

# Northern exposure: HIV in the Northern Rivers region: A joint report

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# Northern exposure

HIV in the Northern Rivers region

## A JOINT REPORT

### PART 1

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The cultural context of HIV and body shape change: a report on the Northern Rivers regional arm of the Side Effects and Lipodystrophy Project 2002–2004

Asha Persson<sup>1</sup>

### PART 2

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Positive Health in the Northern Rivers: an analysis of Northern Rivers data from the Positive Health study

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## **ACRONYMS**

ACON	AIDS Council of New South Wales
AFAO	Australian Federation of AIDS Organisations
ARCSHS	Australian Research Centre in Sex, Health and Society
ATPA	AIDS Treatment Project Australia
NAPWA	National Association of People Living with HIV/AIDS
PLWHA NSW	People Living with HIV/AIDS NSW
SHAIDS	Sexual Health and AIDS Clinic, Lismore



## INTRODUCTION

While the vast majority of Australians with human immunodeficiency virus (HIV) tend to reside in major cities, a significant number live in regional and rural areas (e.g. Grierson et al., 2002, page xxviii). No precise surveillance data are available but anecdotally there are an estimated 250 to 300 HIV-positive people living in the Northern Rivers region.<sup>1</sup> A large proportion of this population is believed to have moved there from Sydney, Melbourne and other cities. But despite a significant migration of positive people to the Northern Rivers there is hardly any literature or research available on the topic and there are scant references in the HIV and gay media to this trend. The aim of this report is to address this gap and provide insight into some of the issues facing people with HIV who move to, and live in, the Northern Rivers region.

The report consists of findings from two separate studies. The first part of the report, 'The cultural context of HIV and body shape change', includes findings from the Northern Rivers regional arm of the Side Effects and Lipodystrophy Project, a qualitative project instigated in 2002 to explore how people with HIV experience and negotiate adverse effects of their antiretroviral therapy, with particular focus on body shape change. In addition to discussing how gay men in the Northern Rivers experience and negotiate lipodystrophy, this part of the report provides an overview of a number of issues significant to HIV-positive people in the region, including sociality, disclosure and access to services.

The second part of the report, 'Positive Health in the Northern Rivers', includes findings from the Positive Health study, a study (which began in 1999) of a longitudinal cohort of HIV-positive men and women from New South Wales and Victoria. This is a quantitative project employing annual interviews, the main aim of which is to examine decisions regarding the uptake and use of antiretroviral treatments, access to and use of services, experiences of health and illness, and attitudes towards HIV and its management. This part of the report focuses on a subsample of respondents drawn from the main Positive Health study to compare the experience of people living with HIV/AIDS in the Northern Rivers to that of people living with HIV/AIDS in Sydney. In addition to providing preliminary data about the differences in health of people who live with HIV/AIDS in the two different regions, this part of the report also explores the use of antiretroviral treatment and complementary and alternative therapies, as well as differences or

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<sup>1</sup>This is according to personal communication with ACON (AIDS Council of New South Wales), with local medical professionals and with ACON Northern Rivers. See also Casey, 2002.



similarities in people's use of services, in their out-of-pocket expenses and in the problems they encounter in accessing services.

The two studies are separate and, in this report, have not been cross-referenced with each other. We have brought them together in the one document for the sake of convenience and because of their relevance to people living in the same geographical area. By publishing them together, we hope all readers will find something of interest, whether it be statistics or narratives or both. While the two parts of the report can and should be read independently, they complement each other in that the qualitative part elucidates findings in the quantitative part and vice versa. Together and separately, these studies raise questions for HIV education and health promotion and for future research on living with HIV in regional and rural areas.

Asha Persson and Andrea Fogarty

# PART 1

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The cultural context of HIV and body shape change:  
a report on the Northern Rivers regional arm of the  
Side Effects and Lipodystrophy Project 2002–2004

Asha Persson

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## INTRODUCTION

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This part of the report includes findings from the regional arm of the Side Effects and Lipodystrophy Project, a qualitative study instigated in 2002 to explore how people with HIV experience and negotiate the adverse effects of their antiretroviral treatment, with particular focus on body shape change (lipodystrophy and lipoatrophy). In addition to discussing how gay men in the Northern Rivers experience and negotiate lipodystrophy, this section provides an overview of some of the issues facing HIV-positive people in the region, including sociality, disclosure, and access to services, issues that may speak more broadly to living with HIV in regional and rural areas.

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## THE SIDE EFFECTS AND LIPODYSTROPHY PROJECT

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### BACKGROUND

While combination therapy has significantly reduced AIDS-related deaths and greatly improved life for many people with HIV in Australia, many also experience a range of unwanted side effects from their HIV medication. These include lipodystrophy and lipoatrophy. Initially identified by Australian medical researchers (Carr et al., 1998, 1999), lipodystrophy is a relatively poorly understood metabolic disorder that involves an unusual process of fat redistribution (resulting in an accumulation of fat in certain body parts) and fat loss (lipoatrophy), which can sometimes have significant impact on life and well-being. This unintended, but rather common, effect of certain HIV drugs has given rise to a repertoire of distinctive and largely irreversible body shape changes that manifest in various combinations. At their most extreme, these symptoms can include a distended belly, severely enlarged breasts (in women), a build-up of fat at the back of the neck and shoulders ('buffalo hump'), flat buttocks, stick-like arms and legs, veins that bulge like 'roadmaps' along the extremities due to loss of subcutaneous fat, and extremely sunken cheeks which are commonly seen as giving a gaunt, 'unwell' impression.

Other metabolic complications associated with lipodystrophy include insulin resistance and high levels of harmful blood fats (cholesterol and triglycerides), which increase the risk of diabetes

and heart disease respectively. The sometimes astonishing levels of cholesterol may also erupt as white lumps on the surface of the body and face. There is still a great deal that is unknown about lipodystrophy in terms of its causes and prevalence. Two people taking the same HIV drugs do not necessarily experience the same kind or degree of symptoms, if any at all. Considerable research has taken place to determine whether lipodystrophy is a single syndrome or a number of conditions caused by different classes of HIV drugs. For example, it is still unclear whether lipodystrophy and lipoatrophy are two separate phenomena. A common theory is that protease inhibitors play a role in lipodystrophy (fat redistribution), but nucleoside analogues are also thought to play a role, particularly in relation to lipoatrophy (fat loss). As is the case with many HIV-treatment-related effects, it is also unclear to what extent these conditions are caused by the drugs or by HIV itself, or a combination of both. In addition, some changes in body fat are common features of normal ageing. Generally, experts agree that the possibility of developing body shape changes increases with age and length of HIV treatment. On the whole, it is likely that these body shape changes are a result of complex interactions between a number of co-factors (age, body mass index, gender, different classes of drugs, length of infection, length of treatment, lifestyle and family history) that are yet to be fully understood (e.g. Bass, 2001; Carr, 2003; Carr et al., 2003; Carter et al., 2001; Miller et al., 2003; Nass, 2003).<sup>2</sup>

At present, there is no known or proven cure for lipodystrophy. A number of substances, such as steroids, human growth hormone and rosiglitazone (a diabetes treatment) have been tested with mixed results (Gold et al., 1996; Wanke et al., 1999; Nass, 2003). In some cases, changing those HIV drugs that contribute to lipodystrophy may alleviate some symptoms, but this is unlikely to reverse them fully (Carr et al., 2001; Carr et al., 2002; Ruiz et al., 2001). However, stopping or switching drugs is not an option for everyone. To counteract facial fat loss, some find New-Fill effective and are generally pleased with the results. New-Fill is a substance (polylactic acid) which is injected into

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<sup>2</sup> In this report, I refer to body shape changes in general as 'lipodystrophy', except when referring to fat loss specifically.

the cheeks or temples to 'fill out' the trademark hollows caused by lipoatrophy (Boix, 2003; Machon, 2003). Currently, the cost of this procedure, which requires repeated treatments, makes it out of reach for many.

