recommendations for expanding and enhancing provision for MSM who are HIV positive in Ireland.

## 2. A RENEWED FOCUS ON HIV PREVENTION AMONG MSM WHO ARE HIV POSITIVE

A new focus on HIV prevention among people who are HIV positive (including MSM), and an acknowledgement that the prevention needs of people who are positive have not been sufficiently addressed in the past, have been key themes in a range of policy, strategy and research literature internationally. A number of reasons have been put forward for the lack of focus on the needs of HIV positive people in this respect. These have included:

- A reluctance to work on HIV/STI prevention with people who are HIV positive because of perceptions that the concept of prevention for people already infected was inherently contradictory.
- Concern, often justifiable, that a strong focus on transmission prevention directed toward HIV positive people would be stigmatising to a population that already faced discrimination and life threatening illness.
- A reluctance to acknowledge that people with HIV have sex and to get to grips with the complex ethical issues surrounding people with HIV's responsibility towards others (Summer and Davis, 2001a, 2001b; International HIV/AIDS Alliance, 2003; California Department of Health Services, 2003).

However, many compelling reasons to reform prevention efforts so that the needs of HIV positive people are included and prioritised can be identified. In particular:

- From an epidemiological and public health perspective, the most important group to address in terms of HIV/STI prevention strategies are those already living with HIV. For example, in the UK strategy report *Making it Count* (2003), which aims to reduce the incidence of HIV infection during sex between men, it is noted that a man with HIV having unprotected anal intercourse with a random partner, will be thirty two times more likely to have a HIV negative partner than a negative man engaged in exactly the same behaviour is to have a positive partner (since the ratio of positive men to negative men in the population in the UK is 1: 32). It also notes that as many men with HIV infection are also enjoying better health and well-being, the frequency with which they are having sex with men without HIV has also increased (2003: 66).
- People living with HIV, as noted by International HIV/AIDS Alliance, have a right to live well with HIV, which includes having a healthy sex life. This requires strategies that support people with HIV to protect their sexual health and to delay HIV/AIDS progression. There is a growing body of evidence in this respect that further prevention strategies are needed to protect people with HIV from HIV infection or super-infection: that is, becoming infected a second time with another strain of HIV, including drug resistant strains (International HIV/AIDS Alliance, 2003). So too are prevention strategies necessary around sexually transmitted infections (STIs), not just because STIs can increase the risk of transmitting HIV to a partner, but also because of the impact of STIs on the health of a person whose immune system is compromised due to HIV infection.
- HIV prevention, treatment, care and support, it has been increasingly highlighted, are inter-related (Summerside and Davis 2001a, International HIV/AIDS Alliance, 2003; Green and Smith, 2004)). Many of the factors associated with unsafe sex also have a negative impact on the capacity of people who are HIV positive to adhere to anti-retroviral drug therapies. For example, findings from a number of studies show a substantial and consistent relationship between adherence to antiretroviral drug regimes and depression (Green and Smith, 2004). Equally, depression has also been linked to a reduced capacity to maintain sexual health and to sustain safer sex practices (State of California Department of Health Services, 2003).

Providing for greater inclusion of people who are HIV positive in prevention work it has been noted, requires some rethinking and clarity around what is meant by primary, secondary and tertiary HIV prevention. For example, in the Terrence Higgins Trust strategy document *Keeping it to Ourselves* (Summerside and Davis, 2001a), the authors refer to a tendency to conceptualise primary HIV prevention as being solely focused around activities with uninfected people to prevent their becoming infected with HIV. Health promotion messages focused solely on HIV avoidance it is noted, implicitly or explicitly assume the entire audience is HIV negative. Such an approach it is stated exacerbates the 'otherness' of people with HIV. It additionally perpetuates myths of very low prevalence and casts diagnosed people as 'failures' who by extrapolation of the language used to exhort HIV negative people to avoid infection have been 'stupid', 'careless' 'bad' or 'irresponsible' in having broken the safer sex rules (2001a:16). Equally, secondary prevention initiatives, where the main focus is on working with people who are HIV positive to stop onward transmission of HIV to uninfected people often failed by being unrelated to the needs of - and placing the sole responsibility on - people who are HIV positive. We do not, it is noted, appeal to uninfected people to remain so solely on the basis that it would be immoral to do otherwise or that it would have wider implications for the spread of the epidemic at a population level. Nor would it be seen as appropriate to merely discuss the feelings of the person from whom they might contract HIV, to the exclusion of exploring their own response. The corollary of this is that we should focus on the thoughts and feelings of, and the implications for the person with HIV (Summerside and Davis, 2002:17).

In recognition of these factors *Keeping it to Ourselves* emphasises the importance of an "inclusive system of HIV prevention" where:

- Primary prevention includes activities with both infected and uninfected people to reduce primary (i.e. initial or new ) HIV infections;
- Secondary Prevention relates to activities to maintain the well-being of people with HIV and to delay disease progression;
- Tertiary prevention relates to activities to minimise the ill-health of people with HIV who have impaired immune systems, particularly those who have any symptomatic HIV related illness or who have developed AIDS.

Implementing such a system then requires a new focus on identifying the needs of people who are HIV positive in relation to each aspect of prevention work and on developing new or reorienting existing services and interventions to meet these needs.

### **3. SEXUAL BEHAVIOUR, HIV TRANSMISSION AND THE PREVENTION NEEDS OF MSM WHO ARE HIV POSITIVE**

The more limited focus on the prevention needs of people who are HIV positive is reflected in the research literature where significant gaps have been identified in relation to what is known about the sexual behaviour and health needs of people who are HIV positive. Substantial gaps have also been identified in relation to the kind of interventions and services found to be effective in meeting these needs (Summerside and Davis, 2001a, International HIV AIDS Alliance, 2003; Health Development Agency, 2003).

To some extent, men who have sex with men (MSM) have been better served in the research literature, although gaps have also been identified including a tendency to underestimate prevalence in some instances and research

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methodologies that have obscured the experiences and needs of MSM who are HIV positive (Summerside and Davis, 2001a).

Nevertheless, a number of recent studies can be identified which do provide very useful information on issues related to calculating prevalence, the sexual experiences of MSM who are HIV positive and the broad needs of people who are positive including sexual health and health needs more generally. The most significant study undertaken in an Irish context in this respect is Vital Statistics Ireland: Findings from the All-Ireland Sex Survey, 2000 (2002), which has been referred to earlier. Issues emerging from this and research material internationally are briefly summarised across the following themes.

### **3.1 CALCULATING HIV PREVALENCE AND HIV INCIDENCE AMONG MEN WHO HAVE SEX WITH MEN**

In *Making it Count* (Hickson, Nutland et al, 2003), the national UK strategy document designed to reduce HIV transmission between men, the authors note that the number of times HIV infected and uninfected men have sex together is rising due to "changes in at least three parameters" (2003: 18).

- The first of these is that the size of the male homosexually active population is increasing; due primarily it is suggested, to the decrease in discrimination toward gay men in the general population.
- Second, thanks to anti-HIV treatments the average time homosexually active men have HIV has been extended considerably by preventing their deaths. This means the prevalence of HIV in the homosexually active population is increasing each year.
- And thirdly, as many men with HIV infection are also enjoying better health and well-being the frequency with which they have sex with others, including with men without HIV has also increased (2003: 18).

In this context it is noted, prioritisation in prevention activities should be given to men who are most likely to be involved in HIV exposure during sex. The first priority group identified in this respect are men with HIV infection, who include those with diagnosed HIV infection and those with undiagnosed infection (estimated at 19% of those with HIV infection in England at the time of writing). The distinction between these two groups is very important it is noted, as men with undiagnosed infection have the greatest unmet prevention needs yet "as they are unidentifiable to themselves and others, they usually go unaddressed in prevention programmes" (2003: 66).

The prevalence of diagnosed HIV infection among all homosexually active men in the England in 2001 was 3% according to *Making it Count*.<sup>2</sup> This figure was arrived at by taking the latest estimates of men living in England with diagnosed homosexually acquired HIV infections and dividing this by the estimated proportion of the total population of males aged 16 years and over who are likely to be homosexually active (estimated to be 2.6% from latest research findings). Adding the estimated number of men with undiagnosed infection, it was concluded that the prevalence of all HIV among homosexually active men in England in 2001 was 3.7%. In addition, the incidence of HIV infection among homosexually active men (in other words the number of new HIV infections as a proportion of the total population of homosexually active men) was estimated to be between 0.21% and 0.35%. However, the authors note that the precise number of men acquiring HIV is difficult to determine (2003: 12).

Equivalent population estimates would suggest a homosexually active population in the Republic of Ireland of 38,759 (2.6% of the total population of males over 16 years of age enumerated in the 2002 Census of Population).

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<sup>2</sup> Prevalence of a condition is defined as the number of existing cases divided by the population at risk. Incidence of a condition is defined as the number of new cases divided by the population at risk.

At the end of 2003 (the last year for which there are full year on year figures) a total of 764 men with diagnosed homosexually acquired HIV infection were identified by the Health Protection Surveillance Centre and 75 new cases of such infection for that year. Taken together, this would indicate a prevalence of diagnosed infection among homosexually active men in the Republic of 2% in 2003 and an incidence for this year of 0.19%. Although lower than the prevalence and incidence rates identified in England for 2001, these figures have to be treated with some caution, taking into account issues such as under-reporting and numbers of MSM who may have received diagnoses abroad.

Vital Statistics, the report of the All Ireland Gay Men's Sex Survey (2000) suggested higher prevalence levels with 3% of those surveyed stating that they had tested positive for HIV and the authors also noting the considerable potential for undiagnosed infection (2000: 19). The authors note however, that in the absence of a sexual behaviour denominator study for Ireland, it is difficult to judge how representative any sample of homosexually active men is of all homosexually men. (2000:11).

