

## **Health literacy and the framing of health messages in the gay community**

An aim of current UK health policy is to ‘fully engage’ not only sick but also well people in pursuit of health (Wanless 2004). In this policy discourse, it is assumed that ‘health literacy’ is one of the vehicles for achieving that full engagement: namely, individuals must understand the best information about how to pursue health, not only have access to it.

The present project focuses on three related issues: (1) how health information is ‘framed’, and (2) how that information is understood, evaluated and acted on by those who receive it and (3) in light of the results, what dimensions ‘health literacy’ must have if changes in health-related behaviour are to ensue.

Our focus is men’s health. It is widely recognised that men are less likely to engage with their own health than women with theirs. We choose gay men as a critical case. We single out varieties of gay men in Manchester and specifically the health issues they share with other men.

### **Background**

The project has its foundations in a previous exploration of the context within which gay men in Manchester live their lives and make sense of their health. Dr John E. Goldring, who is the research fellow for this project, did this work for his PhD<sup>1</sup>. His then supervisor Prof Paul Bellaby and advisor Dr Sara Mackian form the rest of the present team.

Using both ‘immersion’ in face-to-face settings and web-contacts, Goldring identified men both on and off the ‘gay scene’ and different ‘generations’- men whose gay careers began at a range of periods from when homosexual activity was criminalized, through to the present age of consent of 16. With informed consent, a small number of these men took part in one or more intensive interviews.

### **The Problem**

The central issue for the project is not so much how well gay men might understand the messages they receive about their health, as what effect ‘health literacy’ (or lack of it) might have on their health-related behaviour – whether it might account for success/failure among gay men in addressing the health issues they share with other men.

Current health discourse stresses self management of health to an unprecedented degree (Davison, Frankel et al. 1992; Petersen and Lupton 1997; Sihota and Lennard 2004; Wanless 2004). The emphasis on ‘health literacy’ implies that capacity to understand basic health information (Sihota and Lennard 2004; Wanless 2004) may account for differences – inequalities

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even - in health outcomes between social classes and between men and women and other groupings (Lee, Arozullah et al. 2004).

Health literacy has been described as:

The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Vass 2003) (p. 1339)

Wanless suggests that:

Health literacy, particularly the ability to understand information about health and health is an important precondition for taking preventative health action. Differences in health literacy contribute to variations in behaviour and health inequalities (Wanless 2004: p. 158)

There may, however, be danger in using 'health literacy' to inform policy when the concept and its referents have yet to be sufficiently explored. The research over the last 10 years or so has been carried out in the US and Canada (Sihota and Lennard 2004). The Department of Health in the UK recently commissioned Sihota and Lennard to explore the issues surrounding health literacy in the UK. The researchers leaned towards 'illness literacy' rather than health literacy. 'Health' is a multi-dimensional and contested concept (Blaxter 1990). They also tended to focus on the functional, or reading and understanding aspect of health literacy. This limited focus, suggests Gray (2003), is one reason for the continued lack of clarity surrounding health literacy (Gray, Klein et al. 2003). Nutbeam (2000) suggests that there are three elements to health literacy, not just the first - functional (reading and writing), but also two others, critical (evaluating information) and interactive (applying knowledge in everyday activities) (Nutbeam 2000)

Little research anywhere has explored health literacy from the perspective of a marginalised group, such as gay men. Yet, while conducting fieldwork for his PhD, Goldring noted that the health literature and health promotion messages in particular were more often aligned to gay men's representation as a 'risk group' for sexually transmitted disease, notably HIV/AIDS, than to their health needs as men. Thus, whether or not health literacy is problematic among gay men, the way health messages are framed may affect their receptivity to health promotion. And we need to explore the contestability of health information itself, notably the 'medico-moralistic' assumptions within public health (Mort 1987; Petersen and Lupton 1997; Sihota and Lennard 2004). Yamey (2003) points out that in the USA, smoking causes more deaths in gay men than 'AIDS, suicide, homicide and car crashes combined'. The narrow framing of the health discourse about gay men may be working against their inclusion in wider men's health discourses (Ryan, Wortley et al. 2001; Yamey 2003).