By and large, debates on lipodystrophy have been dominated by clinical and public health discourses that tend to position lipodystrophy as a health issue or in terms of long-term treatment difficulties and adherence. These are obviously crucial issues to consider and understand. At the same time, there is a conspicuous absence of research exploring lipodystrophy as a lived experience and a social issue. The notable exceptions are two small studies, one Canadian (Collins et al., 2000) and one British (Power et al., 2003), both of which identify a number of psychosocial effects associated with lipodystrophy, including erosion of self-image and self-esteem, problems in social and sexual relationships, depression, and anxiety around disclosure of serostatus due to the perceived revealing features of lipodystrophy (see also Persson 2002a, 2002b, 2003a, 2003c, 2004).

Considering how body-conscious Western societies are (e.g. Bordo, 1993, 1999; Gilman, 1999) but also how fundamental bodies are to most people's sense of self, to everyday experiences and social interactions (e.g. Merleau-Ponty, 1962; Csordas, 1994; Turner, 1984; Schilder, 1970), it is obvious that unexpected body shape change can have significant and life-changing implications. As such, it poses a challenge not only to affected individuals but also to pharmaceutical companies, the medical profession and gay community as a whole in Australia. Bearing this in mind, it is surprising that such an important subject has been largely neglected.

In response to this gap in the research, the Side Effects and Lipodystrophy Project was initiated by the National Centre in HIV Social Research at the University of New South Wales in collaboration with the National Association of People Living With HIV/AIDS (NAPWA), the Australian Federation of AIDS Organisations (AFAO), the AIDS Treatment Project Australia (ATPA), ACON (the AIDS Council of NSW), and People Living with HIV/AIDS NSW Inc. (PLWHA NSW).

## THE SYDNEY ARM

The aim of the Side Effects and Lipodystrophy Project was to investigate what life is like for those who experience lipodystrophy within the context of inner-city Sydney gay community. In-depth interviews were conducted with 23 participants, most of whom were Anglo-Australian middle-class gay men in their late 30s to mid-50s. Many lived in or near the inner-city area encompassing the neighbourhoods of Darlinghurst and Surry Hills, an area known for its large gay population, its sassy commerce and cafés, its gay venues and businesses, HIV organisations and services, and its party-devoted and intensely body-conscious 'scene'. The majority of informants had been HIV-positive for between 10 and 20 years. Extensive histories of treatment with antiretroviral therapy were the norm, though a number of men were not on treatment at the time of the interview, commonly because of adverse effects of the drugs.

Several issues of concern to the participants were identified in the interviews. Many of these centred on body image and were profoundly informed by cultural constructions of 'healthy' and 'sick' bodies (e.g. Crawford, 1994; Gilman, 1988, 1995). Forced disclosure was by far the most commonly expressed concern. While many people with lipodystrophy are perfectly healthy, most of the study participants felt that lipodystrophy made HIV visible, that it marked them as HIV-positive or 'sick', thus undermining their sense of control over disclosure in social situations and heightening fears of discrimination and stigma, particularly in relation to gay community itself.

For many of the participants, this sense of forced disclosure had a considerable impact on their social and sexual esteem, which was further eroded by anxiety around looking 'different', 'unattractive', or 'prematurely old'. While these feelings were not universal, participants frequently spoke of loss of physical and sexual intimacy, and of avoiding particular social spaces and activities because they feared rejection or felt too self-conscious. Having lipodystrophy meant having to adjust to a certain notion of 'being HIV-positive', one that was visible and identifiable, at least in Sydney gay community where lipodystrophy was perceived to be relatively well known. In this social domain, lipodystrophy is generally construed as a frightening and unappealing condition because of its association with HIV, but also with loss of

'looks' and sexual desirability (e.g. Batrouney, 2001; Canavan, 1998, 2000).

The discomfort that habitually surrounds lipodystrophy can largely be understood in the context of a highly body-conscious social landscape but more importantly in relation to HIV itself. Lipodystrophy tends to compound feelings of 'difference', of having a body already 'set apart' by medical management and by a stigmatised virus. Advertisements in the gay media, with their common emphasis on health, beauty and youth, were raised by many of the participants as particularly unhelpful in coming to terms with lipodystrophy. It was also a recurrent view that the Sydney gay 'scene', which many described as highly body-oriented and 'competitive', unduly exacerbated the difficulties of having lipodystrophy.

In consultation with the study collaborators (see above), a decision was made to undertake a comparative study rather than assume that the findings from a research study located in Sydney's gay community would be applicable to Australia's diverse HIV-positive population. A range of social positions and experiences may shape the way lipodystrophy is perceived and lived, including gender, sexual orientation, age, cultural and linguistic background, as well as the cultural and geographical environment in which people live. This last variable was chosen as the focus for the comparative study.

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## THE CULTURAL CONTEXT OF HIV AND BODY SHAPE CHANGE: THE NORTHERN RIVERS REGIONAL ARM

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The impetus for the regional arm of the Side Effects and Lipodystrophy Project emerged out of an interest in understanding how particular cultural and social contexts frame and influence experiences of HIV-treatment-related body shape change.<sup>3</sup> The objective was to explore lipo-

dystrophy in a milieu partly defined by a comparative absence of an organised and socially connected population of HIV-positive people, no easy access to an array of services, and the absence of the particular cultural expressions that are common to inner-city Sydney gay community. The Northern Rivers region was chosen as a suitable site for the study for a number of reasons: its relatively substantial population of people with HIV, its regional and rural environments, and its specific cultural manifestations of 'alternative' lifestyles.

A number of questions guided the research:

- How is lipodystrophy lived in a social environment where the characteristics and causes of lipodystrophy are presumably less well known?
- Is the notion that lipodystrophy 'signals' HIV specific to the particular context of a 'knowing' community such as inner-city Sydney gay community, or are people still marked as 'sick' in the Northern Rivers even though the specific illness cannot be identified?
- Are there similarities and differences in terms of how people with lipodystrophy relate to the local gay *and* broader community in the region?
- Is the relatively lesser exposure to information, services and urban discussion on lipodystrophy a help or a hindrance in dealing with body shape change?
- What role does the renowned acceptance and celebration of difference that defines part of the cultural landscape in Northern Rivers play in terms of having lipodystrophy?
- And to what extent do the 'alternative' health practices and spiritual orientations that are prevalent in Northern Rivers shape the ways people experience their bodies and live with HIV?

The study thus sought to contextualise a phenomenon that is often dominated by medical and public health discourses. In order to move beyond these discourses, which frequently limit rather than enhance understandings of the everyday realities of lipodystrophy, the study took a more explorative and ethnographic approach to increase the knowledge of how particular bodies are socially and culturally perceived and lived.

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<sup>3</sup> The principle investigator of the Side Effects and Lipodystrophy Project, Asha Persson, received a small research grant from the Faculty of Arts and Social Sciences at the University of New South Wales to carry out this arm of the study under the title 'Locating lipodystrophy: a regional study of the cultural context of HIV and body shape change'.

## METHODOLOGY

In collaboration with ACON Northern Rivers, in-depth research interviews were conducted in Lismore, northern NSW, in November 2002. Ethnographic fieldwork was also undertaken during two weeks in the region, including visits to services commonly used and venues frequented by HIV-positive people in the area, as well as formal and informal discussions with service providers in the local HIV sector and participation in local events. Interview participants were mainly recruited through ACON's newsletter *Rainbow News* and the local HIV peer support group. In addition, advertisements for the study were placed in three local newspapers, and flyers were available at SHAIDS, the local sexual health and AIDS clinic in Lismore.

Of 17 participants, all men, the majority were of Anglo-Australian background. Fourteen men identified as gay, two as heterosexual, and one as bisexual.<sup>4</sup> Their ages ranged from 26 to 58, with a median age of 43. Most of the men were on the pension, though a significant number wanted to work but were unable to find employment in the area. Only one participant worked full-time, while four did casual work and two did some unpaid work. About half of the participants were single, with the rest in regular relationships, all living with their partners, most of whom were also HIV-positive. Except for two men born in the region, all participants had moved to the Northern Rivers from an urban centre, predominantly Sydney or Melbourne. Three men were originally from other Anglo-European countries.