### **3.2 SEXUAL BEHAVIOUR AND PREVENTION NEEDS OF MSM WHO ARE HIV POSITIVE**

#### **3.2.1 METHODOLOGICAL ISSUES**

In the UK National Health Development Agency report HIV Prevention and Sexual Health Promotion with People with HIV (2001b) Summerside and Davis outline some of the limitations of the research literature about the risk practice of people who are HIV positive. A key issue in this respect is a tendency for research on sexual behaviour to be shaped by what they term 'HIV negative normativity'; in other words, the construction of research with the implicit assumption that all respondents are HIV negative such as in the framing of survey questionnaires. An important example in this respect is the infrequency with which questions about testing histories or HIV status have been asked. Whenever these questions are omitted, it is noted, the opportunity is lost to compare responses from respondents of differing HIV status or testing histories (2001b:2).

Other methodological issues identified include the difficulties in finding samples of adequate size and the number of studies based on self report which, in the field of sexual behaviour can be unreliable. In addition, they point to the preponderance of research based on clinical samples that may not be fully representative of the wider population with HIV. They also note the tendency for research on sexual behaviour to be based on psychiatric or psychological concepts, (explaining behaviour in terms of a 'personal deficit model') and the use of relatively narrow public health models of disease containment. Such perspectives, they state, are "limited in their applicability to the design of HIV health promotions as they mask the degree to which risk behaviour can be viewed as a relatively normal, human, occasional failing as it is now usually seen for HIV negative people" (2001b:3).

A final methodological issue identified has to do with the lack of involvement of people with HIV in the way conclusions are drawn from qualitative and quantitative data in research (this issue has also been raised in other reports, see for example the report of the International HIV/AIDS Alliance, 2003). Summerside and Davis state in this respect that "external assertions about the motivations and intentions of people with HIV about sex and safer sex, based on hypotheses or ascriptions, appear more frequently in the literature than actual reflections of the lived experience of people with HIV" (2001b:3). The inherent problems in this are explored in more detail in the strategy document Keeping it to Ourselves (2001a) also by Summerside

and Davis (and on which the National Health Agency report is based). Here for example, the authors note the use in the research of terms such as 'sexual compulsion', 'impulsivity' and 'sexually driven', which are often used to distinguish high and low risk sexual behaviour, but which lead to confusion and can reflect value judgements rather than reported or properly assessed motivations (2001a).

### **3.2.2 RISK BEHAVIOUR FOR HIV TRANSMISSION**

Many of the methodological issues just raised have been addressed in more recent research, particularly in relation to MSM. In the UK for example, Sigma Research has been responsible for undertaking large-scale community based surveys that have included specific questions on HIV status and testing histories. The inclusion of such questions, it has been noted, are important in obtaining a true picture of the dimensions of risky practice in that they allow for distinctions to be drawn between sex that is merely unprotected and sex that is unsafe for primary HIV exposure-i.e. where the sexual partners are sero-discordant.

This is illustrated in Know the Score (Reid et al, 2002) for example, which is the Sigma report of the National Gay Men's Sex Survey conducted across England and Wales in 2001. The report notes that 46.1% of survey respondents who had tested positive for HIV had had insertive anal sex without a condom (the highest risk where the insertive partner is HIV positive) in the previous twelve months. However, 30.3% of these had had such sex with a person they knew to be positive with a much smaller proportion, 9.5%, having had insertive condomless sex with a person they knew to be HIV negative. Almost 24% had had such sex with a person of unknown status (2002: 27).

Similar results have emerged in the All Ireland Gay Men's Sex Survey (2000) mentioned earlier, which was jointly undertaken by members of the Gay Men's Health Network in Ireland and personnel from Sigma Research in the UK. Men who had never tested or who had tested HIV negative were most likely to have unprotected anal intercourse (UAI) with a man they knew at the time to be HIV negative while those who knew they were positive were most likely to have UAI with a man they knew to be positive. A smaller proportion of men who had tested HIV positive had UAI with a partner they knew to be negative (2000: 30).

### **3.3 THE PREVENTION NEEDS OF MSM WHO ARE HIV POSITIVE**

Many factors, it is noted in Making it Count (2003), differentiate those men more likely to be involved in sexual practices that are high risk for transmission of HIV- such as sero-discordant anal intercourse - from those less likely to be. These include a range of evidence-based reasons found to be equally valid for MSM who are HIV positive, those who are HIV negative and those of unknown HIV status. In particular, research would suggest that MSM are more likely to have sero-discordant unprotected anal intercourse if they:

- Have little control over the sex they have;
- Lack the confidence or inter-personal skills required to negotiate sex;
- Are uninformed or misinformed about HIV;
- Are unaware that they and their partner are sero-discordant. (2003: 23).

The aim of prevention interventions should be to address these issues– in other words, prevention services and interventions should aim to ensure that MSM, especially MSM who are HIV positive, have confidence, interpersonal skills, access to condoms and are aware that they and the person they are having sex with are, or might be, sero-discordant for HIV. 'Prevention needs' therefore, can be seen as wide ranging and taking account of social and psychological factors as well.

There is, as noted in the previous section, evidence that MSM who are HIV positive take steps to protect themselves and others –for example by having UAI with those they know to be HIV positive also – but there is also evidence of continued sero-discordant UAI. Making it Count emphasises that receiving an HIV diagnosis does not automatically give men the skills and abilities, or the power, to ensure that their subsequent sexual behaviour never exposes their infection to others (2003: 18). In fact, as noted by Summerside and Davis (2001b), HIV prevention needs can be compounded by HIV diagnosis.

This same point has been raised in an Irish context, where Vital Statistics (2000) found considerable levels of unmet prevention needs among men who are HIV positive. These, in common with those who were HIV negative or those who had never tested, related to knowledge about HIV, the availability of condoms and the confidence and skills to use them. HIV prevention needs were found to be more commonly unmet outside of Dublin and there were also significant levels of need in terms of access to supportive social networks and evidence of a link between broader social exclusion and acquisition of HIV. With regard to the latter, men who tested positive for HIV were less likely to be in employment or in full-time education and more likely to be unemployed or retired (2000:21). Men who were unemployed were also more likely to engage in unprotected anal intercourse (2000: 29).

A range of studies can be identified, mostly from overseas, which explore some of these and other factors relating to sexual risk behaviour in more depth with a particular focus on the perspectives of people who are HIV positive. While it is not possible in the context of this study to provide an exhaustive review of this material, the following sections outlines some of the key themes emerging in relation to the prevention and broader needs of people with HIV.

### **3.3.1 DISCLOSURE AND RELATIONSHIPS**

Disclosure of HIV status has been the subject of some debate and controversy and there is now a substantial body of research and policy literature exploring the implications of approaches such as partner notification (sometimes called 'contact tracing' and more recently 'partner counselling') and whether this should be mandatory in all situations (Canadian Strategy on HIV/AIDS, 2004). The impact of criminalising people who recklessly or intentionally transmit HIV has also been documented, with some evidence presented on the negative impact of this on uptake of HIV testing (see for example: AIDS FONDS Executive Committee on AIDS and Policy and Criminal Law, 2004; Green and Smith, 2004 and; International HIVAIDS Alliance, 2003)<sup>3</sup>.

An interesting review of the research on disclosure is contained in the National Health Service professional briefing HIV Prevention and Sexual Health Promotion with HIV (Summerside and Davis, 2001b) mentioned earlier and in the strategy report on which it is based, Keeping it to Ourselves (2001a). The authors note that much of the research and practice about disclosure relates to approaches that are more relevant to retrospective 'contact tracing' than to building the capacity of individuals to manage disclosure as part of a healthy sex life (2001: b). Building such a capacity it is noted, requires more in-depth understanding of the complex personal and social contexts of sexual needs and interaction.

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<sup>3</sup> The Terrence Higgins Trust (THT) in the UK have developed a comprehensive policy on the issue of criminal prosecution designed to inform legal practice in this area and to ensure that the law is in keeping with best practice in public health. A summary of the policy is outlined on the THT website [www.tht.org.uk](http://www.tht.org.uk).

The document highlights a 'double bind' for gay men. If they did not disclose their HIV status to their partner, then they felt they had to take all the responsibility for the safety of the sexual encounter. On the other hand, if they did disclose they risked rejection, the ending of a valued relationship or moral recrimination (2001a: 49). Examples here include the situation where a casual sexual encounter occurs without disclosure of HIV status but the relationship then develops into a more long-standing one. Lack of disclosure therefore changes into having kept something from the partner. Not surprisingly, gay men who found they were HIV positive reported needing time to relearn sexual negotiation skills in order to handle these situations (2001a: 49).

Casual sex brings up different issues about disclosure. For many gay men, casual encounters can be fleeting and non-verbal. For gay men with HIV, this may not be a preferred form of sexual expression, but "it can represent an attempt to maintain some kind of sex life while avoiding the imposed social norms of universal disclosure" (2001b: 4). Further, in the context of casual sex, research evidence indicates that participants state they can follow non-verbal cues in assessing risk and the likely HIV status of their sexual partner. There is, it is noted, considerable potential here for mis-communication which can lead to mistaken assumptions about the risk of sex without condoms. Studies were identified in this respect showing that gay men sometimes use outward characteristics in judging the likelihood of HIV positive sero-status or that risky practice is judged according to moral frameworks (2001:49).

Another issue identified in *Keeping it to Ourselves* around disclosure with casual partners is the results of Sigma research in the UK which found that in the context of sex without a condom, men who were negative or who had never tested for HIV were more likely to expect a man with HIV to tell them he was positive than was the case for men who were HIV positive. The researchers in this study concluded that gay men who have not had an HIV positive test result need to be informed that men with HIV may not always disclose their HIV status (2001: 50).

