

# An exploration of the views of gay and bisexual men in one London borough of both their primary care needs and the practice of primary care practitioners

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This study explored the experiences of gay and bisexual men in primary care. The study was mindful of both the wider context of the HIV epidemic and the increasing acknowledgement of the role of social factors in determining health and well-being. The study informants were 17 gay and bisexual men, all of whom were registered with general practices. Two major barriers to effective communication and possibly treatment were identified. First, despite the fact that all the informants had come out – or disclosed their sexuality – in many areas of their lives, there was considerable anxiety and fear of stigmatisation in relation to doing so in the context of primary care. Second, many practices and practitioners appeared to assume that all their patients were heterosexual; there were few signals in practice environments of any awareness of gay and bisexual men. This generated problems for men wishing to discuss health needs and treatments in relation to their sexuality and to gay social networks; few practitioners had made referrals to any these networks as part of their health promotion strategy. The study raises questions about the organisation of primary care provision and its willingness to acknowledge and form partnerships with gay social networks.

**Key words:** communication; gay and bisexual men; primary care; social networks; stigma

## Introduction

Despite the focus on the health of gay and bisexual men in relation to the HIV epidemic, the general health and well-being of gay and bisexual men has not featured prominently in the wider public debates around primary care. This research explores gaps, barriers and noncommunication as perceived by gay and bisexual men in a suburban London borough in their contacts with primary care, the frontline of the health service.

Each year since 1990, the number of gay, bisexual and other homosexually active men in

England infected with HIV has been around 1500 (PHLS, 1999). The Department of Health (1995) has recommended that such men be among the key groups targeted in HIV prevention activity and the commercial gay scene has become the major setting for such targeted community development activity. This particular borough was, for the most part, affluent and had a wide range of services and social meeting places, but there were no meeting places, such as bars or clubs, primarily focused at attracting gay and bisexual male customers. There was, therefore, no opportunity for HIV-related community development activity with gay and bisexual men in social settings of this nature. There was a need to develop other approaches to provide gay and bisexual men with the opportunity to access, as appropriate, HIV prevention resources and community development.

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Literature also reveals the extent to which gay and bisexual men experience health problems associated with their sexuality which can manifest themselves through mental health problems, eating disorders, addictive behaviours, stress-related problems, isolation, etc (PACE, 1999; Rivers, 1997; Stagg Elliott, 1997). There are a number of agencies, particularly in London, which offer support and advice to gay men, bisexual people and lesbians about, for example, mental health and alcohol problems and their practice relates specifically to the lifestyles and social networks which are widespread among this constituency.

Gay social networks are increasingly being recognised in the mainstream of society (Annetts *et al.*, 1996; Cant and Hemmings, 1988; Weeks, 1977). Thousands of groups and venues targeted at gay men, lesbians and bisexual people exist in the UK alone (Gay Times, 1999). Some of these are particularly concerned with sexuality and sexual health, while others seek to bring together people because of their sexuality and their particular interest in, for example, football or parenting or religious faith. While gay men, lesbians and bisexual people increasingly seek to minimise divisions within their lives between their sexual activity and their sociocultural activity, this process is not always endorsed or even tolerated by health-providing and care-providing agencies. Some health professionals assume all gay men are HIV-positive (PACE, 1999); the health of lesbians is often ignored completely (Mugglestone, 1999). It is not difficult for gay men, lesbians and bisexual people to be concerned that their exclusion – and perceived exclusion – from the world of medicine is a health-endangering practice.

This research focused on the situation of gay and bisexual men in one London suburban borough and sought to give them an opportunity to articulate both their experiences and their concerns about their health needs in primary care settings. At a time when health providers and planners are being encouraged to address inequalities within health (Acheson, 1998), to be inclusive (DoH, 1999) and to develop partnerships with patients (Richards, 1998), this research provides a timely insight into an often neglected population group.

Primary care is the one health care setting of which virtually every member of the population has experience. Men, as a group, make less use of general practice than do women (Fleming, 1989),

but the high level of registration with general practitioners means that there is a possibility of reaching gay and bisexual men through this route on a scale which does not exist elsewhere. There is an opportunity to reach gay and bisexual men whether they are teenagers still living in the family home, single men with busy social lives, couples living a monogamous lifestyle, men living with HIV, retired men living a quiet, discreet lifestyle – or combinations of these. Given the stigma which still attaches to gay lifestyles (Palmer, 1994; Palmer and Mason, 1996) and the fact that relations between gay men and GPs (Bhugra and King, 1989; Fitzpatrick, 1994; Wadsworth and McCann, 1992) are often reported as problematic, it cannot be taken for granted that primary care will be a place which is hospitable to gay and bisexual men. As a result of new treatments many people infected with HIV are living longer and so there is a growing body of HIV-positive men seeking primary care treatment (Mocroft *et al.*, 1998). A need was, therefore, identified to explore both the experiences and aspirations of gay and bisexual men in relation to primary care.