The interviews were conducted in a conversational style but included a number of thematic questions to ensure consistency across the interviews for the purpose of comparability. To provide context and background, participants were asked open-ended questions about their reasons for moving to the Northern Rivers, the advantages and disadvantages of living in the area, their experiences of and interaction with local HIV-related services and health services generally, and their attitudes to HIV therapy and other forms

of health management. Considerable time was then devoted to exploring participants' experiences of body shape change (lipodystrophy and lipotrophy) in relation to body image, self-esteem, social and sexual interactions, treatment decisions and everyday negotiation of life in a regional area. All interviews took place at ACON Northern Rivers. On average, interviews lasted two hours and were tape recorded. Taped interviews were later transcribed and thematically coded and analysed. As most interview participants lived outside Lismore in hamlets and towns across the region, all were reimbursed for travel expenses associated with getting to the interview location.

The conceptual framework of the study was primarily informed by social and phenomenological anthropology. In this approach, the lived experience of the research subjects is given primacy and is understood in the context of particular social 'life-worlds'.<sup>5</sup> In addition, with this grounding in the empirical, the researcher sought to avoid limiting the research findings, allowing any additional theoretical and thematic directions to emerge from the participants' stories. Accordingly, several themes and issues besides lipodystrophy are discussed in this part of the report because of their recurrence in interviews and the significance given to them by the interview participants. These issues are examined first, providing a suitable background and context for the ensuing discussion of lipodystrophy.

Quotes from the interviews are used extensively in this part of the report to provide the opportunity and space for the study participants to express in their own words the many issues of living with HIV in the Northern Rivers region.

<sup>4</sup> While the study was open to both men and women, recruitment of women unfortunately proved unsuccessful.

<sup>5</sup> Here I follow Jackson's and Schutz's definitions of 'lifeworld'. Jackson describes lifeworld as 'that domain of everyday, immediate social existence and practical activity, with all its habituality, its crises, its vernacular and idiomatic character, its biographical particularities, its decisive events and indecisive strategies' (1996, pp. 7–8). In Schutz's interpretation, 'life-world' is 'the quintessence of a reality that is lived, experienced and endured. It is, however, also a reality that is mastered by action and the reality in which – and on which – our action fails. Especially for the everyday life-world, it holds good that we engage in it by acting and change it by our actions. Everyday life is that province of reality in which we encounter directly, as the condition of our life, natural and social givens as pre-given realities with which we must try to cope' (in Schutz and Luckmann, 1989, p. 1).

## NORTHERN RIVERS REGION

The Northern Rivers region<sup>6</sup> is located in the far north of New South Wales and covers an area of around 20 000 square kilometres. It stretches from the Clarence River in the south to Tweed Heads (on the Queensland border) in the north to the foothills of the Great Dividing Range in the west. The environment is highly diverse with natural coastline and beaches, rolling countryside, rain-forests, mountains and gorges, as well as several World-Heritage-listed national parks and wilderness reserves. The area includes country centres such as Lismore, Murwillumbah, Grafton, and Casino; the seaside towns of Yamba, Ballina, Tweed Heads and Byron Bay; and larger 'villages' such as Bangalow, Mullumbimby and Nimbin.

Primary industry, agriculture and dairy farming were long the economic and cultural basis of the region, but today major industries also include tourism, retail, and manufacturing. Since the 1970s the area has been famous for its surf culture and its counter-cultural history, with places such as Byron Bay and Nimbin being widely associated with environmental activism and alternative lifestyles. The area has seen an unprecedented inward migration, particularly of retirees and sea-changing urbanites, with the population more than doubling over the past three decades. The population of Byron Bay alone grew 30% in the past ten years. The present population of the Northern Rivers is about 255 000 and is a diverse mix of rural people, metropolitan expatriates and 'alternative' lifestyles. The population is largely concentrated along the coast and around Lismore. As growing numbers of people have gravitated to the area to live or visit, towns such as Byron Bay have

ballooned and there has been a proliferation of local businesses, spiritual retreats and luxury health resorts. This has brought ongoing conflicts over land use, development, infrastructure, services and resources. However, many people who move to the area choose not to live in the increasingly busy coastal settlements in favour of quieter country hamlets and towns which, nonetheless, have their own economic and structural issues.

While the region is experiencing significant economic growth, it is unable to keep pace with the employment demands of the growing population. According to the Australian Bureau of Statistics, the region has one of the highest regional unemployment rates in Australia. Unemployment rates are particularly high in coastal local government areas where most of the economic and population growth is taking place, such as Byron Shire, Tweed Shire and Ballina Shire. Census data indicate a trend of structurally entrenched unemployment in the region and a significantly higher level of economic disadvantage among the population compared to the rest of NSW. Household income tends to be well below the NSW average. People receiving income support from Centrelink are over-represented. Regional unemployment rates are an obvious reason for this, but the higher than average proportion of older people in the region is also a contributing factor. A lack of public transport and the considerable cost of owning and driving a private vehicle also play a role in unemployment and in economic and social marginalisation, as well as making it difficult to access government and health services.

The region has a considerable population of gays and lesbians, and a number of local networks and organisations such as Tropical Fruits which organises annual events and celebrations that attract gays and lesbians not only from the region but from all over NSW (e.g. *Sydney Star Observer*, 8 January, 2004, p.3). There are few gay venues in the region, though there are a number of gay-friendly places. The Winsome Hotel in Lismore was a popular meeting place before it closed in early 2004. There is also a sizeable population of HIV-positive people living across the region. While the vast majority of Australians with HIV tend to reside in major cities, a significant number do not. In *Futures 3* (Grierson et al., 2002, page xxviii), a survey of people with HIV in Australia, 12.5% of

<sup>6</sup> In this part of the report, information about the Northern Rivers region is drawn from the ACON website ([www.acon.org.au](http://www.acon.org.au)) and the following documents:

Department of Transport and Regional Services (2003). *A regional profile: Far north east NSW region*. Commonwealth of Australia

Northern Rivers Social Development Council (1998). *Employment/unemployment in the Northern Rivers region of NSW – A social perspective: NRSDC submission to the senate inquiry into regional employment and unemployment*.

St Lawrence, V. (1996). *Northern Rivers regional strategy: A discussion paper prepared for the management committee on social issues*, North Coast Area Assistance Scheme.

Davis, R. (2001). *PLWHA, Gay, Lesbian and Transgender Community Survey results*. ACON, Northern Rivers.



respondents reported living in larger regional centres, while 9.1% lived in rural areas. Over the past 10 years, in particular, many people with HIV have moved to the Northern Rivers. Indeed, Northern Rivers has a higher proportion of HIV-positive people than other regional areas in NSW, with an estimated population of 250 to 300 people (Casey, 2002). Despite a significant migration trend of positive people from urban centres to the Northern Rivers, there is hardly any literature or research available on the topic. In addition, a review of HIV and gay media over the past three years found scant references to this trend.<sup>7</sup>

People with HIV in the region are represented and assisted by ACON Northern Rivers which is located in Lismore and covers the area from Grafton in the south to the Queensland border in the north. The organisation operates out of a discreet, suburban-looking house on a wide street outside the town centre a few minutes walk from Lismore Base Hospital. According to the ACON website, ACON Northern Rivers provides a number of services, including treatments information, health and welfare counselling, educational resource material, referral and advocacy, housing information, drop-in facilities, access to financial assistance, peer support, workshops and health retreats. Situated in the same vicinity is the local sexual health and AIDS clinic (SHAIDS). At the time of the research, there were two HIV specialists at the clinic which also provides a counselling service and outreach to Byron Bay and Ballina. The service is free, but does not deal with health problems unrelated to HIV, hepatitis C and sexually transmitted infections. Other than SHAIDS, the nearest HIV specialist services were located in Brisbane and on the Gold Coast. There were a couple of GP S100 prescribers in Byron Bay and Tweed, with the Australasian Society for HIV Medicine reportedly working to train more S100 prescribers in 2002 to address the drastic shortage and meet the needs of the local HIV-positive population (Casey, 2002).

<sup>7</sup> The following media were searched: *Talkabout*, *HIV Australia*, *Positive Living*, as well as *Focus* and *Sydney Star Observer*. Thanks to Mark Adnum for conducting this review.