The implications of disclosure of HIV status are also illustrated in *What Do You Need?* (Weatherburn et al, 2004), a report of the findings of a national survey of people who are HIV positive in the UK. A significant number of survey respondents (the majority of whom were gay men) reported being too worried about passing on HIV to have sex, including sex with established partners. More than 64% of respondents reported that they had not received any help in dealing with these issues and when asked what help they required, answers related to the need for counselling to address fear and to build or re-establish confidence. Some respondents however, just wanted to talk to someone about the complications of having sex as a person with HIV (2004: 54).

The actual experience of rejection by partners upon disclosure, new and old, was common among survey respondents in *What do You Need?* (2004: 52). The report also illustrates the wider risks of disclosure and the justifiable concern people with HIV have about maintaining confidentiality and disclosing on their own terms. These include the loss of friendships and exclusion from other social networks, exposure to discrimination in different situations –for example in the workplace- and more direct and violent forms of social rejection such as verbal and physical abuse (2004: 66).

### **3.3.2 MENTAL HEALTH**

In a review of the literature on the psychosocial needs of people who are HIV positive in the UK and Ireland, Green and Smith (2004) note that one of the key impacts of highly active anti-retroviral therapies (HAART) for people with HIV has been a shift from a focus on illness and dying to a focus on learning to live again and planning for a long-term future. However, even in the context of the health benefits of HAART many problems remain (or new challenges have emerged) relating to mental health. For example:

- A diagnosis of HIV, it is noted, continues to be profoundly traumatic and can lead to poor psychological adjustment including self-blame, denial, fear of disclosure, low self-esteem, isolation and feelings of depression. Adjustment to a HIV diagnosis and living well thereafter is clearly influenced by the continuing stigma attached to HIV. The 'double stigma' of HIV identified in the 1980s where HIV related stigma is based not only on HIV status but also on association with marginalized groups such as gay men, is still apparent. (2004: 23).
- Reference is made to research on mental health services in London comparing patterns of mental health issues arising in pre and post HAART periods. This showed a notable decrease in the proportion of referrals related to "adjustment disorders" and "organic brain syndromes" but an increase in the proportion of individuals with HIV experiencing depressive disorders and sexual dysfunction. Higher rates of sexual dysfunction and psychosexual morbidity among people who are HIV positive people it is noted, have also been reported elsewhere (2004: 20).
- In a section on severe mental illness, reference is made to the protection HAART can provide against neurocognitive decline and the associated decline in the incidence rates of HIV dementia. The ageing of the population who are HIV positive it is suggested may counteract this trend however and note is also made of ongoing research on the neurocognitive side effects of HAART (2004: 21).

Mental health issues for people with HIV have also been explored in *What Do You Need?* (Weatherburn et al, 2004), referred to earlier. For survey respondents the most common 'need' related to anxiety and depression. This, it was found, related to living with an HIV diagnosis and the many uncertainties, particularly for prospects of health and well-being, this created. Forty five percent of respondents in all had ongoing problems with anxiety or depression and felt that further help or support would be useful (2004: 39).

Beyond the shared reality of HIV infection itself, other causes of anxiety and depression identified included isolation and loneliness, coping with illness and breakdowns in relationships (2004: 38). Many respondents described the breakdown of relationships with partners arising from their HIV status but also the loss of friendships. This led to considerable anxiety about disclosing HIV status to friends; leading people to conceal their HIV status (2004:44).

### **3.3.3 IMPACT OF HAART**

Some very particular impacts of Highly Active Anti-Retroviral Therapies (HAART) have been identified in the research literature, which have implications for the prevention and broader health needs of MSM who are HIV positive. For example:

- The US Health Resources and Services Administration (2003) has noted that the success of HAART may 'lull' people - both those who are positive and those who are negative- into believing that HIV prevention is no longer crucial. Such 'treatment optimism can especially affect younger generations who may not have witnessed the most devastating effects of the early years of the epidemic.
  - A key aspect of 'treatment optimism' for people who are HIV positive, it has been noted, is the confusion and conflicting information on whether or not HIV infectiousness is reduced (or eliminated) if a person with HIV has a low or undetectable viral load (Summerside and Davis, 2001a: 43). Many people with HIV, as noted by the California Department of Health Services (2003) find themselves uncertain about what viral
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load test results mean in terms of transmission risk and some, understandably it is noted, believe that "no detectable viral load" means the same thing as "virus free" (2003: 7).

- Similar confusion has been reported about the subject of "re-infection" or "super-infection"; in other words, the potential for people with HIV to be "re-infected" via unsafe behaviours with a different strain of HIV that may be drug resistant or more virulent. While cases of re-infection have been reported, it is noted, the questions surrounding it may contribute to a sense of denial among people who are HIV positive that can compromise efforts to protect themselves and others from the possibility of re-infection (State of California Department of Health Services, 2003:7).
- Adhering to HAART also presents challenges with some studies showing substantial and consistent relationships between adherence to anti-retroviral drug regimes and depression (Green and Smith, 2004). Other barriers to adherence identified have included the practical difficulties of fitting treatment-taking into daily life at home, at work and while out socialising. The difficulties in this respect included unpredictable routines, the inconvenience of carrying and taking medicines and loss of confidentiality in public (Weatherburn et al, 2004: 59).
- A number of physical side effects of HAART have also been of concern to people with HIV; particularly, the redistribution of body fat known as lipodystrophy<sup>4</sup>. The impact of this condition is explored in some detail by Green and Smith (2004). They note that the condition (experienced by some people on HAART) can not only damage a person's self esteem and body image, it can also unintentionally disclose HIV status. The condition in this respect has been likened to Kaposi's sarcoma in the pre-HAART era, in that it is a visible identifier of HIV, forcing one's HIV status into the public domain, particularly within the gay community where the physical signs of lipodystrophy are likely to be better known (2004: 27)<sup>5</sup>.

Some research studies have also referred to the "technologisation" of HIV care and the implications for doctor patient relationships. Smith and Green, for example, refer to the increased demand on the part of HIV medical specialists to engage with complex molecular-based knowledge in dealing with the side effects of anti-retroviral drug therapies. In keeping abreast of very complex treatment issues, there is a danger, it has been suggested of less time being available in a clinical setting to consider broader issues of lived experience. The level of expertise needed to keep abreast of developments in anti-retroviral drug therapies and their effects, it has been noted by a number of services providers interviewed in the context of this current research, also makes it increasingly difficult to devolve HIV care to primary service providers such as GPs.

### 3.3.4 STIGMA, POVERTY AND SOCIAL EXCLUSION

While the factors that lead to HIV exposure and infection are behavioural and biological, these, as noted in *Making it Count* (2003), involve people and are shaped and determined by social processes. Many barriers to health promotion can be identified in relation to MSM in this respect, not least being the continued social taboo of homosexuality generally, discrimination against gay men in particular, discrimination against people with diagnosed HIV infection and the isolation these social exclusions create and maintain. Stigma and discrimination it is noted, not only reduces the control people have over their own lives (including their sexual lives); it also reduces access to services and compromises the effectiveness of services when they are used (2003: 5).

Experiences of discrimination, poverty and social exclusion, which can be compounded by HIV diagnosis, are illustrated in *What do You Need?* (2004), the UK survey report mentioned earlier. For example:

<sup>4</sup> Lipodystrophy is a condition that includes metabolic changes and fat retribution (re-accumulation) may result in visible changes in body shape, including visceral, breast and/or local fat accumulation or diminution of subcutaneous fat-the latter known as lipodystrophy (Green and Smith, 2004)

<sup>5</sup> Attitudes to lipodystrophy have also been found to differ among people who are HIV positive, depending in particular on how long people have been living with HIV. Research from Canada indicates that the impact of lipodystrophy on quality of life was much greater among younger age groups (2004: 27)

- Discrimination on the basis of HIV diagnosis was widely identified, but respondents also described experiences of discrimination on the basis of other grounds, particularly around their sexuality (20% of all respondents had experienced some form of discrimination in the previous 12 months). Respondents were most likely to experience discrimination when they had to use health or social services for reasons other than HIV treatment and care. The single biggest problem identified in this respect, was finding a dentist willing to treat someone with HIV, followed by similar problems with GPs (2004: 63).
- As referred to earlier in relation to mental health, social rejection and exclusion came from many different directions: from friends partners, families, neighbours and the wider community. The more direct and violent forms of social rejection -verbal and physical abuse-were predominantly homophobic in nature reflecting the visibility of respondent's sexuality. Most abuse in this respect came from neighbours or strangers and included comments and jibes from passers-by, threats, spitting and beatings (2004: 66).

Similar issues have been documented in the Terrence Higgins Trust report *Prejudice, Discrimination and HIV* (Kinniburgh et al, 2001). With regard to accessing health services for example, gay men were found to use a small number of HIV clinics where they knew they were unlikely to encounter prejudice (2001: 4). This study also looked at the literature on employment, noting that since the introduction of HAART many people with HIV have become well enough to return to work. However, direct and indirect discrimination on the basis of HIV were noted. As a result, many people with HIV often chose to remain silent about their status and /or other factors (2001: 4).

Discrimination on the basis of a HIV diagnosis has also been demonstrated in an Irish context. In 2003 for example, a survey by the European Network of Sexual Health of people living with HIV in nine countries found significant levels of discrimination experienced by people with HIV in Ireland. Based on 204 questionnaire returns from treatment centres, HIV/AIDS organisations and clients of POZ Ireland (the NGO which facilitated the dissemination of questionnaires in Ireland), the study found that:

- 95% of those surveyed stated that they had experienced discrimination or stigmatisation in their private and social life because of their HIV status;
- 46% reported discrimination from employers, with 7% of respondents stating that they had lost their jobs because of their HIV status;
- 50% of respondents had difficulties in accessing life assurance and mortgage protection policies.