Finally, understanding of health messages tends to vary by social and cultural context, but, to date, most of the sociological dimensions of health literacy remain unexplored (Sihota and Lennard 2004). Investigation of health literacy needs to be grounded in the social context and lived experience of different groups. Gay men may ascribe different meanings to health messages than their heterosexual counterparts and the various 'identity fractions' to be found in the gay community may vary among themselves in how they understand, critically evaluate and interact with health messages.

Social class is so likely to have an influence on how men of any sexual orientation perceive their health and messages about it that it has to be controlled for in a study of gay men. There is a stereotype of gay men as affluent and middle class (Rofes 1998; Keogh, Dodds et al. 2004). Although it is impossible to know the full breakdown, research suggests that the gay community is made up of a rich and diverse mix of men from all walks of life and backgrounds (Rofes 1998; Dowsett 2001). Yet their representation as affluent middle class men might lead to the assumption that they are without significant health need – HIV/AIDS apart (Keogh, Dodds et al. 2004).

## **Research Questions**

- To what extent does the concept of 'health literacy' help in explaining how gay men manage their health?
- Are there barriers that can contribute to poor understanding of health messages?
- Are there facilitators that can contribute to good understanding of health messages and, if so, how do they translate into positive health seeking behaviours?
- How far do adequate levels of health literacy in one area, such as HIV/AIDS, translate or fail to translate to other aspects of gay men's health?

## **Objectives**

- To explore by ethnographic methods 'health literacy' in the social and cultural contexts of three contrasting gay sub-groups.
- To document the main themes within health messages aimed specifically at gay men and how they are presented.
- To explore how gay men as a whole and gay men of various identity fractions typically interpret messages aimed at men's health in general.

## **Methods**

The study has been conducted within the qualitative paradigm, based broadly upon Glaser's and Strauss's 'grounded theory'. Grounded theory has three important characteristics. Firstly, it works on the premise that the data are the sample, and the aim to map the main variations in 'type'. This makes it difficult to estimate in advance the numbers of cases required. The second consideration is the idea of saturation, which implies that recruitment ceases when additional cases fail to generate new information (Taylor and Bogdan 1998). Finally, it seeks to develop theory inductively. In this project, however, we have brought some a priori concepts to bear on the analysis, such as

'health literacy' and 'framing'. Proponents of such an approach call it 'analytic induction'.

Three different groups have been purposively sampled:

- a sports and fitness group (as a putatively health-conscious group)
- the 'bear' community (as a group that may not be health conscious)
- a group not connected to either of these yet affiliated to the gay community (as a foil – a group of mixed views on health)

For planning purposes, it was envisaged that saturation should be achieved with around 10 participants to each group, making a total of 30. Actual numbers were lower: 12 in all, four in each group. This was because of acute difficulties with recruiting enough members of the bear community and having to match them with equal numbers of the other groups.

Because the gay community lacks geographical form or visible boundaries, a variety of complementary strategies had to be used in recruiting a sample. Groups 'on the gay scene' were accessed before recruitment commenced, by the researcher 'being seen' (Whyte 1959) and establishing a presence. In particular, key stakeholders/gatekeepers were identified through whom less prominent members of the community might be accessed. Thus 'immersion' was complemented by the snowballing/referring sampling technique. In addition, the internet provided opportunity samples. Its value in accessing hard-to-find groups has been established in other research studies (Murray and Sixsmith 1998; Goldring 1999; Mann and Stewart 2002).

Semi-structured interviews, computer mediated communications (CMC) and field dairies were the data-collection methods used with the groups. The data have been analysed thematically, with the aid of NVivo software. Established health promotion messages have also been analysed, both for discursive themes and for their style and presentation, and in some cases their authors have commented upon how they were framed.

## **Activities**

Goldring and Bellaby have contributed to the ESRC Seminar series on Self-Management of Illness (2007), led by Dr Sally Lindsay, and are part of the network formed around that. All three co-investigators participated in and MacKian organised the RGS/IBG panel on Geographies of Sexuality, Health & Wellbeing' at Imperial College in September 2006. They are also presenting on this theme to the BSA Annual Medical Sociology Conference in September 2007.