## REASONS FOR MOVING TO THE NORTHERN RIVERS

The number of years the participants had lived in the region ranged from four months to 14 years, with a median time of 3.5 years. Searching for a better quality of life was by far the most common reason for moving to the Northern Rivers, though a couple of participants said they had retired there 'to die' prior to the introduction of HAART in 1996. Many participants had fallen in love with the region when visiting on holiday and had subsequently decided to relocate. There was a common perception among the participants that the stresses of city life had a detrimental effect on them and that the relaxed lifestyle and natural surroundings of the Northern Rivers region would be more conducive to their health and their management of HIV. Corey, for example, explained why he and his partner had chosen to move to the area:

*Well, certainly a lifestyle change, which everybody sort of says and does. Primarily it was for health reasons. To get out of the rat race, so to speak, and move to a more gentle environment. Just to enjoy life a little more, instead of being stressed. We've also found that we were always sick in Sydney, always getting a cold or a flu or something like that, always! And since we've been up here we've never been sick. So it says a lot.*

The decision to move was also influenced by a common impression that Northern Rivers had a substantial population of HIV-positive people and that relevant health services would therefore be reasonably good and available. As Leroy put it:

*Yeah, I just loved the area and I realised it was—there were a lot of gay people here. There seemed to be quite a good HIV support. My doctor in Darlinghurst initially—when I told him I was going to the country and I said ... 'Oh, the Northern Rivers', he said, 'Oh, that's all right.' He said, 'Anywhere else I would have sort of hesitated, but', he said, 'I know the services up there for HIV-positive people are quite good.' So, that was good, hearing that.*

Most participants said that they were very happy with their decision and that they intended to stay, even though many found that the region was not

quite what they had expected in terms of services. While some speculated that they might be forced to move one day should their health deteriorate, only one man, Bruce, expressed a clear intention to move back to Sydney. He had grown up in the region but had lived most of his adult years in Sydney. In the late 80s, he said, he was 'sent home' by his then doctor to prepare for an impending death, but he now wanted to return to Sydney because he believed more support would be available there and because of his desire to live in what he defined as a more cohesive gay community.

*I mean, when you live around here, it's really a straight community. Whereas in Sydney you can live in the gay community, you know? There's so many, it's so wonderful, the gay community. But up here you've really got to, you've got to really survive up here. It's really hard because there's no support up here. If you're sick, it's very hard up here.*

While Bruce was the only participant who expressed any major dissatisfaction with his life in the Northern Rivers, issues to do with gay community and HIV support in the region were frequently brought up in the interviews. A variety of views were expressed by the participants and these will be discussed later in the report. However, the participants generally raised a number of advantages and disadvantages of living in the region. The perceived disadvantages were largely consistent across the interviews and were often regarded as quite considerable and difficult to negotiate but, for the majority of participants, the advantages outweighed the disadvantages. One example of this is Denton's statement:

*It's very different to living in a city and it has positives and negatives ... I think that apart from the fact that, you know, I'm going to live in poverty for the rest of my, well, semi-poverty for the rest of my life, because I haven't been working continuously enough to have, you know, built up any substantial superannuation. Aside from that, I think that adopting a more relaxed lifestyle in the Northern Rivers here has been good for me personally, but it does have its downside in that I'm not going to be able to live as comfortably as I would, as I might have been able to, had I continued to work in Sydney and been employed for sort of a more, on a more constant basis.*

## PERCEIVED ADVANTAGES AND DISADVANTAGES OF LIVING IN THE NORTHERN RIVERS REGION

The most frequently cited advantages of living in the Northern Rivers were the gentler, slower pace, the beautiful environment, the climate, the healthy outdoor lifestyle, the friendly people in the area, and the lack of traffic, pollution, crowds and noise. Clive described it in this way:

*Yeah, I like living up here because it's much more relaxing. Basically, the group of people that we move amongst up here, a lot of them have come from Sydney and some have come from Melbourne. They're in the thirties through to fifties age group. Everybody likes living up here more than Sydney. It's not crowded. It's not noisy. It's not dirty. When they go back to the city, all come back and say, 'Oh, why did we go there? We hated it!' ... You don't have sirens, violence, burglar alarms, you don't have to lock your doors and windows all the time. It's just all those things that make it really a much nicer place to live ... You don't have to deal with traffic, people pushing, crowded supermarkets. Just all that stuff that goes to everyday city pressures and living. It just doesn't happen up here. And you really forget about it until you go down there, yeah. So I think it's good not to have all that.*

A few men said that one advantage of living in the Northern Rivers was less daily awareness of being HIV-positive because there were less gay people, gay venues and media to remind them. To cite Clive again:

*I'm less aware of being a positive person, living up here. You're not going out to gay venues. You don't read the gay paper every week. You see, you see less gay people, less positive people. Well, the positive people I'm seeing are like the same group of people, sort of thing. So it's a less prominent part of my life ... I think it's a bit better. Because it's not, it's not a pressure or a worry. It's back there rather than ... it's not popping to the forefront that I'm a positive person, sort of thing ... It's just, I think I'm not being made to think about it. I'm not being reminded that I'm a positive person.*

Overwhelmingly, a lack of appropriate health services and HIV expertise was seen as the greatest

disadvantage of living in Northern Rivers. Many said that there was an acute shortage of GPs with HIV experience and that existing GPs and specialists were stretched to the absolute limit. As Corey stated:

*Yes, there are some disadvantages. The main thing is, I guess, in the health industry, the lack of professional health carers here. And that's probably the only part that really is, that's a setback. I've had to go to Sydney quite a few times for different things, because there just aren't the people here with the background, I guess, in HIV or, indeed, hep C.*

In addition to the commonly expressed concern over a shortage of services for HIV and hepatitis C, the even greater lack of mental health services in the region was frequently raised by participants. Closely following were the lack of public transport, the dependence on cars, and the long and costly travelling distances (for example, Nimbin to Lismore is a 45-minute drive). According to some, the distances and transport difficulties made it more difficult to build social networks in a geographically dispersed area, hence isolation was often raised as an issue. In relation to this, some participants mentioned missing friends and family as one of the disadvantages of having moved to the Northern Rivers. Max commented:

*You know, there are, there are absolutely major disadvantages. You have to put a lot more effort into your social networks up here. They don't just happen. Distance is a big concern. Petrol on a shortened, on a small wage, certainly packs a punch ... Well, I think because you're more, yeah, it's more disparate.*

None of the participants who were in a relationship had met their partners in the region; they had moved there with their partners as couples. Among the participants who were single, living in the Northern Rivers was generally not seen as particularly conducive to meeting a partner, as Stuart explained:

*Finding a relationship is a lot harder up here than it would be in Sydney. You know, I think if I really want a relationship I would probably have to move back to Sydney. But could I? And I weigh it all up; I just don't think I could go back down to Sydney. But that's where*

*most, you know, most gay men live in Sydney. And there's a lot more, there's a lot more opportunities to meet gay men in Sydney than there is up here.*

Lack of work was also mentioned by many as a significant drawback. Almost all of those who worked did so on a casual basis. The chronic shortage of employment in the region prevented some participants from working even though they wanted to. In addition, fluctuating health and medical side effects often impeded their work prospects further, as in Ethan's case:

*The only thing I'm not happy about is [not] working. After working for twenty years and then just stopping, it still is, after two years, a big issue for me. I've had casual work here and there. But just doing that, I don't think I could do full-time work again, just that medical side of it.*

Some of the themes raised so far, specifically issues to do with community, social connectedness and isolation, as well as HIV-related health services and support, are discussed in more detail below.