Instances of discrimination were also noted in relation to accessing health services, banking and social services (A summary of survey results is outlined on POZ Ireland website [www.pozireland.org](http://www.pozireland.org)).

The Vital Statistics report (2000) also showed a link between social exclusion and acquisition of HIV; with people who were unemployed for example, being more likely to engage in unprotected anal intercourse. In addition, there are studies which illustrate a link between anti-gay prejudice and social exclusion. For example, *Poverty; Lesbian and Gay Men* (1995) showed that discrimination against lesbians and gay men in areas such as education, employment and access to services increased the risk of poverty among the gay community generally and further disadvantaged those already poor due to other factors (GLEN/Nexus, 1995). 

### 3.4 SUMMARY

A key issue raised in the research literature on HIV prevention, is the significant gaps around what is known about the needs and life experiences of people living with HIV, including men who have sex with men (MSM). Factors associated with this include the tendency in the past to focus on the needs of people who are negative for HIV in prevention work and the difficulties in accessing populations of people with HIV due to the stigma attached to the infection. Nevertheless, a range of more recent studies has been identified, including primary research undertaken in an Irish context, which do provide some insight into the dimensions of HIV among MSM and the circumstances and needs of those who are HIV positive.

The research literature reviewed in this chapter indicates that the number of times MSM with HIV and those negative for HIV are having sex is rising. This is due to a number of factors including increases in the male homosexually active population (as prejudice and discrimination against men has reduced), increases in the incidence of new HIV infections and the fact that MSM who are HIV positive are now living longer and are well enough to have sex.

Research, both internationally and in Ireland, also indicates that some MSM who are HIV positive do engage in unprotected anal intercourse, which is a particularly risky practice for the transmission of HIV. Some of this sex however, was sero-concordant (where unprotected sex was between people the person with HIV knew to be HIV positive also), although a significant proportion of was also with people of unknown HIV status (who could be either sero-concordant or sero-discordant for HIV). Relatively few MSM who are positive have reported having unprotected anal sex with someone they knew to be sero-discordant or negative for HIV.

A range of factors are linked to unprotected sex that is sero-discordant. In particular, in common with those who are HIV negative, MSM who are HIV positive are more likely to have sero-discordant unprotected sex where they have little control over the sex they have, lack the confidence or skills to negotiate safer sex, are uninformed or misinformed about HIV and are unaware that they and their partner are sero-discordant. Particular issues arising for MSM who are HIV positive in relation to information and skills included:

- The difficulties in disclosing HIV status given the continued stigma attached to HIV. Fears around relationship breakdown, exclusion from family and friendships networks and discrimination in society were a significant barrier to HIV disclosure.
- Disclosure can be problematic in the context of casual sex where encounters can be fleeting and non-verbal and where the potential for mis-communication is considerable. Studies show in this context that MSM who are HIV negative are more likely to expect a man with HIV to tell them he was HIV positive than was the case with MSM who are HIV positive.
- The diagnosis of HIV is still a traumatic event for people and the various uncertainties and difficulties experienced by MSM who are HIV positive can cause mental health problems, particularly depression. Depression in turn has been linked to unsafe sexual practices.
- The efficacy of HAART has led to some complacency around the seriousness of HIV infection. Issues identified for MSM who are positive include a lack of clarity around low viral loads and infectiousness.
- Significant links have been established between HIV infection and social exclusion. On the one hand, social exclusion can be a causal factor in HIV transmission, with research in Ireland indicating that those who

tested positive were more likely to be unemployed. People who were unemployed or living outside of Dublin were also more likely to engage in unprotected anal sex.

- On the other hand, the various difficulties experienced by MSM who are HIV positive, including the effects of discrimination, can lead to or reinforce social exclusion. Significant levels of discrimination on the basis of HIV status have been reported in Ireland across a whole range of areas, including employment, access to health services and life assurance.

#### **4. STRATEGIES FOR MEETING THE PREVENTION NEEDS OF MSM**

The more limited focus on HIV prevention with people who are HIV positive is reflected not just in the research literature on prevention needs (as outlined in the previous chapter), but also in the literature on prevention practice. Comparatively little has been written on prevention work with people who are HIV positive it has been noted (International HIV/AIDS Alliance 2003). Particular gaps have also been identified in the evaluation literature, which can make it difficult to assess the impact of HIV prevention work with people who are HIV positive in different settings and among different population groups. For example, in a recent "review of reviews" on HIV prevention practice undertaken for the UK Health Development Agency [HDA] (Ellis et al, 2003) the authors found "no review-level evidence either to support or discount the effectiveness of any interventions with people with HIV" (2003: 5).

Limitations in the data on prevention initiatives have also been noted by Summerside and Davis (2001b) in their strategy report referred to earlier. However, from their review of literature available at the time of writing, they were able to identify a broad typology of prevention methods focused at different levels. These included:

- Interventions designed to re-orient services to make them more responsive to the health and sexual health needs of people who are HIV positive. Significant examples here include the development of links between treatment and prevention services and the development of links between the statutory and non-statutory sector.
- Interventions with a focus on individuals and couples to address issues such as disclosure of HIV status, anxiety about sex and unsafe sex, interpreting information about treatments (including viral loads and re-infection) and negotiation and skills development around condom use. Methods used in this respect include counselling, telephone helplines and group work.
- Interventions with a focus on the broad social environment such as policy work and "social marketing" to address the stigma of HIV and to promote awareness of the complexity and challenges faced by people who are HIV positive in developing and sustaining their sexual health and health more generally.
- Initiatives focused on communities and social networks (social and sexual) to address issues such as the "contradictions of expectations" with regard to safer sex among people who are HIV negative and those who are HIV positive-including assumption-making about HIV status in casual sex (referred to in the chapter 3 above). Methods here include "social marketing", peer education and the development of community 'capacity' (2001b: 5).

Examples of prevention approaches identified in the research literature at these different levels are outlined in more detail in the following sections. However, as with HIV prevention needs, it not possible to be fully comprehensive in this respect - the intention is simply to illustrate some of the new approaches that have been developed to meet the prevention needs of MSM who are HIV positive and to identify some of the challenges and outcomes emerging from a relatively new field of work.

##### **4.1 INTEGRATING PREVENTION AND CLINICAL SERVICES**

There has been an increased focus internationally on integrating HIV prevention into the care and treatment of HIV. In the US for example, a group of national agencies including the Centers for Disease Control and Prevention

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(CDC), the Health Resources and Administration Services and the National Institutes of Health have recently developed Recommendations for Incorporating HIV Prevention into the Medical Care of Persons Living with HIV (CDC et al 2004). These have included recommendations for risk screening, provision of or referral to appropriate services and partner counselling and referral services (CDC et al, 2004).

The US Human Resources and Services Administration (HRSA) has also outlined the opportunities and operational challenges to integrating care and prevention in their report Prevention is Treatment: Prevention With Positives in Clinical Care (2003). In framing prevention interventions in this context they note that experience shows that HIV prevention programmes that are comprehensive in nature are most effective. A brochure and condoms are not enough it is stated "People engaging in HIV risk behaviours need an array of prevention messages, skills and support" (2003: 3). Also, for some individuals, harm reduction approaches are necessary; in other words supporting individuals to safe behaviours based on what they are able to achieve today may be more effective than strategies that promote only the ideal (2003: 3).

In a section on the barriers to implementing HIV prevention in a clinical setting the HRSA focuses on client related barriers, system related barriers and barriers relating to service providers. With regard to clients for example, they refer to many of the issues already outlined in chapter 3 above, including the enduring stigma of HIV, 'prevention burnout', 'treatment optimism' and the link between mental health, prevention and adherence to anti-retroviral drug therapies (2003: 3-5).

System related barriers related to the focus in the US health system on treatment as opposed to prevention with some areas of legislation placing prevention outside the realm of fundable services. On the other hand, prevention activities, it is noted, targeted people who are HIV negative to a much greater extent than people living with HIV. Fallout from the separation of prevention and care therefore, resulted in a lack of co-ordination between providers of prevention and care services (2003: 6).

And lastly, with regard to "provider-related barriers" the HRSA notes the results of a number of studies indicating that care providers are often ill-equipped to offer adequate prevention services to HIV positive persons. In particular:

- Some clinical care providers were uncomfortable or were unable to offer preventions services;
- Some providers did not see prevention as part of their clinical duties and felt some tension between their role as patient advocates and their broad public health role.
- Prevention was sometimes given a lower priority by providers relative to the more pressing health needs of a client who is HIV positive. In an environment of increasing demands on providers, lack of time in this respect was an issue of critical concern (2003: 7).

The HRSA conclude by stating a number of overarching goals for developing or enhancing prevention work with people who are HIV positive in a clinical setting. In particular:

- From a service provider perspective, they stress that a common understanding of the services needed for prevention with people who are HIV positive must be developed in collaboration with all stakeholders and these services should then be made part of the standard of care.
  - From a funding perspective they state that prevention with people who are HIV positive needs to become
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a "concrete, billable, fundable" activity. And from this perspective also, barriers separating care and prevention should be minimised, emphasising the idea that prevention is care.

- Finally, they recommend that a protocol for establishing successful HIV prevention programmes for all risk groups be established and that people who are HIV positive need to be included and involved in the process of developing and evaluating programme models (2003: 10).