The research, therefore, emerged from a number of factors:

- local concerns about enabling gay and bisexual men to access HIV prevention resources within the borough;
- the identification, within literature, of non-HIV-related health problems widely experienced by gay and bisexual men;
- as primary care was recognised as the health care setting within the borough most likely to be accessed by all gay and bisexual men, a need was identified to explore both their experiences and their aspirations in this setting.

The research aimed to establish if primary care was a setting where gay and bisexual men could expect practitioners to engage with the complexities of their health concerns associated with the experience of homosexuality.

## Methods

Qualitative research has been said to be about understanding ‘social phenomena in natural (rather than experimental) settings, giving due emphasis to the meanings, experiences and views of all the

participants' (Pope and Mays, 1995). The stigma which attaches to gay and bisexual men means that it is extremely difficult to access – or even define – a representative sample of this population group. It has been acknowledged that most research studies about homosexually active men recruit their samples from the gay scene and gay social networks; such men are defined not only by their sexual activity but also by their socio-sexual identity as gay men (Hickson *et al.*, 1997). A qualitative approach – involving a literature review, semi-structured interviews and a focus group – allowed light to be cast upon a complex range of frequently hidden or partially hidden experiences, aspirations and areas of interest. While a growing number of studies have, since the late 1970s, focused on gay and bisexual men, few of these have been in either a primary care setting or a suburban context. Grounded theory was used to analyse the data on the grounds that it is 'inductively derived from the study of the phenomenon it represents. ... One does not begin with a theory, then prove it. Rather one begins with an area of study and what is relevant to that area is allowed to emerge' (Strauss and Corbin, 1990).

Seventeen men were recruited as the sample for this research. They all lived and/or worked, and/or studied within the boundaries of the borough. They all accessed the services of the gay commercial scene outside the local area and belonged to gay social networks. Some of these networks were within the borough; some crossed over borough boundaries and existed on a south London level, or a pan-London level, or a national level, or an international level. They were, therefore, not only homosexually active, but had some sense of their socio-sexual identity as being gay or bisexual.

They were recruited through several channels: three social groups for gay men, lesbians and bisexual people in the borough; networks of service users and volunteers at an HIV drop-in centre; referrals via other health professionals; snowballing from these sources; advertising in the *Pink Paper* (the leading national weekly gay and lesbian newspaper). The sample ranged in age from 21 to 58 years; 14 of them defined themselves as White UK or White English; three defined themselves as belonging to ethnic minority groups. A number chose to disclose their HIV status – as positive, negative, or untested. Anonymity was guaranteed to the informants.

Semistructured interviews were conducted with the 17 men. The interviews lasted approximately 1 hour and everyone was asked five questions with opportunity for supplementary questions and the development of discussion. The questions focused on experiences of general practice; sexual health and HIV; alternatives to general practice; experiences of gay-friendly primary care provision; and general experiences of coming out. These questions had been identified as a result of my professional experience as Gay and Bisexual Men's Worker for this particular health authority and as a result of issues identified from the ongoing literature review. A focus group of six men, four of whom had been interviewed and two of whom had not, was held to explore in greater depth the themes which had emerged from the interviews. The focus group was held in an HIV drop-in centre which was used by many local gay men.

The interviews were taped and transcribed verbatim; the data were read and reread to pull out thematic categories of concern. A content analysis of the collected data identified the sets of feelings illustrated by the informants. The experiences of the informants were not uniformly the same, and the analysis explored and gave the opportunity to reflect both on similarities and on incidences of 'deviance' or divergence in the research findings.

## Results

All the informants were registered with general practitioners and were, therefore, in a position to draw on their experiences of general practice. Two major elements ran through the findings. First, while gay and bisexual men are increasingly likely in society as a whole to choose to come out or to disclose honestly to others the nature of their sexuality, there was still great uncertainty about the impact of coming out in a primary care setting. The second element was about the perceived assumptions of primary care providers with regard to the sexuality, lifestyle and social networks of their patients and the impact which these assumptions had on their overall experience within primary care.