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## COMMUNITY, SOCIAL CONNECTEDNESS AND ISOLATION

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The idea of a local gay community varied among the participants. There was a feeling among some that there is no 'gay community' as such in the Northern Rivers. This view was most explicitly put forward among some of the older gay men, whereas younger men would speak of relatively cohesive gay and lesbian groups or 'queer collectives'. Bruce, who is in his 50s, said:

*There's not really a gay community. Like, there's a gay community around here, but I don't know what it is; they seem to be very disjointed. They don't seem to have a common theme or common grouping or common place where they meet. And I don't know what it is. To me, it seems, I don't—it doesn't seem as though I'm really part of the gay scene up here. It's funny, isn't it? But, I mean, down in Sydney, I go back there and I fit in like that, you know?*

Alternatively, some participants described what they saw as a 'fragmented' and 'disjointed' gay community with separate 'gay groups' in different local areas.<sup>8</sup> Alexander, for example, stated:

*Like, there's a Byron crowd who we know nothing about, and Bangalow. There's Tweed, that's totally separate. Like, there's a big Nimbin group, which is even separate probably to Lismore. So it's very separate, sort of, the whole area ... And there's a big sort of social group at Bangalow that play tennis, that we know nothing about ... So, they're very, yeah, distinct groups ... They don't sort of mix. It's funny.*

One ACON employee described these groups as rather 'close-knit'. Being gay or HIV-positive did not translate into immediate inclusion in a social circle. Time and effort was often required, according to most participants, in a way that was seen as different from their previous urban experience, not only because of the distances and travelling involved, but also because of the particular dynamics of a social environment in which the population was partly defined by transience and migration. Max explained:

*There is a collective of gay and lesbian people up here and people living with HIV, but there's a certain amount of work that you have to put in to accessing those people, forming relationships with them, and then, you know, they becoming part of your life and you part of theirs. So, you know, you start that very basic social stuff where you do get people ringing up and saying, 'Oh, hi. Just ringing, you know, because I wanted to chat.' All of that stuff takes time ... It's more spread out and you're mixing with people that have been up here for a long, long time and have very, very firm friendships. Plus, you know, all the brand new people. And I think people up here, also, they're very used to people coming up and maybe even travelling on further or going back*

*to Sydney. So, they want to be sure before they put time into you.*

Overall, most participants said that their social networks tended to be made up of a mixture of gay and straight friends, neighbours, and peer support groups.<sup>9</sup> There was a definite tendency for those relationships to be with other urban expatriates, rather than with local people. While many agreed that building friendships took a long time, some also commented that these friendships tended to be strong and genuine because people had more time and were more reliant on each other than in the cities. Long travelling distances also meant that people tended to socialise differently, often staying overnight or visiting each other over a weekend. This is what Vincent said:

*And, like, as I've said to a lot of people, being up here in the Northern Rivers for twelve months, I basically have more friends than I've had after fourteen years of living in Sydney, that I would call good friends, that you could sit down and have a nice conversation with, that would do something for you, as I would for them, without hesitation ... Why? Maybe because a lot of the pressures in Sydney aren't up here. People have more time up here.*

While most participants claimed to have reasonably healthy social networks, social isolation was a common theme in the interviews. Max, for example, talked of his initial loneliness and isolation when he first moved to the area:

*When I moved up here, I was extraordinarily stressed. I then, you know, got a diagnosis I wasn't expecting [results indicating treatment failure]. I then got physically very, very unwell. I was very isolated. The usual horror story of*

<sup>8</sup> See findings on attitudes, participation, and interpretations in relation to 'community' in Davis, R. *PLWHA, Gay, Lesbian and Transgender Community Survey results, 2001*. ACON, Northern Rivers (pp. 16–21). Thirty-two per cent of respondents answered 'Not at all' to the question 'How connected is your local community?' (46% answered 'satisfactory'); and 35% answered 'No' to the question 'Are you happy with your level of attachment with your gay, lesbian and transgender community?' (65% answered 'Yes').

<sup>9</sup> That 'peer support group' was mentioned as an important part of social networks was undoubtedly influenced by the fact that most of the participants in the study were recruited through peer support networks. See Davis, R. *PLWHA, Gay, Lesbian and Transgender Community Survey results, 2001*. ACON, Northern Rivers. When asked to describe 'your community', survey respondents gave a wide variety of answers: 'diverse'; 'scattered'; 'friends and neighbours of all sexualities'; 'friends, colleagues, service providers'; 'closeted'; 'accepting and tolerant'; 'bitchy, gossipy, nasty'; 'fragmented'; 'like-minded people'; 'What community?'; 'queer'; 'insular'; 'I have none'; 'virtually non-existent'; 'broad'; 'lonely'; 'supportive'; 'bitter and twisted queens'; 'disjointed'; 'My community incorporates all!'; 'an eclectic bunch'; 'I have always had problems with the idea that I belong to a single community', etc. (pp.104–106).

*moving up here, you know, moving up here without really realising what it was about, but knowing that if you wanted to move up here you most probably had to just jump in the deep end. So, the first year was pretty difficult.*

A number of service providers to whom I spoke in Lismore mentioned what they saw as a common problem: people with HIV moving to the Northern Rivers with high expectations and hopes of a better life and better health, only to find a lonely life on some secluded property in the hills, which often resulted in excessive alcohol and drug consumption and deterioration in physical and mental health. Vincent spoke of how he had headed down that path when he first arrived:

*Well, it's sort of isolated. I was on my own. I knew no one up here when I moved here. Although I quickly met people through the tennis club that I play with, I may have been a bit lonely and I was drinking, more than I ever had in Sydney—because I wasn't working, except out on the property. So I basically had more time. I was around the house. The alcohol was there. And sitting night after night on your own, 'Hey, let's have a drink.' So, I did and I think that may have caused my liver to finally say, you know, 'Slow down.'*

Many participants, however, spoke of social isolation not in relation to their own experience, but anecdotally as pertaining to the region generally or, in some cases, friends and acquaintances. In other words, it was broadly seen as a common local problem.<sup>10</sup> Stuart, who himself was quite socially active, said the following:

*Just in terms of support, just having somebody to call up and call around. I mean, I think a lot of people leave their social networks in Sydney to move up here for the better lifestyle, but it means they've lost their whole social network ... You have to make this whole network of new friends and stuff and I just think it's very difficult. There needs to be some support around that stuff. Because I think people are, a lot of positive people are moving away from the city, because they want a less stressful*

*lifestyle. And yet they're moving to a rural area and there's no support, and, yeah, it can be very difficult.*

Those who spoke about isolation from a personal perspective usually did so in terms of past experiences, as with Max and Vincent, or else tended not to be involved in the local peer support group. Nathan, a heterosexual man in his mid-20s, spoke at length about not fitting in either in the straight community or among other positive people.

*The health side of it isn't as big a concern as the social side. It's just being positive heterosexually around here; it's as if I seem to be the minority of a minority group. And that plays on my, sort of, depression and self-esteem too. Because it's—a lot of guys my age, they sort of have one girlfriend after another. And, like, I like female company and then it's hard to know when to tell them to back off or, you know, it's either disclose to them or just let them sort of drift off by themselves so I don't have to tell them. So, that's harder than, more than any medical stuff at the moment ... There's a lot of outings and workshops and talks and discussion groups. And it's either all in Sydney or with the gay and lesbian community up here. A lot of it's to do with just social, a social outing, social groups, networks. And I just don't have, I don't seem to have anyone I can sort of talk to that I can, that understands. Like a lot of people, they're understanding about my condition, but they don't sort of know what it's like to be that way ... A lot of them say, like, when they find out, like face to face, they say, 'Oh, that doesn't bother me.' But then, you know, I don't see them again, or I only see them in passing. A lot of friends have dropped off. They'll still say 'hello' but that's it. They don't, they don't ask what I'm doing, they don't invite me to their place or they don't come up to my place ... A lot of the time I do feel isolated.*

Nathan's account raises important issues around the lack of peers and support that some people with HIV may experience.<sup>11</sup> It also raises issues of HIV stigma and disclosure generally for people with HIV in regional areas.

<sup>10</sup> Isolation was the fourth most cited health concern (after HIV/AIDS, relationships, and depression) among gay men in Davis, R. PLWHA, Gay, Lesbian and Transgender Community Survey results, 2001. ACON, Northern Rivers, p. 39.

<sup>11</sup> Since the time of the research, a support group for HIV-positive heterosexuals has reportedly been established in the Northern Rivers.