## **Outputs**

A linked contribution to the ESRC Seminar series on Self-Management of Illness is being submitted for review for a monograph/special issue of the *Sociology of Health Illness* edited by Dr Lindsay. Other former conference papers are being prepared for submission to refereed journals. The principal investigator is in correspondence with the UK Data Archive about what parts if any of the rather sensitive data collected are to be archived.

## **Impacts**

Though the findings in full have yet to be disseminated to users (as the EoG report form suggests, there are confidentiality issues to resolve), the Lesbian and Gay Foundation in Manchester is receptive to the study, as is the Gay Men's Health Network. Goldring plans a poster presentation at the LGBT Health Summit, and to confer with the publishers of *Out Northwest*, especially about how some groups found their magazine useful and others thought they were not the target audience.

## **Future Research Priorities**

More work is needed to explore the relationship between diet and exercise in different groups of gay men. Further research could also explore the subtle signals embedded in various media that either target or miss sections of the gay audience. The media representations (both gay and straight) of gay men seem to miss the majority who are not under 30, hairless or slim.

An implied foil for our intensive investigation of gay men's health literacy is the equivalent for heterosexual men. Gough has recently reported on masculinity and how it shapes framing of dietary messages relevant to men generally. Further research is needed on heterosexual reading, interpretation and action upon these messages.

Another tacit element in our study has been the implications of framing 'risk' for gay men as STD- or even more narrowly HIV-related. Again there is clear value in investigating the underside of the original study, by focusing on messages and responses about sexual health and perhaps also comparing the same among gay and heterosexual men.

## **Ethics**

Ethical approval was sought and gained from the Salford University Research Ethics and Governance Committee. The main ethical issues that required attention were obtaining informed consent, confidentiality and participant well-being.

Most health issues are personal and confidentiality has to be respected. Only the researcher knew participants' full details. Each consenting participant was allocated a unique identifying number and pseudonym that linked them with their data. The consent form was the only document that combined the identifying number and their personal details and it has been kept in a secure place away from the data. Other identifying features within the data have been removed from material that is archived or published.

The participants provided potentially sensitive information at interview, and thoroughly debriefing them was important to ensure their well being. This has taken place as soon as data collection has finished. Participants have been encouraged to ask questions, seek clarification and discuss the research experience in order to highlight any unforeseen issues that the interview may have brought up. Feedback provided an opportunity to remind participants that they had the right to withdraw all or part of their data, without reason,

before it could be used in publications or archived. Links were established with a gay counselling service to provide individual support. Lastly, a standardised debriefing form was given to every participant, which included helpline telephone numbers and other useful information.

Another issue was the potential risk the researcher faced in meeting people not known to him in unfamiliar environments. To combat this a signing in and out system was adopted with 'head office'. Using the internet as a means of community immersion, recruitment and data collection involved cyber venues such as 'Gaydar' or 'Eurowoof' that may have sexually explicit pictures on them. The research project obtained approval for Extraordinary Access to the Internet.

For participants to give their informed consent they had to be made fully aware of what the research was about and what their involvement would entail. An information sheet explained the true purpose of the research; the responsibilities of the researcher; and their rights as participants. The form was read out to each participant, who was encouraged to ask questions and seek clarification. They were all made aware of the level of commitment needed of them, including that ESRC might require that the data they provided be archived, and might be used by other academics, but that archived data would be anonymised. Finally, they were informed that their data might be published in the final report and in academic journals but assured that all identifying features would be removed prior to this. No participant was included in the study without receiving their consent in person, which was usually obtained at least 24 hours prior to being interviewed.

## Results

### *Recruitment*

Recruitment of participants was purposive. Each group was selected for their expected different orientation to health, while each was also meant to contain a similar balance of demographic characteristics. A short survey was constructed to help select participants. Obviously, they all had to associate with one identity fraction or another but it was also important that all members had access to the Internet and were registered with a GP. Beyond that, the intention was to include a range of differences. Age ranged from 21 to 59 throughout the groups, but the mean ages differed for each group. The athletes were youngest and the neutrals marginally oldest:

Table 1 - Demographics of participants

Identity fraction	Age range	Mean age	Long-term health conditions	Internet access	Registered with GP
Athletes	21-38	29	3	All	All
Neutral	39-59	48	3	All	All
Bears	28-45	37	3	All	All