Barriers to integration of HIV prevention and care services have also been explored in a recent policy document of the Department of Health Services in the State of California entitled *Prevention with Positives: A Guide to Effective Programs* (2003). The goals and objectives of care and prevention, it is noted, can present challenges and contradictions as illustrated by one organisation:

*"Our Agency tried to integrate our prevention and our client services departments and it was very difficult. Prevention was telling people 'This is horrible, you don't want to get it' and the Client Services was going 'Oh it's alright. You know it not so bad' "(Quoted by the state of California Department Health Services, 2003: 13)<sup>6</sup>.*

The Department of Health Services notes (in common with the UK Health Development Agency referred to above) that HIV interventions with people who are HIV positive are a relatively new presence on the prevention scene and it is not possible to determine which approaches are most successful. However, reviews of literature it is noted have highlighted some general characteristics that increase effectiveness in risk reduction programme for people who are HIV positive. Such characteristics it is stated include:

- Structuring programmes around the specific culture, behaviours and circumstances of the person being served;
- Designing programmes for people living with HIV rather than adapting programmes developed for HIV negative populations;
- Emphasising incremental, achievable steps toward behaviour change;
- Providing multiple contacts with clients and/or providing long-term contact with clients (sustained interventions lead to sustained behaviour change it is noted);
- Structuring interventions to provide individual and small-group work;
- Using harm reduction based approaches;
- Using motivational interviewing as a baseline to determine readiness for change;
- Maintaining a dynamic balance between peer support and use of professional staff (both are needed they state);
- Using behavioural objectives that are specific and achievable from the perspective of the client;
- Explicitly defining follow-up methods such as phone calls, street outreach or home visits for those who are difficult to engage or who face barriers to participation (2003: 28).

<sup>6</sup> This particular challenge has also been raised by a number of medical practitioners interviewed in this current research where some concern was expressed that people had lost their fear of HIV (personal communication, 2004).

The need for professional training and development in clinical settings has also been emphasised by Green and Smith (2004). As well as knowledge and skills, they state that health care workers need awareness and understanding of social, psychological and cultural issues affecting individuals affected by HIV. Training on ethical and attitudinal issues it is noted, such as confidentiality and being non-judgemental, is particularly important in view of the stigma associated with HIV (2004: 32-33).

#### **4.2 PREVENTION INTERVENTIONS TARGETED AT INDIVIDUALS WHO ARE HIV POSITIVE**

##### **INFORMATION PROVISION**

Summerside and Davis in their review of prevention literature noted that safer sex information often focused solely on onward transmission and neglected the needs of people with HIV; for example issues around HIV positive partners, re-infection and sexually transmitted infections (STIs) and HIV infection (2001a). Examples of work to address these gaps identified in the course of this current research includes the work of the Terrence Higgins Trust (THT) in the UK who have developed a range of cards and booklets designed to inform and support people who are HIV positive in relation to these different needs. Booklets and information packages have included the following:

- Sex and Relationships for Gay Men with HIV (2001), a booklet which looks at the common anxieties gay men with HIV have about sex and relationships and then presents the "facts and the fiction" regarding HIV risks including issues such as viral load and the possibilities of re-infection.
- Gay Men and Combination therapy (undated), is a short booklet that outlines the difficulties, and factors found to be helpful, in adhering to anti-retroviral therapies. The booklet also looks at the side effects of drug therapies and discusses issues such as the possibility of taking therapy 'breaks'.
- Should I Tell (2002) is a leaflet about making decisions about disclosure of HIV. Issues considered include why a person wants to disclose, what people are likely to do with the information, assessments of people's capacity to keep a confidence and the benefits and disadvantages of disclosure.

Other booklets focused on people who are HIV positive produced by THT cover issues such as "getting the most from your HIV clinic", returning to work and a booklet on disclosure of HIV status to a GP and the issues this might raise. Small post cards have also been produced covering these issues more succinctly (Material identified through personal communication with THT).

Examples of information targeted at or inclusive of the needs of gay men who are HIV positive are also outlined by Bleys (1999) in a section of the final report to the European Commission by the European Gay AIDS Prevention Network (2001). The author noted the work of the Terrence Higgins Trust in this respect and also forthcoming publications addressing the needs of MSM who are HIV positive in the Netherlands, Flanders and the rest of Belgium. Publications have also been developed in France it is noted, taking the life experience of gay men with HIV as their starting points (2001: 12).

Research literature on prevention with people who are HIV positive has also noted the advent of "social marketing" in relation to the development and dissemination of HIV prevention messages. "Social marketing" differs from other health education strategies only in its approach, which is based upon commercial marketing

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techniques. Components can include marketing and consumer research, advertising and promotion, market segmentation, message design and testing and media strategy and planning (Health Canada, 2003). The concept of social marketing, it has been noted by Summerside and Davis, with its focus on the diversity of target populations helps explain why safer sex advertising directed at an imagined HIV negative audience will fail to be relevant to people with HIV (2001a: 70).

## **COUNSELLING**

Individual counselling is an important support for people who are HIV positive. Understandably perhaps, counselling has often focused on issues of immediate concern however, especially the crisis presented by diagnosis of HIV. In this context concern has been expressed that prevention may be given less priority in counselling and that some counsellors may not be sufficiently trained to address the prevention needs of gay men-although reference is made to organisations such as the Terrence Higgins Trust which specifically provides safer sex counselling for gay men with HIV (Bleys 1999: 12).

Counselling and broader psychotherapeutic interventions are also discussed by Green and Smith in their review of the psychological needs of people who are HIV positive mentioned earlier. They note that a number of therapeutic approaches have been associated with psychosocial well-being of people with HIV, but that there is a lack of rigorous evaluations with long-term follow-up (2004: 36).

Summerside and Davis (2001a) also note the development of couples counselling which provide MSM with an opportunity to discuss differences in sero-status identities, the negative effects of HIV on sex and to develop communication skills and openness in order to reduce risk (2001a: 70).

## **GROUP WORK**

Group work, as noted by Devlin, Keogh et al (2003) describes a variety of interventions delivered to a collection of people with a common interest. Groups can have a number of functions including the imparting of information, the resolution of psychosocial conflict and the building of social capacity. Such work has been a popular approach in meeting the needs of people who are HIV positive.

### **4.3 INCORPORATING THE NEEDS OF PEOPLE WHO ARE HIV POSITIVE INTO BROADER PREVENTION STRATEGIES**

Significant examples of  group work can be identified which have sought to include the needs of MSM who are HIV positive in broader HIV prevention and health promotion strategies. This has included the development of 'guiding principles' for such inclusion and then specific measures and actions in the context of strategy development and implementation. In the UK for example, the Network of Self Help HIV and AIDS Groups in association with the CHAPS Development Project published Making It Better (Ward, 2001) which sets out principles for inclusion of the needs of MSM who are HIV positive<sup>7</sup>.

The report emphasises the need to redefine the concepts of primary, secondary and tertiary prevention adopting the more inclusive definitions outlined in the strategy report Keeping it to Ourselves (mentioned earlier). Primary prevention therefore, includes activities with both infected and uninfected men to reduce primary (initial or new)

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<sup>7</sup> The report is based on consultations with gay men with HIV and with representatives of the CHAPS partner agencies which includes Gay Men Fighting AIDS, Sigma Research and the Terrence Higgins Trust.

HIV infections and secondary prevention includes activities to maintain the well-being of men with HIV and to delay disease progression. Tertiary prevention relates to activities to minimise the ill-health of those with HIV who have impaired immune systems. (2001: 5).

Making it Better sets out four strategic objectives to ensure that sexual health promotion and primary prevention work is inclusive of the needs and rights of gay men with HIV. These are:

1. Gay men with HIV, as groups and individuals are central to any effective intervention, and this should be recognised.
2. Gay men with HIV should be recognised as essential players in the prevention of HIV, but not be perceived or portrayed as wholly responsible for transmission of HIV.
3. Gay men with HIV are not perceived as a homogenous group whose needs can be universally addressed.
4. The health, emotional and sexual well-being of gay men with HIV is recognised as being as important as that of HIV negative or untested men (2001:18).

A broad set of 'guiding principles' are then set out to address these key objectives which cover issues such as equity, addressing stigma attached to HIV and responsiveness to the diversity of needs in more depth.

Principles to guide good practice in meeting the needs of people who are HIV positive are also set out in the National Health Service professional briefing HIV Prevention and Sexual Health Promotion with People with HIV (Summerside and Davis, 2001b) referred to previously. These include:

- The need for continued sub-targeting of people with HIV to reflect the diversity of population groups most affected by HIV.
- Harm minimisation, which is now being adopted in other health situations, which recognises that health care and health promotion should not and cannot expect to have control over people's lives.
- Supporting self-management in recognition of the value of formal and informal social support networks of people with the same long-term medical condition.
- Sexual well-being and 'sex positive' approaches. Traditionally it is noted; "patterns of service provision" as well as of research seem to have reflected an implicit belief that anyone with HIV doesn't have sex and definitely not unprotected sex. Tied to this it is noted, is the sense that anyone who does have sex, especially if unprotected, is either 'flawed' or has malicious intentions (2001b: 6-7).

Many of these principles are explicitly or implicitly reflected in Making it Count (2003); the national HIV prevention strategy for MSM mentioned earlier which was developed on behalf of the CHAPS partnership. A central principle of health promotion, it is noted, is that the promotion of one person's health must not be at the expense of another's. In line with this not all activities to prevent HIV infection can be considered health promotion. For example, "discouraging men with diagnosed HIV infection from having any sex may reduce the number of exposures that occur in the population, yet it cannot be considered health promotion because it involves removing some men's right to a satisfying and fulfilling sex life" (2003: 3).

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Making it Count also takes a harm reduction approach to reducing sexual practices most risky for the transmission of HIV. For example, recognising that sero-discordant unprotected anal intercourse (UAI) is most risky if the insertive partner is HIV positive, the first strategic aim of the strategy is to reduce the number of occasions of sero discordant UAI where the infected partner is insertive. A second strategic aim then is to reduce the proportion of MSM with HIV who have receptive UAI with a person they know to be HIV negative. An additional strategic aim in this respect is to reduce the number of sero-discordant unprotected oral intercourse where the insertive partner is HIV positive.