## DISCLOSURE AND HIV STIGMA

Most participants said that HIV stigma and disclosure were of greater concern in Northern Rivers than in the urban environments where they had previously lived. This concern was largely based on a perceived lack of understanding and knowledge on the part of the local population, or what some referred to more bluntly as 'redneck' attitudes, as illustrated by these two quotes:

*I think some people are less accepting, and I think simply some people have, just haven't had any contact with HIV-positive people, and really don't know a lot about it. And that's not impugning them; it's just they're country people and they just haven't been around it. (Leroy)*

*I mean, in Sydney I will stand on a podium and say, 'I'm [Walter], I'm HIV-positive, I'm a gay man', blah, blah, blah. I'm not likely to stand in the middle of the street here and do that. And that's because it's the country. There are rednecks around, you know. But I haven't been confronted with the problem. I just think it's more sensible not to, you know? Everybody I meet will know sooner or later that I'm gay and that I've got HIV. I'm not hiding it. (Walter)*

While most participants dealt with potential stigma by choosing not to disclose their HIV status other than to a few friends or peers, several men stated that the issue of how to negotiate disclosure in a small community and when accessing services was a common topic discussed in the peer support group, something which often confronted or surprised newcomers. Leroy stated:

*When I first came up here, like, a lot of guys didn't like being seen walking into ACON for that reason. Because someone, a neighbour, might be driving along the road, and up here everyone knows what sort of car you've got and they can see, 'Oh, there's your car, parked outside ACON. Oh, why were you in ACON?' and stuff like that. And a lot of meetings we've had here, exactly about that subject, about disclosure, and how they don't like anyone to know, apart from their HIV peers I suppose, that they're HIV, whereas in Sydney it was quite different ... A lot of the local boys up here have a really big thing about disclosure, whereas for us, when we came up from Sydney,*

*it wasn't such a big thing, because living in a big town people are used to it really ... In Sydney, I didn't really care, actually. I could sort of blend in or get away with it or not have any problems. I never had any problems with it in Sydney. But it's different up here. I guess, in some ways, even I feel a little bit vulnerable, too, living out in the country. I don't want our neighbours to know. It's none of their business and being a small place it would get around, and there would be some ignorant people who think they're going to catch it living up the road from me. I don't know whether people still think like that, but probably some might up here, who knows! So, yeah that's a bit of an issue.*

Like Leroy, most participants, when moving to the Northern Rivers, were made acutely aware that disclosure and stigma were generally seen as significant issues in the area. As a result, they often became more cautious in their interactions with the local population and with various government and health services. However, some newcomers decided to simply carry on as they had when they lived in the city, like Ethan:

*I know it is a big issue in the country for people who were brought up in the country and people who have been up here for a long time. Just from meetings that I've been to. They find it very hard and confronting. They have to go to social security and something has got to be brought up, they find even that confronting ... When I first moved up here I was a bit hesitant, but I found just different sections of the hospital quite fine with it. Different departments, government departments that you have to deal with, people being pensioners and things, that's been brought up quite a lot from the people that have been in this area for a long time, or grown up here, that they still find it very difficult, whereas I don't find it confronting at all. If it comes up, in an application or something like that, then, you know, I just say, 'Yeah, yep'. If they [service providers] have a problem with it, then it's not my worry. That's the way I see it.*

Many participants, however, agreed that the community of Lismore, one of the larger towns in the region, was generally quite accepting. It was interesting to note that, during my stay in Lismore, the names and photos of several of the men from the peer support group appeared on the front cover

of the local newspaper in an article about the National AIDS Awareness Week and the AIDS Memorial Quilt on display at the Lismore Base Hospital. According to a couple of people I spoke to who were involved in the event, there were apparently concerns raised within the hospital itself, including an alleged petition to remove the quilt. However, the article itself, which was one of the first of its kind, did not appear to create any problems for those who had publicly 'outed' themselves. As Alexander commented: 'The further west you go it's a bit more redneck. But people [in Lismore] don't, they don't seem to care. Like the front cover of the local paper today has got gay front page.'

Only a few of the participants said they had experienced overt discrimination in relation to HIV.<sup>12</sup> The most explicit account of stigma and discrimination was given by Nathan, a young local man with a background of injecting drug use. He said that his HIV status was well known among other users in the area following years of circulating rumours, after he had been outed by a former girlfriend. Not only had this resulted in significant loss of privacy in Nathan's everyday life in the community, but it had also resulted in several instances of threats and physical bashings:

*An ex-girlfriend of mine, who, when I was diagnosed, at the time, like, she knew that I, she found out. And out of spite she told a lot of people, and it's spread since then. Like, I've had people come up to me on the street, who I've never seen before, and they've asked me, 'Are you the one that's got AIDS?' ... [It] doesn't make me feel very good. And it seems as though that's how they know me: 'Oh, you know the one that's positive?' 'Oh, the one that's got AIDS?' ... It doesn't do much for your self-esteem, you know? I've been named, that's the reason, that's how they identify me ... And I've had, I've been threatened a few times, [I've] been run out of town ... Their idea is,*

*'Oh, we've got to shoot up in the same town as you'. Well, what's that got to do with it? 'Oh, we don't want infected people like this', you know?*

While Nathan's situation was different from that of the other participants in that he did not have the support of understanding peers, there were also similarities. When issues to do with stigma were raised by participants, it was not always in terms of the broader community but, as in Nathan's case, often in relation to a specific social group. Several participants spoke of widespread discrimination by local gay men towards HIV-positive gay men in the area. This is what Leroy said:

*[T]here's discrimination within the gay community to HIV-positive people as well ... I found, like, with a lot of local boys that have been up here all their lives, they're a bit insulated from any HIV-positive people ... It's just some of the local boys, I find, you know, not part of the HIV peer group of course, but, you know, sort of more the young gay country boys, haven't had much contact with it and I'd dare say would freak out a little bit.*

Both Leroy and Ethan talked about how stigma and discrimination against men with HIV figured in local gay circles, through rumours, 'talk', and sly comments at the pub, such as 'Don't go home with him; he's positive', or 'Don't touch him; he's got AIDS.' They argued that social avoidance and sexual rejection were common. 'It's like they don't want to be around anyone who's got it in case they catch it', Ethan said. For many of the participants, this environment intensified the difficulties of negotiating disclosure in casual sexual encounters. The risks of disclosing to a potential casual partner in a small community where there was little anonymity and much talk were considered high. 'Yes, because they would go and tell their friends for sure', Leroy explained. Most of the sexually active participants said they used a condom when having casual sex, a practice that they felt released them from having to disclose their status. Many of the participants did not have casual sex, not only because of barriers posed by stigma and disclosure, but also for reasons to do with depression, lack of suitable venues, and travel distance.

Overall, the participants were relatively circumscribed and careful in terms of disclosing in social and sexual situations. I was repeatedly told

<sup>12</sup> See findings on homophobia and discrimination in Davis, R. *PLWHA, Gay, Lesbian and Transgender Community Survey results, 2001*. ACON, Northern Rivers. Forty-nine per cent of survey respondents said they had experienced some form of discrimination and harassment (name-calling, gossip, verbal threats, physical abuse, denial of service, etc.) relating to their being gay men in the Northern Rivers (pp. 42–43). Sixty-seven per cent of respondents with HIV said they had not experienced any type of discrimination or harassment relating to their HIV status. Of the 33% who said they had, many cited instances of discrimination in relation to service provision (pp. 67–68).

that people would often be friends for quite some time before feeling ready or sufficiently safe to disclose. During my visit to Lismore, one particularly revealing incident underscored the secrecy around HIV and how confronting issues to do with disclosure can be. While I was conducting the research, all the interviews were organised in collaboration with ACON and were carried out at the ACON premises with the participants' full understanding and consent. One day, a staff member who helped to organise interview times showed me the interview list and pointed to a name saying, somewhat puzzled, that he was not sure if the person in question 'qualified' and that I should perhaps ring him to make sure. However, everything was perfectly fine; the man (who was not recruited through the peer group) arrived for his interview and told his story of living with HIV in Northern Rivers. After the interview the staff member shook his head in disbelief, saying that he'd had dinner with this man several times 'and he never told me'. Not only does this incident point to the level of confidentiality seen as necessary by some positive people living in the region, even when among peers, but it perhaps also suggests a certain implicit expectation that people with HIV will automatically trust one another and disclose to one another.