Credentials were also a factor in selection. Two participants had GCSE or equivalent; three had A levels or their equivalent (of whom two were studying for degrees as mature students); four had degrees (of which one was studying for a masters); three had higher degrees (there was a spread throughout each group – see table below):

Table 2 – Educational level of participants

	Athletes	Neutral	Bears
GCSE		1	1
A-Level	1	1	1
Degree	2	1	1
Higher degree	1	1	1

These figures could be viewed in relation to the age at which participants finished their continuous education. For the athletes, it was between 18 and 21 although two were still students. For the neutral group, it was between 15 and 21 and for the bears it was between 16 and 21 years with one participant still being a student. There was a range of occupations from scientist to delivery man.

In terms of self-rated health, none of the participants described it as ‘poor’ or ‘bad’. Just one participant, in the neutral group, stated ‘good all things considered’. The rest ranged from ‘good’ to ‘very good’. Several participants were experiencing long-term health conditions, while all had experienced some acute illness in the recent past.

The rationale for recruiting this way was to compare and contrast individuals with similar or divergent demographics. For instance, comparing the narrative of those with higher degrees continues to show that their overall approaches to health were consistent with that particular group. This was also true for those with comparable qualifications.

***Functional, Interpretive and Critical Literacy***

‘Health literacy’ at first sight means ability to decipher messages about health – i.e. functional literacy. But while functional literacy may be necessary it is not sufficient to guide behaviour. The recipient of the messages must also interpret them critically as relevant to him, otherwise he could ‘know’ what to do but not consider it appropriate to do it. ‘Engagement’ with one’s own health also suggests more than passive acceptance of the message: it implies interacting with it and changing behaviour should the message suggest this.

Examination of official health campaigns suggested the possibility that gay men might not interpret themselves as targets of messages in which men are (perhaps unconsciously) depicted as heterosexual. They might, on the contrary, identify readily with campaigns for which the targets seem to be gay men. These campaigns tend to be about ‘safe sex’ between men. The marginalizing of gay men and the battle with HIV/AIDs – maybe more so in the past than now – have tended to reinforce not make permeable the symbolic barriers between gay men’s and all men’s health.

Even so, interviews with the men themselves showed that there was more to whether they engaged with their own health than how health messages were framed by senders and interpreted by receivers. Critical awareness mattered too. Thus some gay men engaged with their health, others did not. This related to a considerable extent to the identity fraction of the wider 'gay community' with which they were identified. The critical awareness of athletes about their health was far greater than that of 'bears', for whom obesity, high alcohol consumption, smoking and not exercising can be markers of identity. The surprise came with the 'health-neutral' group seeming less engaged with their health than the bears. Socio-economic status did not affect either recruitment to the fractions or individual variations within the fractions in this small sample.

Functional health literacy was measured using the three questions suggested by Chew et al (2004). There were varying degrees of aptitude in functional health literacy. However overall, most participants' responses indicated high levels. One only had inadequate health literacy. In the accounts from other participants, there is evidence of a range of functional health literacy from average to very high. Garry (athlete), and Stephen (bear) seemed to make a hobby of reading medical literature and journals. Though Garry had high functional health literacy, he suggested that he occasionally had problems learning about medical conditions, because he had difficulty understanding written information. Further investigation of his narrative reveals that his response to the question did not arise out of lack of knowledge or any problem in learning, but rather, because he had a deep understanding of the complexities of the topic.

Among the bears, only Chris indicated that he sometimes found health literature difficult to read and understand. He was a stated dyslexic. Dyslexia did not prevent him from eventually understanding health messages, but did cause him to take longer to grasp the meaning. He often felt rushed when with health professionals who did not take the time necessary to explain things fully. This resulted in his conducting self-directed research, usually online, to aid his understanding. It also resulted in his making another appointment to clarify that he had fully understood what he had learnt.

In order to indicate critical health literacy skills, we looked for evidence of participants seeking health information and evaluating its quality. They used various strategies to obtain health information. Self directed research was important for the athletes, whereas face-to-face encounters with health professionals were an important resource for the neutral group and the bears. Sometimes informal social networks were used, although it seems that only the athletes had the necessary confidence to engage with information from peers without the need to check its reliability with an 'expert'. Moreover, the athletes actively sought information relating to both their health and their illnesses, whereas members of the other two groups would more often seek health information for a condition they had experienced and which had already been labelled by a health professional.