The prevention needs of people who are HIV positive have also been more fully included in The National Strategy for Sexual Health and HIV produced by the UK Government Department of Health in 2001. To help reduce the incidence of HIV the Department commits to:

*"Make sure that services for people living with HIV help them to deal confidently with issues around disclosure, condom use and safer sex, so they can maintain their own health and reduce transmission" (Department of Health, 2001: 16.*

As a first step in enhancing services the Department refers to the resource guide for professionals produced by the Terrence Higgins Trust and the Health Development Agency: HIV Prevention and Sexual Health Promotion with People with HIV, which has been referred to in this current research (Summerside and Davis, 2001b).

#### **4.4 SUMMARY**

The legacy of a past lack of focus on the prevention needs of people who are HIV positive is reflected in the policy and research literature in this area, where comparatively little has been written on prevention approaches and interventions with people who are HIV positive.

However, a number of significant new approaches to prevention can be identified internationally, which are likely to have implications for practice in an Irish setting. In particular:

- A greater focus has been placed, for example in the United States, on building a greater prevention capacity within clinical treatment services for HIV. Barriers identified in doing this include the increased demands on the part of clinicians due to the demands of drug treatment management. Also noted has been the potential conflicts between prevention and care messages, the former emphasising the life threatening nature of the infection so as to prevent new infections, the latter emphasising the strides made in controlling the condition and the capacity of people to live well with HIV.
- Programmes found to be effective in reducing risk taking in relation to HIV in these settings have included those which incorporate harm reduction approaches (where the person who is HIV positive is encouraged to focus on achievable prevention goals), maintaining a balance between peer support and support from professional staff and ongoing contact with between staff and clients, including outreach programmes to involve those not engaged with a treatment service.
- Examples of prevention approaches targeted at MSM who are HIV positive have been identified. In line with more inclusive concepts of primary and secondary HIV prevention, these have focused on issues of direct relevance to the needs and circumstances of MSM who are positive including issues such as disclosure of HIV status, negotiating sex within relationships and accessing various drug treatments. Also important has

been counselling, peer group support and the advent of 'social marketing' based on commercial marketing techniques which among other things have concentrated on reducing the stigma attached to HIV.

- Examples have also been identified of more inclusive incorporation of the needs and circumstances of MSM who are HIV positive into broader prevention strategies. This has included the formulation of key principles including the need to involve people who are HIV positive in the identification and development of interventions around HIV prevention and the promotion of sexual health more generally.

## 5. HIV PREVENTION WORK WITH MSM WHO ARE HIV POSITIVE IN IRELAND

Based on the review of policy documentation and interviews with key informants, the following chapter outlines some of the issues emerging in an Irish context in relation to the prevention needs of MSM who are HIV positive. These are considered in relation to the broad strategic areas outlined in the previous section, including research on needs, prevention in a clinical setting, targeted interventions and the inclusion of MSM who are HIV positive in more general HIV prevention strategies. The Chapter also outlines some of the emerging opportunities identified which have the potential to build on work already undertaken and to address gaps in provision.

### 5.1 RESEARCH INTO THE NEEDS OF MSM WHO ARE HIV POSITIVE

Discussions with those interviewed in the course of this research would suggest that some progress is being made in relation to identifying the needs and circumstances of MSM who are HIV positive. Vital Statistics Ireland (2002) for example, has been one of the most comprehensive pieces of quantitative research undertaken on sex among MSM's (based on a survey undertaken in 2000) and although not specifically focused on MSM who are HIV positive, provides important data on a range of issues relating to the prevention needs of this group. Other key developments in relation to research and needs identification include the following:

- Updating of the Vital Statistics research which is currently being undertaken by the Gay Men's Health Project, Sigma Research and the Rainbow Project.
- The HIV Services Network, a network of HIV services which is funded through the Department of Health and Children, has held three conferences on the needs of people who are HIV positive, including MSM.
- Positive Voices, POZ Ireland and Positive Input, all of which are groups representative of MSM who are HIV positive, have provided an important basis both for identifying and articulating the needs and circumstances of MSM.
- POZ Ireland, as referred to in Chapter 3 of this report, has facilitated research in Ireland for the European Network of Sexual Health in 2003 which looked at experiences of discrimination among people who are HIV positive.
- Papers have been prepared to inform the deliberations of the Working Committee of the National AIDS Strategy Committee (NASC) focused on the issue of 'notifiability' and disclosure around HIV.

*[note: an outline of each of the agencies and organisations mentioned is contained in the annex to this report]:*

However, no comprehensive study along the lines of the UK study "What do You Need" (mentioned in the previous chapter), which looked at the needs and circumstances of MSM who are HIV positive across a range of social, economic and health areas, has yet been undertaken in an Irish context. The need for research on needs in this respect, as noted by the Gay Men's Health Project, has been raised at the NASC Education and Prevention Sub-Committee which has been focusing on the issue of secondary prevention.

Other issues identified by informants in relation to needs identification has been the importance of ensuring an environment of safety, trust and understanding in a clinical setting when discussing sexual health issues with MSM

who are HIV positive. Such an environment makes it more likely for people to be open about their needs and experiences, and provides service providers with a more realistic understanding of risk factors and pressures faced by people who are HIV positive around their sexual health and lives more generally. Information garnered from these sources it was noted, with appropriate allowances for confidentiality, should provide valuable information on the kind of strategies necessary for effective for care and prevention.

## 5.2 PREVENTION IN A CLINICAL SETTING

Examples of progress made in terms of building a prevention focus for MSM who are HIV positive into work in a clinical setting have included:

- Social workers are in place in the sexual health clinics in a number of hospital settings including St. James and the Mater hospitals in Dublin and in the University College Hospital in Cork. These social workers work with people who are HIV positive in relation to areas such as treatment adherence, sexual health and general health.
- The Gay Men's Health Project (GMHP), based in Dublin, provides a range of support services for MSM around sexual health including a weekly clinic for HIV and sexual transmitted infections (STIs). It provides treatments for STIs and refers people who are diagnosed HIV positive to hospital clinics for medical treatment. While HIV is managed at the hospital clinics, many MSM who are HIV positive choose to present at the GMHP clinics for their broader sexual health needs.
- Southern Gay Men's Project and GMHP provide training to HSE staff and other agencies on sexuality and around creating positive, safe and friendly service environments for gay people.
- In St. James Hospital some work has been undertaken by social workers and health advisers on conducting sexual health assessments with MSM.

However, a number of overarching constraints have been identified in relation to incorporating a greater focus on prevention into the hospital setting where treatment HIV is delivered. For example, the Report by the Care and Management Sub-Committee of the National AIDS Strategy Committee on HIV/STI Services in Ireland (2003) - based on visits to a range of STI and HIV services in Dublin, Cork and Galway<sup>8</sup> - found that:

- Most of the services visited were at capacity level, both in terms of physical capacity and staffing. This was due largely to a significant increase in demands on services arising from factors such as increases in STI incidence, increases in rates of risky sexual behaviour and increases in the number of non-EU nationals presenting for treatment, particularly in relation to HIV infection (2003: 30).
- The study also referred to a lack of the full range of staff disciplines required in order to provide appropriate services delivery, including a number of services which did not have health advisers or clinical nurse specialists. This was important given, it is noted, the importance of education and awareness around HIV and sexual health and the provision of specific prevention functions such as contact tracing and partner notification (2003: 30).
- The need for better epidemiological knowledge of STIs was also noted in order to develop an effective sexual health strategy. Gaps identified in this respect included the need for inclusion of information on area

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<sup>8</sup> Representatives of the Care and Management Sub Committee visited the following centres that provide STI and HIV services: Our Lady's Hospital, Crumlin; Merchant's Quay Project, Dublin; University College Hospital, Cork; Limerick Regional Hospital; Waterford Regional Hospital; Mater Hospital, Dublin; Beaumont Hospital, Dublin; St. James's Hospital Dublin; University Hospital, Galway.

of residence to allow for estimation of incidence rates at health board level and below (2003: 32).

Similar constraints were raised by a number of key informants interviewed in the course of this study. In addition, reference was made to the increased demands on the part of HIV specialists around the management of anti-retroviral drug therapies, including the need to keep abreast of rapidly evolving and complex developments in drug therapies. As a result, less time was available on the part of clinicians around prevention issues, increasing the need for more broadly focused health and sexual health advisers even more<sup>9</sup>.

### 5.3 TARGETED INTERVENTIONS

As noted in the previous chapter, interventions targeted at the actual needs of MSM who are HIV positive have become a key focus in relation to more inclusive secondary prevention internationally. Examples of progress made in community and statutory service provision around this issue in Ireland include:

- The Gay Men's Health Project has run personal development courses for MSM who are HIV positive.
- The Gay Health Network has issued advertising and booklets focused on STIs and HIV testing. These publications were aimed at both MSM who are HIV positive and negative.
- Open Heart House provides support to those who are HIV positive including specific supports for MSM who are HIV positive. These include facilitation of a peer support group and complementary therapies.
- POZ Ireland provides a comprehensive web site and publications on various medical aspects of HIV treatments and treatment issues.
- Gay Community News, the monthly national lesbian, gay and bisexual publication have a health editor, run a monthly column on living with HIV and run regular feature articles on different aspects of HIV.
- Positive Voices, an interagency project for people who are HIV positive have held residential weekends of people, including a number for MSM who are HIV positive.