## HEALTH, HIV TREATMENT, AND COMPLEMENTARY THERAPY

The majority of research participants had been HIV-positive for a long time, with a median of 13 years, but only a few had experienced HIV-related illness in the past. Most described their current health as 'good' or 'fine', and some felt that their health had improved since they moved to the Northern Rivers. While a couple of the men were struggling with serious conditions such as cancer and vascular necrosis, overall, the most commonly cited HIV-related health issues were low energy and side effects from antiretroviral therapy. Besides lipodystrophy, which was a focus of the study, the most common side effects included diarrhoea, closely followed by nausea, fatigue/tiredness and, to a lesser degree, peripheral neuropathy. Six participants said they had experienced mildly unpleasant to severely debilitating psychological effects from taking Efavirenz, with one man attempting suicide as a

result. Four participants were co-infected with hepatitis C, including both heterosexual men. Of these, only one man had been on treatment for hepatitis C. Apart from matters associated with these viruses, one of the most frequently mentioned health issues was that of mental health.<sup>13</sup> Eight of the 17 men reported a history of bipolar disorder, severe depression and other mental health problems. Most said their condition pre-dated HIV, though many felt it had been worsened by their HIV diagnosis. Several of these men stated that their mental health problems were far more difficult to cope with than the HIV. Max was one of them:

*Mental health just does me in. I'm an incredibly unstable person that lives with major depression, who can, you know, be really, really well, or I could be really, really sick and a pain in the bum. And, you know, that just seems to have been quite a predominant feature since moving up here. Particularly the last four months, I haven't been that well ... I struggle with maintaining a stable, you know, stable frame. But physically, yeah, I'm pretty lucky, I think ... My saying for depression is that it beats HIV hands down. HIV is a breeze. In fact, having major depression made living with HIV much easier. I got it into a perspective [laughs]. So, yes, that's my view on depression. HIV any day, thank you very much!*

Of the 17 participants, seven were not on any treatment for HIV at the time of their interview, though all of them had been in the past.<sup>14</sup> Most of the men had long and complex histories of HIV therapy. Changes in treatment combination were common due to insufficient virological response, adherence difficulties and side effects. Problems with a variety of side effects were by far the most common reason for stopping treatment, though a few mentioned viral resistance as an issue, and one man said he had to stop for medical reasons

<sup>13</sup> Depression was the third most cited health concern (after HIV/AIDS and relationships) among gay men in Davis, R. *PLWHA, Gay, Lesbian and Transgender Community Survey results, 2001*, ACON Northern Rivers, p. 39. For HIV-positive respondents, depression, anxiety and mental health problems were the second most cited concerns (after treatments/side effects), p. 59.

<sup>14</sup> This corresponds with findings in Davis, R. *PLWHA, Gay, Lesbian and Transgender Community Survey results, 2001*, ACON Northern Rivers. Forty per cent of survey respondents said they were not currently on HIV treatments.



while on treatment for hepatitis C. Concerns about developing lipodystrophy also influenced decisions to cease antiretroviral therapy, as did positive feedback from others who had taken drug breaks or 'holidays'.

Three of the men who had discontinued HIV therapy said that they had no intention of starting again and would only consider doing so if their health deteriorated significantly. Two of these men stated that their viral load was still undetectable after two to three years without any treatment. The others described their decision to stop as more of a temporary measure to resolve side effects and to give their bodies a 'break' from the drugs. While the Northern Rivers participants seemed to be similarly informed and knowledgeable about HIV treatments when compared to the participants in Sydney, they seemed to have a greater tendency to experiment with their regimen and dosage, and a greater readiness to stop treatment or take breaks.

Perhaps surprisingly, considering the region's renowned 'alternative' culture and lifestyle, a majority of participants did not use complementary therapies.<sup>15</sup> One obvious reason for this was the prohibitive cost of such therapies when living on a pension, but many also said they were not particularly interested in or convinced about the benefits, as illustrated in these quotes by, firstly, Stuart and, secondly, Ethan:

*I mean a lot of these things are wonderful, all this herbal stuff, but it's also expensive. And if you're on a pension, you try to—it's just too much to pay for all this, you know. You can have all these, you know, acidophilus tablets and stuff like that, but it's just too—it's twenty-two dollars for, you know, for a thing. And twenty-two dollars out of your pension is a lot of money.*

*I'm not one really for the complementary therapies, apart from massages. Yeah, I don't think anyone would say 'no' to a massage! But, yeah, some people suggested I try yoga and different other type of things. But I just find I, other things like that, I'm not interested. And you've really got to want to do it for it to have some benefit to you.*

<sup>15</sup> This finding is different from figures presented in the second part of the report and may simply be a result of sampling.

However, those few who did use complementary therapies were heavy users and highly committed to predominantly vitamins, supplements and herbs as an integral part of their health management. Only two participants practised some kind of 'spiritual' technique such as yoga and meditation on a regular basis, while one referred to himself as a Buddhist. However, several men subscribed to a general kind of New Age discourse of holistic health and 'positive thinking'. Participants who were engaged in these 'alternative' practices and ideas included men who were taking treatment as well as those who were not. They did not tend to be more (nor less) critical of HIV therapy than those who did not draw on complementary therapies or alternative ideas.

The health management routine of many participants consisted of going to the gym and regular, mainly outdoor, exercise such as surfing, swimming, running or walking on the beach, and gardening.

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## REGIONAL HIV HEALTH AND SUPPORT SERVICES

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Issues to do with services in the area were a recurring topic in many interviews. Most participants agreed that there was a lack of HIV-related services, both health services and support services similar to the Community Service Network (CSN) in Sydney. The limited choice of doctors and the lack of local GPs with HIV experience were major concerns, as were the lack of professional expertise and home care in the event of declining health. In late 2002 there were hardly any GPs with HIV experience available in the region and only a few S100 prescribers. Most participants accessed the sexual health clinic in Lismore (SHAIDS), often out of necessity as much as by choice. When I visited the area, an extremely popular GP with a heavy HIV case load had recently given up his practice (burn-out was widely thought to be the cause), much to the grief of his patients, many of whom I interviewed. Stuart was one of them:

*I mean, that's one of the problems with living in a country town, is, you don't have much choice. You've got SHAIDS or that's it! Well, for a long time we had SHAIDS and then we had a GP who came who was doing HIV. So,*

*most people moved, left SHAIDS, and went to him, because they weren't happy with their service. And then, then we all had to go back to SHAIDS once he, because he decided to go into another field. And he was really good. He was just like, it was probably the best relationship I've ever had with a doctor, because you felt like he was a friend, as well as a GP. That's very difficult.*

Unlike Stuart, most were very happy or reasonably happy with the doctors at SHAIDS, saying they did their best under the circumstances. But the clinic was generally seen as severely overstretched, straining to meet the needs of the HIV-positive population in the region. Some felt this impacted negatively on the quality of care available, or found their health needs beyond HIV inadequately met. In addition, many mentioned having to wait several weeks for an appointment to see the specialists at SHAIDS. Denton commented:

*That was one thing when I moved up here was that I did not have a GP that I could discuss my HIV treatment with, whenever I was going to the doctor for any health issue. There was a SHAIDS clinic here and there were specialists, you know, HIV practitioners, but they made it clear that they didn't want to see you for non-HIV-related health issues, 'cause they were pretty stressed and the clinic was overutilised. And there were big notices up in the waiting room.*

These professional constraints had significant consequences for some. Corey told how his HIV had become resistant to three classes of anti-retroviral drugs, in his view a result of a number of inadvertent oversights and complex events:

*I think having more practitioners—because the ones we have are under an enormous amount of stress because they have such an enormous workload. And sometimes things get missed, like what happened with me. So, I think having possibly more people in the area, professionals in the health care industry that could alleviate some of that, would help.*

This lack of available services, general practitioners and specialised expertise in the Northern Rivers was not mentioned exclusively in relation to HIV, but was seen as a problem across the board, with mental health being singled out by

many participants as particularly wanting. Merlin, for example, observed:

*I think that's the scary part. There is no service out there for people with mental problems and what do you do? ... I mean, there's nowhere to turn to. Especially up here. And, if you can turn somewhere, who's got a hundred and fifty-one dollars to go and see a psych? You know, if you're one of the lucky ones and find one who'll bulk bill.*

It was quite common for the participants to stay in touch with their former doctor or health practitioner in the city where they had previously lived, such as Sydney or Melbourne. They would call on these practitioners when faced with complicated medical issues or decisions, and would go to see them at their clinic when visiting the city. One reason for this was the perceived paucity of expertise in the region, but another reason was the desire to get as much input and advice as possible, especially from medical professionals familiar with their case history. Max explained his arrangement:

*I think most probably for big decisions I'll keep the relationship going with Sydney. I do like that guy. And up here's just monitoring. But for any big decisions, I'll be going down there. And it's got nothing to do with the quality of the service up here. It's just I'm very—I think these are important decisions. If I'm going to take highly toxic drugs, I want to feel as comfortable with it as I can. And part of that comfort is my interaction with my practitioners. So, while there's a choice I'll be going down there, you know.*

The participants seemed divided over the issue of insufficient services. Some argued that this was to be expected in a regional area, or that the available services were pretty good all things considered, while others felt that more money and resources should be allocated to the region taking into account the growing population of people with HIV.