Another signifier of the level of critical engagement was response to how the message was framed and the medium in which it was sent. In all instances, participants could easily demonstrate critical awareness of the HIV message. Often participants could demonstrate critical awareness for other sexually transmitted diseases. Clearly these messages have been framed with gay men in mind. However, other equally important health messages were missed. For instance, several participants throughout the groups provided accounts of problem drinking. However, they were not always aware of what a unit of alcohol was, nor of what constituted 'binge drinking'. In one such case, the safer sex message was redundant because the participant did not engage in unsafe sexual activities. The athletes were more aware than others of the health messages surrounding the risk activities they engaged in, and in this demonstrated a greater level of critical sophistication in securing good quality health information.

The groups differed in which media they trusted as sources for health information. For the athletes, the source was the gay media, often *Out Northwest*, a monthly magazine published by the Lesbian & Gay Foundation. The other two groups seemed to rely on the mainstream heterosexual media or the information provided by their GP.

There were thus two issues dividing the athletes from the other groups: first, bears and neutrals were more responsive than athletes to messages framed with 'illness' in mind; second, athletes were more likely than others to respond to messages framed to match their sense of gay 'identity'. What might be significant is that the neutral and bears groups did not seem to consider that the gay media were targeting them.

The interactive element of health literacy refers to applying health knowledge in everyday activities. Examination of the lifestyle choices that participants made in their everyday lives revealed how all had, at some level, modified aspects of their behaviour as a result of health discourse. However, what became apparent was that it was not necessary to engage critically with the information in order to make the necessary changes. Some participants had a passive approach to their health. They amended their behaviours, not because they understood the risk or had critically engaged with health information, but rather because they had been told to do so by a medical professional. This passive approach to health was found in the neutral group and to a lesser extent among the bears.

In all groups, diet and exercise dominated the discourse. But words and deeds did not always match. For instance, the bears spoke of the health benefits of the gym and the physical exercise of walking, cycling and swimming. However, none actually engaged in any exercise. Instead they committed themselves to doing these activities in the future. Thus, being able to critically engage with health messages is not sufficient to lead to action, any more than it is necessary for action.

### ***The Framing of Health Promotion Materials***

Most of the health material targeting gay men relates to HIV and AIDS and - to a lesser extent - other sexually transmitted diseases. All participants in all groups were able to provide accounts of material they had seen relating to HIV prevention. Often, it was the initial TV campaign of 'don't die of ignorance' even though some of the participants would have been quite young at the time.

There were differences in the material that the groups had engaged with. The bears and the neutral group tended to be influenced more by the mainstream media (for all health issues), whereas the athletes had a mixed approach. For HIV, safer sex and STI prevention, they provided accounts that were located in the gay media. They also characterised material found in gay media as opposed to mainstream media as 'more hard-hitting' and so superior. If they were to be influenced by health material relating to other fields, such as smoking, diet and exercise, they had to respond to the mainstream media, because the gay media did not address such issues. On the other hand, the mainstream media do not 'explicitly' target gay men with their health messages. The one advert that several participants recalled was the British Heart Foundations' advert: A chest pain is your body saying call 999.



Being aware of that health campaign did not necessarily translate into participants considering it to be targeted at them. Only one of the bears was aware of the campaign and he actually worked in a health care setting. All members of the neutral group had some awareness of material relating to a healthy heart, although they considered it to be directed at those who were overweight. It did not provide the necessary impetus to change their behaviour, in spite of several of them highlighting how their diets could be improved.

Several of the participants in all groups provide accounts of the smoking cessation campaigns that have been run by the BHF (one of which told of how smoking clogs the arteries and showed fat dripping from a cigarette and a clogged up artery). However, only 2 of the entire sample actually smoked (both in the athlete group). Several of the other participants had close family, partners or friends who smoked, which might account for their recollection of the material. It might also be the sheer pervasiveness of the material, which at the time of interviewing, was quite extensively shown. By their own reports, sexual orientation was not explicitly considered by those who designed the campaign about the clogged up arteries. Our review of the testimonials used in the adverts of people dying of smoking-induced diseases and their families talking about the damage smoking had done, reveal that sexual orientation

was not a significant factor in choosing the testimonials shown. Nor did the family members used include recognisably gay identifiers.