### Coming out

The process of coming out as gay or bisexual gives men the opportunity to create a narrative that

helps them to make sense of their lives. It is difficult to quantify exactly the number who had come out to primary care practitioners; at least four had come out to a practice nurse, but not to a GP; at least three had come out to GPs in practices other than those where they were registered; eight informants had not come out to anyone in the general practice where they were registered. Some of the fear of coming out in this context was traced back to negative experiences earlier on in their life, such as bullying at school or parents referring their teenage sons to doctors; there were also accounts given of discrimination in a wider, more general sense. While many of the men had come out to work colleagues, most had not come out to their employer. The sense of the possibilities of interlocking patterns of discrimination was present among those men who had not come out.

There was a widespread fear, expressed by 10 of the informants, that information on their medical records might be made available to agencies other than the general practice itself. They expressed a particular concern about the possibility that disclosures about their sexuality might be made available to mortgage companies and insurance societies. 'It was a conscious decision not to come out to my GP; it has all sorts of implications with mortgages and insurance companies ... and if they want to discriminate against you they can do that and there's nothing you can do about it, unless there's legal protection – which there isn't' (Informant No. 4).

Those who had come out to their GP had had mixed experiences. Those whose experiences had been positive cherished the fact that communication had taken place; one man said that he appreciated the fact that his doctor 'had been a very positive force; both personally and professionally she has supported me' (Informant No. 11). Once the coming out process had happened, there was an expectation that this would open up a more open pattern of communication between doctor and patient. 'I certainly wouldn't want to have a lifestyle where I was permanently hiding what I do. I'm a very honest open person; I just expect equality and I get annoyed when there isn't equality' (Informant No. 10).

Some of those men who had not come out to their GP felt unconfident about possible responses to raising any issues which related to their sexuality. One man who had been queer-bashed (i.e.

physically assaulted in relation to his sexuality) had not gone to seek any treatment or support from his GP; 'I don't trust the doctors to understand enough about what I'm saying; there isn't time ... and I'd be worried about any kind of prejudice; the last thing you want if you've been beaten up is for someone to sit in judgement on you' (Informant No. 2). There was concern that GPs would not be sensitive to the social situation in which gay men live their lives.

### **Confidentiality**

The growing trend towards group practices and the devolving of responsibilities in primary care health teams means that once information about a patient's sexuality has been disclosed to one practitioner it is likely to be shared with other members of the team. For many of the informants in this study the implications of team confidentiality are troubling, because of the social networks that exist in what is, after all, a small community. No-one offered any evidence of their confidentiality having been breached, but their general fear of stigma led them to be concerned that information about them and their sexuality might travel quickly and damagingly around their local community.

### **Practice environment**

The concern among all the informants about the assumptions on the part of the primary care practitioners took several forms. Some of this concern related to the mode of organisation of the environment of the surgery. Waiting room walls and display boards have become the location of much health promotion activity, often targeted at particular groups. Comments were made about the fact that all these materials were clearly targeted at families with children, at an ageing population concerned about flu jabs, at people at risk of diabetes or meningitis or skin cancer, at people with alcohol problems. There were no reports of any materials which, in any way, targeted the health needs of gay and bisexual men. Although gay men are the group most likely to be infected with HIV in the UK, there were no reports of HIV materials which appeared to be targeted at them; as one man said: 'even the HIV leaflets don't look gay – just plain and general' (Informant No. 14). No-one reported any messages from their experience of general practice in the UK that would indicate that the existence of gay men was acknowledged at all;

there was even less indication that they would be welcomed. There were no citations of gay-friendly posters and no evidence that staff had, for example, worn red ribbons to denote their awareness of HIV. 'Why not have some stuff that's obviously gay and is appropriate for a GP practice ... if you see something like that it does give you a lot of confidence' (Informant No. 8). The environment of the practice is just one way in which the assumptions of the primary care practitioners about their patients are made evident; the absence of gay-friendly signs led many of these men to believe that it was assumed that gay men did not live within the catchment area of their particular practices.