While the value of all of this work was emphasised by key informants interviewed, concern has been expressed about funding constraints and significant gaps in provision relevant to the full spectrum of needs that MSM who are positive are likely to have. In particular:

- Voluntary /community organisations representative of MSM who are HIV positive (including POZ Ireland, Positive Voices and Positive Input) largely depend on the voluntary input of their members. If the perspectives of MSM who are positive are to influence policy, services planning and provision this will need to be effectively resourced.
- Significant areas of information needs identified by MSM who are positive are underdeveloped in an Irish context. These include targeted information around issues that are very specific to the needs of MSM who are HIV positive, including prevention messages, treatment options, disclosure and negotiation of safer sex and living well with HIV more broadly.

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<sup>9</sup> This issue was also noted in the report of the National AIDS Strategy Committee in 2000. The availability of HAART, it states, has shifted emphasis at HIV treatment centres from symptom management and prevention counselling to focusing on planned medical treatment (2000: 40).

An issue of broader concern for MSM who are HIV positive, it was noted by a number of informants, is the enduring stigma attached to HIV, among MSM as well as society more generally. Making it safe to disclose one's HIV status without experiencing discrimination and exclusion was highlighted as a critical step in ensuring that MSM who are HIV positive are accessing the services they need.

#### **5.4 INCORPORATING NEEDS OF MSM WITH HIV INTO BROADER PREVENTION AND CARE STRATEGIES**

Some progress has been identified in relation to incorporating, or at least providing a channel for the articulation of the needs of MSM who are HIV positive into national HIV prevention strategies. For example, following a recommendation from the Report of the National AIDS Strategy Committee 2000 (NASC), the Education and Prevention Sub-committee has included a person living with HIV as a member. The remit of this Sub-committee has been to examine "the primary role of prevention and education as an integral part of an overall strategy to prevent the transmission of HIV and AIDS (2005: 28)". As referred to above, one of the proposals emerging is for research on the needs and circumstances of people who are HIV positive.

With regard to sexual health more generally however, Ireland (unlike the UK) does not have a national action plan on sexual health and safer sex practices. The need for such a plan has been proposed by the National Health Strategy 2001 and has been highlighted in the recently developed Sexual Health Strategy of the Health Services Executive (2005). The latter Strategy does not specifically address the particular needs of MSM who are HIV positive but does outline a series of recommendations for sexual health that are of relevance to this group. Areas covered in this respect include:

- Information provision which should be easily accessible to all and be provided in a number of settings to different clients groups.
- Health promotion, including the designation of Health Promotion officers in the region whose remit includes sexual health.
- Organisation of sexual health services at three key levels. These include the primary care level (dealing with prevention, education, screening etc.), specialised clinical care (for more complex sexual health management- Gay Men's Health Project was mentioned as a model in this respect) and hospital based consultancy led services. Health advisors, it is noted should be available at all hospital based STI clinics.
- Under the heading of 'special groups' recommendations include the development of best practice at national level for doctors and other health professionals for the provision of advice and treatment for young people.

The Strategy also outlines a number of key principles and values, identified in the consultation process that should be adhered to in the development of sexual health services and programmes. Services, it is noted, should be: accessible, provided in partnership with patients and carers, effective and evidence based focused on patients, confidential and non- judgemental. Key values informing services include:

- Sexual health as a human right;
  - Respect for values and beliefs of communities and patients;
-

- Equity in the provision of care and prevention services;
- Transparency in relation to allocation of resources (2005: 51).

## STRATEGIES ON SOCIAL EXCLUSION GENERALLY

Very little evidence was found of the needs of MSM who are HIV positive being addressed in other policy areas. However, the broad range of needs arising for MSM who are HIV positive (encompassing, as noted in this study, issues such as discrimination, mental health issues and social exclusion suggest) suggest a need to include provision for MSM who are HIV positive in a whole spectrum of policy and service areas beyond specific HIV treatment and sexual health. Examples identified by informants in this respect include:

- Given the extent of discrimination documented in relation to HIV status, the need to deepen links with the Equality Authority to address such discrimination was highlighted. The Equality Authority has a key role in implementing the provisions of the Equal Status Acts 2000-2004 and the employment Equality Act 1998 which prohibit discrimination on nine grounds, including sexual orientation and disability.
- The Primary Health Care Strategy and the preparation by Expert Advisory Group on Mental Health Policy of a new national policy framework for mental health services provide an opportunity to influence service developments in line with the needs identified in relation to accessing primary health care and in addressing mental health issues experienced.
- The current process to development a national strategy for men's health also provides an opportunity to raise the specific issues faced by MSM who are HIV positive.

An overarching issue, as already referred to, is the need to resource the participation of MSM who are HIV in these and other policies and strategies relevant to meeting the needs. As noted, there are already a number of organisations that have been articulating issues for MSM who are HIV positive, but these have largely been operating on a voluntary basis.

## 5.5 SUMMARY

The evolving concepts of primary and secondary HIV prevention mentioned in earlier chapters, where there is a greater focus on the inclusion of the needs of people who are HIV positive, have not to date been formally articulated in health policy in an Irish context. Nevertheless, examples of progress have been identified in meeting the needs of MSM who are HIV positive across a number of strategic areas, including needs identification, prevention work in a clinical setting (including training around sexuality), targeted interventions (in which representative groups of MSM who are HIV positive have been key) and some provision for the inclusion of the perspectives of MSM in the development of HIV prevention policy.

However, a number of gaps have also been identified by key informants interviewed in the course of this research and through the review of policy and research literature. These include:

- Lack of funding and resources for group development of, and networking between, representative groups of MSM who are HIV positive.

- Lack of comprehensive research on the needs and circumstances of MSM, encompassing not just treatment issues and sexual health, but also broader social and economic issues related to well-being.
- Limitations on the resources available for prevention work in a clinical setting which has become more critical given new demands on the services. The need for more health advisers around HIV and broader sexual health has been highlighted in this respect.
- Need for more targeted interventions for MSM who are HIV positive, including information addressing needs specific to MSM who are HIV positive in relation to prevention messages, treatment options, disclosure, relationships and living well with HIV more broadly.

Although there is currently no national action plan on sexual health and safer sex practice, regional sexual health strategies -such as the recent Sexual Health Strategy of the Eastern Regional HSE- outline a set of service responses and principles and values which are of direct relevance to incorporating the needs of MSM. A range of other policy opportunities have also been identified relevant to broader needs including the development of new national policies around men's health and mental health. The Equal Status Acts 2000-2004 and the Employment Equality Act 1998 also provide an important opportunity to address discrimination on the basis of HIV status. The capacity to 'come out' safely around HIV status has been highlighted as an key issue for the health and well being of people who are HIV positive.

## **6. CONCLUSIONS AND OUTLINE OF POSSIBLE STRATEGIC WAYS FORWARD**

### **6.1 SUMMARY AND CONCLUSIONS**

There has been a significant shift in HIV prevention approaches internationally towards providing for greater inclusion of people who are HIV positive. This, it has been noted in the policy and research literature reviewed in this study, is not only justified from an epidemiological and perspective, but also from the perspective of people who are HIV positive themselves. People who are HIV positive it has been emphasised, have the right to live well with HIV, which includes having a healthy sex life. HIV prevention and care and treatment of HIV are also inter-related, with many of the factors associated with sustained safer sex also linked to a capacity to adhere to anti-retroviral drug therapies.

### **PRIMARY AND SECONDARY HIV PREVENTION AND THE NEEDS OF MSM WHO ARE HIV POSITIVE**

Providing for greater inclusion of people who are HIV positive in prevention work, including  who have sex with men (MSM), has required some rethinking around what is meant by the concepts of primary, secondary and tertiary HIV prevention. Primary prevention for example, has increasingly been seen as involving activities with people who are HIV negative and those who are HIV positive to reduce primary (initial or new) infections. Secondary prevention in turn has shifted from a central focus on working with people who are HIV positive with the objective of reducing onward transmission, to a more effective approach of meeting the specific needs, including the sexual health needs, of people who are positive themselves.

In line with these approaches, there has been a new focus in research, especially in relation to MSM, on the needs of those who are HIV positive. Results of this research both internationally and in Ireland indicate that MSM who are HIV positive are more likely to have sero-discordant unprotected sex where they have little control over the sex they have, lack the confidence or skills to negotiate safer sex, are uninformed or misinformed about HIV and are unaware that they and their partner are sero-discordant. Particular issues arising for MSM who are HIV positive in relation to information and skills include the difficulties around disclosure of HIV status, the trauma of a HIV diagnosis and the implications for the mental health of some people, social exclusion (which can be both a causal factor as well as a consequence of HIV infection) and the enduring stigma attached to HIV.

### **RESPONDING TO NEEDS**

Responses to the prevention needs of MSM who are HIV positive have encompassed a number of strategic areas. These have included comprehensive needs analyses, a greater focus on integrating prevention and care in a clinical setting, interventions specifically targeted at the needs of MSM who are HIV positive (especially with regard to information provision) and the incorporation of the needs of MSM who are HIV positive into broader strategies related to prevention, sexual health, anti-discrimination and social inclusion. With regard to the latter, a key development internationally has the identification and elaboration of 'guiding principles' for the involvement of people who are HIV positive in strategy development.

In Ireland, examples of new approaches and interventions have been identified across the strategic areas just outlined. Important actors in this have included the of organisation such as: Open heart House; the Gay Men's Health Project; the sexual health clinics in hospitals (such as St. James's, the Mater Hospital Dublin and Cork University Hospital); Gay Health Network; the Rainbow Project, Southern Gay Men's Health Project and the HIV Services Network. Also critical has been the work of groups representative of MSM who are HIV positive such as POZ Ireland, Positive Voices and Positive Input.