### ***Identity Fractions and different Constructions of the Health Messages***

The three groups had very different approaches to how they understood the many competing health messages. The most prominent messages were about diet and physical activities. Many of all groups were able to provide an account of the 'five-a-day' fruit and vegetables. They also highlighted the benefits of doing some form of regular exercise. Although there were similarities in each group's 'public' account of these current guidelines, each group constructed 'private' meaning differently. The neutral group subscribed to the current health discourse surrounding diet and exercise because it was what they thought was expected of them as health citizens. The athletes used diet and physical activities as a means to 'be' fit and healthy and maintain health in the long term. They linked physical activities with both mental and physical well-being. For the bears, good diet and exercise were means to 'become' healthy, from an unhealthy start.

The bears engaged with the same health messages to the same degree as the athletes but with subtle differences. For the athletes, physical activity was a daily event and often incorporated using a gym. For the bears, physical activity was something to strive towards but, at the time of interview, none of the participants actually engaged in any: they had plans for the future. They had all tried using the gym but had stopped for one reason or another. The neutral group did not speak of using the gym as a means of exercising. Instead, they seemed to invoke the current guidelines of walking three times a week for 30 minutes, or cycling to work and so on. Two of the neutral groups had bought dogs so that they could increase the amount they walked.

It therefore seems that health messages on diet and physical activities are being interpreted differently. Among the athletes it was common to speak (in effect) of 'counterbalance'. Unlike the other groups, they critically engaged with health messages and then applied their knowledge to benefit health or reduce risk. Yet they often acted in ways they knew were a risk to health. When they had done so, they offset or counterbalanced negative health behaviour with positive. For instance, eating or drinking too much was meticulously offset by physical exercise.

The bears offered accounts that stressed the need for moderation in all things – a balanced diet to be sure, but also not being too 'obsessed' with exercise. The neutral group thought in terms of having 'treats', to reward themselves for abstinence. For example, they might not drink throughout the week but then binge drink at the weekend. They might avoid fat or eat five fruits and vegetables in the week, but then indulge themselves on cream cakes. Whereas the athletes measured the exercise by which they compensated for risky behaviour, the bears and the neutral group just let it all hang out.

## **Conclusions**

The results suggest that there is more to health literacy by far than functional literacy. Nutbeam usefully adds critical understanding of the message and

interaction with the message in order to introduce a change in behaviour. However, a key finding of this project is that critical understanding of the health message is neither sufficient nor necessary for behaviour to change as prescribed. Several men in this study took a passive approach and did as they were told by health professionals. Still others critically engaged with the message but did not change their behaviour.

A key element in health literacy missing from Nutbeam's account is whether messages are framed with a target audience in mind and whether the audience intended identifies itself within the message. Gay men have, for the last 20 years and more, been characterised in public health as a 'risk group' for HIV/AIDS, with the possible effect that the risks to health that they share with other men may not seem to apply to them and instead to apply to other people.

Messages may be framed with illness in mind rather than ways of maintaining good health. In this sample, athletes and bears seem to have divergent critical awareness of their health needs. Athletes sought to maintain good health, whereas bears sought to become healthy from a position of near-illness.

Messages may also carry latent information about the identities of those to whom they apply. Gay men tend not to feature in 'mainstream' health promotion for men, yet the conditions they share with other men tend also to be omitted from gay community health messages. Moreover, the athletes could identify themselves in gay community messages, whereas the bears and the members of the neutral group did not do so.

It follows that, while gay men need to be targeted by 'men's health' promotion, 'fractional' differences within the gay community need to be problematised and health messages tailored to each of them. Only when this is achieved is it likely that many gay men will become 'fully engaged' with the health needs they share with all men.

In this project, gay men have served as a 'critical case'. It follows that further research is needed, both among heterosexual men and among women, focused on the different identity fractions of which they are constituted, so that health messages can be targeted more effectively. In health as in other areas of 'public engagement' activity *the* public has for too long been assumed, whereas there are really many *publics*.