### **Treatment and care**

The perceived assumptions and preconceptions of practitioners were also identified as crucial in relation to the nature and quality of the treatment and care actually received. Sometimes there was embarrassment which would, in turn, lead to inaccurate diagnosis; sometimes the fact that the doctor spoke to the patient as though he was heterosexual would make it difficult for him to discuss the aspect of his lifestyle that was causing him to be distressed, or isolated, or in pain and resulted in him not receiving an appropriate referral. 'I went to see this doctor about this stress thing and he was saying: Oh, you're a man ... you'll get over this girl' (Informant No. 7). Sometimes the apparent assumption of the heterosexuality of the patient would generate difficulties for the partner of the patient being involved in a next-of-kin role; 'You are wanting help for your partner and you are anxious ... and you'll get a question like: Well, who are you, anyway?' (Informant No. 13). One distressed man, who did not share the religious views of his GP, was offered evangelical religious counselling to 'cure' him of his homosexuality. 'His attitude was that being gay was something that the Bible spoke against and perhaps I should reconsider my position' (Informant No. 1). There was little expectation that their GPs should be experts in matters relating to sexuality. However, there was an expectation that they should approach their patients with an open mind, listen to them and engage with their experience. 'They don't have to do an awful lot to be gay-friendly – they've just got to keep their wits about them and be able to talk intelligently' (Informant No. 16).

The apparent assumptions on the part of primary

care practitioners led to particularly low expectations among gay and bisexual men when it came to sexual health and HIV. Almost all the men claimed to have got most of their information about these issues through their own social networks – through the gay press, in gay bars, at the Pride festival, from friends. Disappointment with primary care providers in this context was widespread; one man explained that before a homophobic rebuff he had viewed the GP 'as the first point of call' (Informant No. 10). Without access to gay social networks, and given the difficulties in networking for gay and bisexual men in this suburban borough, it is difficult to know how gay and bisexual men, who were young, or vulnerable, or disadvantaged, could have accessed appropriately useful information about sexual health.

All the men in the study who had been diagnosed as HIV-positive had taken responsibility for finding the latest information and debates about the virus and about treatments by accessing the internet or the HIV-positive press. This had had a beneficial effect on their confidence and on the quality of communication about their treatment and care. One man summed it up thus: 'You need to be well informed if you're talking to a GP. I think it's the same with all tradesmen – if you have a plumber come round to do a job you need to know what you're expecting' (Informant No. 15).

### **Discussion**

The research illustrates difficulties experienced by gay and bisexual men in communicating their personal needs and the social context of their lives to primary care providers. It reveals the enormous difficulties which all the informants had in disclosing or discussing matters relating to their sexuality in primary care settings. The fear of the consequences of doing so can be related to wider social patterns of stigmatization and discrimination, but these fears were exacerbated by the failure of all practices and most individual practitioners to give any sign of awareness of the existence or health needs of gay and bisexual men. The research also reveals the extent to which the perceived assumptions of primary care practitioners can act as a barrier to open discussion of the social context in which gay and bisexual men experienced health and well-being. There was a general appreciation

on the part of the informants that primary care practitioners were *general* practitioners; what was being looked for was not so much specialist expertise as the kind of open mindedness that would enable practitioners to ask nonjudgmental questions and to make referrals to community organizations which would be better equipped to enhance the general well-being and/or sexual well-being of gay and bisexual men.

All the informants belonged to several gay social networks. While previous studies (Fitzpatrick, 1994; Wadsworth and McCann, 1992) have explored relations between gay men and primary care practitioners from attitudinal perspectives, no-one had previously studied the impact that gay social networks might have on relations in primary care settings. Another study has illustrated the quality of social support provided by the social networks of HIV-positive gay men (White and Cant, 1999). It is through such networks that gay and bisexual men have the opportunity to enrich the quality of their life and to empower themselves along with others who share their experience of life. Referrals to community groups and networks are increasingly advocated as having a key role within healthcare. Referrals of women considering mastectomies (Kenny *et al.*, 1999) or people suffering from rheumatoid arthritis (Millett *et al.*, 1999) to self-help groups of people sharing those experiences are acknowledged as having a positive impact. Advocacy of the benefits of networks and, where appropriate, referral to gay social networks might enable them to participate in a range of health promotion activities that would be beneficial to, for example, their social well-being, sexual health, mental health, etc.

The pattern of exclusion reflects a deeper lack of awareness on the part of health providers. Instances were cited of homophobia on the part of individual practitioners, but the lack of awareness of the social networks within which gay and bisexual men conduct their lives and the potential for support within these networks was more pervasive than direct, overt discrimination.

The fact that boroughs such as this one had no visible gay meeting places highlights the difficulty of relying on local and geographically defined notions of community for the purposes of community development. At a time when there is an ethos of partnership and inclusivity, thought needs to be given about how to develop policy and part-

nerships between primary care practitioners and the user groups and agencies representing the needs of dispersed networks of gay and bisexual men.

This study highlighted the need for further research into:

- Gay social networks and their health dimensions
- Socially inclusive practice – including gay-friendly practice – in primary care;
- The partnership opportunities for gay men's networks in the delivery of primary care.

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