However, a number of issues were identified which will need to be addressed in order to expand and enhance provision for MSM who are HIV positive. These included:

- Lack of funding and resources for group development of and networking between representative groups of MSM who are HIV positive.
- Lack of comprehensive research on the needs and circumstances of MSM, encompassing not just treatment issues and sexual health, but also broader social and economic issues related to well-being (this issue has for example, been raised by the NASC Education and Prevention Sub-committee).
- Limitations on the resources available for prevention work in a clinical setting which have become more critical given new demands on the services. The need for more health advisers around HIV and broader sexual health has been highlighted in a number of reports including a report by the NASC Care and Management Sub-committee on HIV/STI services in Ireland.
- The need for more targeted interventions for MSM who are HIV positive, including information addressing needs specific to MSM who are HIV positive in relation to prevention messages, treatment options, disclosure, relationships and living well with HIV more broadly.

## 6.2 RECOMMENDATIONS

To address these gaps, this resource report puts forward a number of recommendations. In particular:

1. To inform future strategy on HIV prevention and to ensure it is inclusive of the needs of MSM who are HIV positive, the Health Services Executive should commission research exploring the needs of this population group in an Irish context.
  2. Resources should be made available to MSM who are HIV positive to build networks to facilitate the identification of needs and the capacity to advocate in relation to these needs.
  3. The development of the national HIV prevention strategy for gay men should also include channels for the participation of networks of MSM who are HIV positive in strategy development, implementation and review.
  4. Health promotion and psychosocial support staff should be available to meet the specific needs of MSM in a clinical setting and to develop the capacity to make effective referrals to other services.
  5. The primary health care strategy and other strategies being developed around mental health should incorporate the needs and circumstances of MSM who are HIV positive.
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## **APPENDIX 1: ORGANISATIONS**

### **THE HSN (HIV SERVICES NETWORK)**

The HIV Services Network came into existence in Spring 2000 in response to a growing demand for improved co-operation and skills development amongst those working within the HIV sector in Ireland. The Network is open to any individual or agency providing services to those affected by HIV.

The goal of HSN is "To foster best practice in service provision through the open sharing and discussion of ideas, information and difficulties and to promote better networking, co-operation and skills development throughout the HIV/AIDS field, incorporating other related issues as necessary"

### **GAY HEALTH NETWORK:**

Gay Health Network is an all-Ireland network of gay and bi-sexual men involved in HIV and sexual health, in the voluntary or statutory sector. The network established in 1994 provides a forum to explore the health needs of gay and bisexual men. Since its inception the network has been working to fill the gaps by producing education and prevention materials targeting gay and bisexual men. The Network and Sigma Research has also published ' Vital Statistics Ireland/ Findings from the All- Ireland Gay Men's Sex Survey, 2000'.

### **GAY MENS HEALTH PROJECT**

The Gay Men's Health project is a statutory (HSE Eastern Region) service which provides support, sexual health promotion and screening services for men who have sex with men in the Eastern Region. Sexual health promotion and education is provided at the project and through outreach services. services are provided at the project location and through an outreach network.

The Gay Men's Health Project also provides services to all men who have sex with men and those who work in the sex industry. The project provides STI screening and management services, counselling, information and advice.

### **RAINBOW PROJECT**

Northern Ireland's only gay and bisexual men's health organisation and houses the only gay male specific counselling and support service available in Northern Ireland. Rainbow also distributes free condoms, lubricant and safer sex information in gay and gay-friendly commercial and educational venues.

### **GAY HIV STRATEGIES**

Gay HIV Strategies is a non-governmental organisation, which is core funded by the Department of Health and Children. Gay HIV Strategies works to facilitate the development of new programmes, resources, linkages and strategies for effective HIV prevention, health promotion and community development for Gay men.

### **POZ IRELAND**

Poz Ireland provides vital information on the diagnosis and treatment of HIV disease to those affected by HIV and AIDS. Compelling research in people with HIV shows that those who are better informed about HIV and its opportunistic infections, extend their overall survival, improve their quality of life and reduce the incidence of opportunistic infections. Poz Ireland provides this information free in their Treatment Directory and electronically.

### **POSITIVE INPUT**

Positive Input is an advocacy group of and for people living with HIV in Ireland. The aim of the organisation is to give people living with HIV "a say in the decisions which affect them and ensure that undertakings made by government and other bodies are followed through.

### **POSITIVE VOICES**

Positive Voices provides support to HIV positive people experiencing social exclusion and or rural isolation by bringing people together in a friendly environment. This project is a cross-border initiative and is facilitated by the Rainbow Project Derry.

### **OPEN HEART HOUSE**

Open Heart House (OHH) an HIV Positive (HIV+) member-led organization which aims to empower and enhance the lives of people living with HIV & AIDS. Supports. It offers a wide range of complementary therapies such as acupuncture, massage and reflexology. Other services on offer include a Meals Programme, Education and Information, and a Befriending service. Open Heart House runs a First Tuesday club for MSM who are HIV Positive.

### **THE SOUTHERN GAY MEN'S HEALTH PROJECT**

This project, based in Cork City and covering the Southern region, focuses on sexual health issues for MSM. They offer a range of services, including information, support and education on issues relating to sexual health, lifestyle and sexuality, including a HIV support group. Other services include sexual health promotion, HIV and STI prevention, one-to-one counselling and support, outreach, telephone helpline, addiction services and a variety of support and self-awareness groups.

### **GUIDE CLINIC, ST. JAMES HOSPITAL, DUBLIN.**

The Genito-Urinary Medicine and Infectious Diseases Clinic (G.U.I.D.E.) is the largest STI and HIV clinic in the country, offering a range of clinics for HIV and STIs. The Clinic also provides support services including pre and post HIV test counselling and ongoing psychosocial support for people living with HIV.

### **MATER HOSPITAL, DUBLIN**

A multi-disciplinary team, which includes a social work counselling service, pharmacology and dietary advice as well as medical treatment and testing, targeting people with HIV and STIs operates at the Mater Hospital. The service provides specialist care to both in-patients and outpatients. Their outpatient service also provides a diagnostic and treatment service to those with sexually transmissible infections (STIs) including HIV. Counselling and pre-HIV test counselling is available to patients as needed.

### **CORK UNIVERSITY HOSPITAL**

HIV Services provided include community welfare, referrals to psychologist, medical care, nursing care, pharmacological services, in-patient and out-patient care, physiotherapy and occupational therapy, social work, dental care and laboratory services.

## APPENDIX 2: LIST OF THOSE CONSULTED

### International Contacts

Staffan Hallin	RFSL, Stockholm, Sweden
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Will Nutland	Terrence Higgins Trust, London
Alberto Martin-Perez	Cogam, Madrid, Spain
Jacob Haff	Stop Aids, Copenhagen, Denmark
Mark Maguire	Health Promotion Services, Camden and Islington Health Trust, London
JanDirk Veenstra	Schorerstichting, Amsterdam, Holland
Stephen Barris	ILGA Europe, Brussels
Chris Lambrechts	Aidsteam, Flanders, Belgium
Thierry Martin	Ex Aequo, Brussels, Belgium
Manuel Morais	ILGA Portugal, Lisbon, Portugal
Fraser Serle	Health Development Manager, Southwark Health Trust, London

### Contacts in Ireland

Donal Traynor	Social Worker, GUIDE Clinic, St. James
Bill Foley	Social Worker, Mater Hospital
Maeve Foreman	Social Worker, GUIDE Clinic, St. James
Mick Quinlan	Gay Men's Health Project, Dublin
Paula and James O'Connor	Open Heart House, Dublin
Erin Nugent	Dublin Aids Alliance
Dr. Mary Cronin	National Disease Surveillance Centre
John Williams	Poz Ireland
Noel Walsh	HIV Editor, Gay Community News
Dr. Grainne Courtney	Senior Specialist in HIV, St. James Hospital
Olive McGovern	HPU, Dept. of Health and Children
Mike Hackett	Director, Gay Switchboard Dublin

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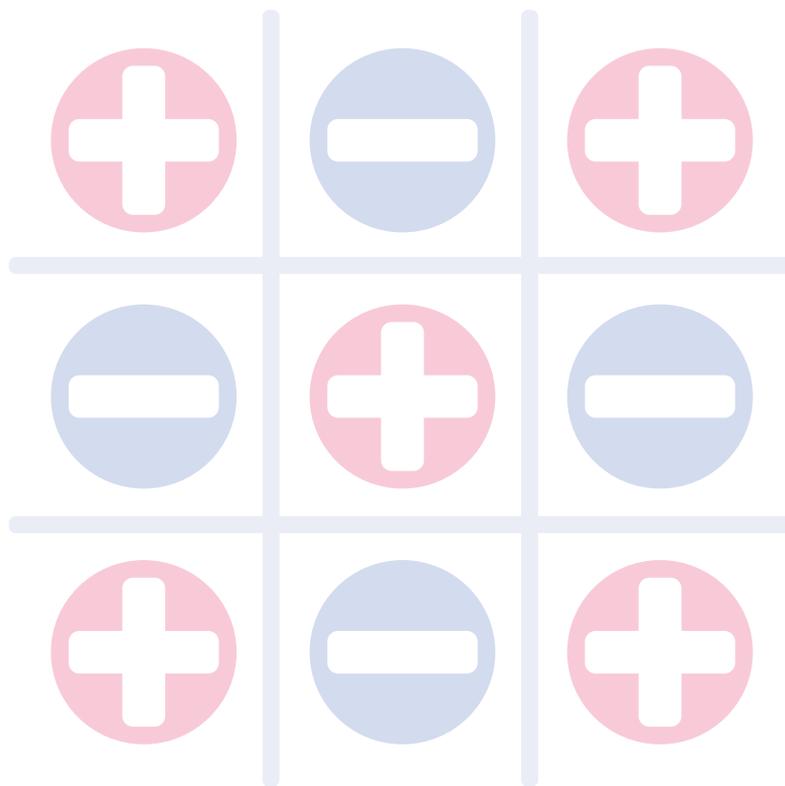
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