There was also some division among the participants over the perceived role and responsibilities of the local ACON. The AIDS Council was commonly praised for its 'excellent' retreats, for its peer support group, and for the level of knowledge and engagement of its staff, particularly in the areas of social work and HIV

treatments. A small minority was scathing in their critique of what they referred to as ‘too much politics and bullshit’ and what they saw as a lack of hands-on, everyday support and assistance for positive people who were sick or had limited ability to care for themselves.

In relation to these contrasting views on ACON, one theme that was frequently and passionately raised in many of the interviews was that of the so-called ‘whingers’. This was purportedly a group of positive people who were seen to habitually make unreasonable demands and complaints, unduly causing ‘troubles’ and tension. There was a great deal of frustration directed towards this group generally, while two interview participants who thought they might be seen as part of this group said they felt silenced and vilified. At the time of the research, the issue seemed to be a considerable and complex one for both the local AIDS Council and the community. This tension is likely to be a reflection of a number of knotty issues—not only the changing dynamic of the epidemic, but the fact that the local ACON is the only HIV organisation in a large geographical area, making it difficult to meet all the demands and needs of a growing and dispersed positive population, and the fact that these constraints, which are frustrating for everyone involved, are played out in a small community where conflicts easily become personalised (see Appendix 1 for changes at ACON Northern Rivers since the time of the research).

## LIPODYSTROPHY

As described in the introduction, one aim of the study was to investigate how particular cultural and geographical environments influence body image and lived experiences of body shape change. At least 14 of the participants reported some degree of body shape change, with eight men reporting major symptoms. Some had had lipodystrophy diagnosed by a medical professional and some had not. While there are certain clinical methods to determine the symptoms and severity of lipodystrophy, body shape change is highly subjective and people’s personal experience and knowledge of their bodies may not always coincide with clinical interpretations. Nor are these physical changes always obvious to other people due to lack of expertise or unfamiliarity with the person

and their previous appearance. And nor is there necessarily a straightforward correspondence between severity of symptoms and severity of impact on people’s lives. Unexpected and unwanted physical change, no matter how subtle, can be distressing in and of itself and produce feelings of uncertainty and loss of control: What is happening? Where will it end? For these reasons, the participants were asked to describe their symptoms to get a sense of how they themselves perceived their bodies. Their descriptions included most of the ‘classic’ symptoms of lipodystrophy such as facial fat loss, distended belly, slender limbs, protruding veins, and generalised wasting. Most believed that antiretroviral therapy was the cause of these symptoms, but many also mentioned ageing as a related factor, saying that the drugs had accelerated and altered the natural ageing process. Their emotional and social experiences of lipodystrophy were both similar and different to those of the participants in the urban arm of the Side Effects and Lipodystrophy Project.

### A SIGN OF HIV AND SICKNESS

Concerns that lipodystrophy, in particular facial fat loss, could be seen as a ‘sign’ of HIV and sickness were common to both groups. Among the Sydney participants, this sense of forced disclosure was primarily a concern in relation to gay community because of a widespread perception that lipodystrophy was well known in that social domain. The Northern Rivers participants also believed that most gay men would be familiar with the physical features and implications of lipodystrophy, a troubling notion to some due to the perceived stigma of HIV in the region, as Lewis and Ethan explained respectively:

*It changes how you feel about yourself, because it changes how you look. And it can also be, in the gay world—it sort of can also be quite a giveaway. We all know why people have got lipodystrophy. People don’t get lipodystrophy for nothing. So, if you see someone naked or semi-naked, or you see some symptoms, you know that they’re on antivirals. So, it’s a bit like, sort of, it’s a bit like advertisement in the gay world, ‘Hey! I’m on antivirals!’*

*Gay community, most of them know ... And I suppose in some ways, I don’t want the gay community as a whole to know that I’ve got*

*it, just from the fact that there is still a lot of stigma out there, even in the gay community I've found.*

However, in the Northern Rivers, the feeling of being 'outed' by one's own body was a significant concern also in relation to the broader community for a number of reasons. As mentioned earlier, there was a feeling that local people were 'really straight' and less accepting or less understanding than in cities. Thus many participants felt a need to carefully protect their HIV status. While most did not believe that the broader community knew about lipodystrophy and body shape change, many were concerned that people might think they looked 'sick' because of a sunken face or wasted body, or that they might think 'that there is something wrong with you'. This is how Leroy expressed it:

*I think people can, even if they don't know it's the virus, they still know that it looks like there's something seriously wrong with you. And I don't want people to know that about me. You know, my friends are different, but just people—acquaintances or tradesmen that you meet or people you have business dealings with. Yeah, I don't want them to know ... Simply because people can tell there is something wrong with you and will treat you differently.*

The Sydney participants believed they 'stood out' by virtue of living in a 'knowing' community, a community well aware of lipodystrophy. The men in the Northern Rivers arm also believed they stood out, but for different reasons. Many thought that lipodystrophy, or any kind of difference, was likely to be more noticeable in the Northern Rivers than in Sydney because of the higher degree of visibility and 'talk' that comes with living in a smaller community. In this regard, wasting and facial fat loss were clearly thought to be more noticeable than a distended belly which, some participants noted, would most likely be seen by most people in the region as a common beer gut. Leroy reflected on how loss of anonymity was the price or disadvantage of wanting to live in a more intimate community:

*Up here it's—the whole town can see that there's probably something wrong with you, whereas in Sydney, people probably wouldn't*

*take as much notice. Yeah, I suppose being a smaller town. That's the main thing I've noticed—is adjusting to being in a smaller town where you go to town and you're bound to run into a few people you know, whereas in Sydney, it's quite often not the case, simply because of the size. Yeah, and that isn't always a good thing sometimes. But then, for myself, that's what I wanted. I wanted to be in a community where I knew—a closer-knit community, whereas I didn't have that in Sydney. So, it's a two-edged sword really, isn't it?*

However, while many felt their body shape changes made them 'stand out' in the local landscape, they also observed that it was easier 'to hide' in the country than in the city, a dynamic that made it both easier and more difficult to have lipodystrophy in the Northern Rivers than in an urban environment, according to several participants. One of them was Vincent who described his body shape changes as overall weight loss and facial wasting:

*In some ways it's probably easier and in other ways it's harder. I'd say it's easier because you can, depending where you live, isolate yourself, if that's what you need to do. It's probably harder because there's less people like you around. And there's less people around overall, so you probably are more visible than you would be if you were walking around, you know, Oxford Street or Darlinghurst area.*

Yet, as Vincent pointed out, the negative consequence of 'hiding' as a way to deal with lipodystrophy was increased isolation, especially in an environment where people often had to work hard at building and maintaining their social networks, as mentioned earlier:

*It's not as if I think about [lipodystrophy] all the time, but it does have an effect. It does, as I speak to my counsellor about, make me feel like wanting to be a recluse ... And I think, in some ways, cutting myself off is not a good thing for, obviously, maintaining relationships with people. Like, people keep asking me, you know, 'Come around', and you keep saying, 'No, no, no'. Then there'll come a day when they won't bother asking you again. So, I do try ... All I can say is, if it gets any worse, I can see myself becoming more isolated. Because I just won't feel comfortable. Except by being*

*around people I already know, that have seen the changes happen to me.*

## BODY IMAGE

Among the Sydney participants, forced disclosure, body image, and loss of 'looks' and sexual desirability were the most frequently raised issues around lipodystrophy and were largely conceived as concerns within the context of gay community. As shown, forced disclosure was a concern for participants in the Northern Rivers as well, not only in relation to other gay men, but also in relation to the broader local population. However, in contrast to what many Sydney participants referred to as the body-oriented Sydney gay 'scene', body image was seen as *less* of an issue among the men in Northern Rivers. In fact, several men thought that issues around lipodystrophy were *different* in Sydney compared to the Northern Rivers precisely along these lines, as typified in this quote by Ethan:

*The way I see it, people in Sydney, it's more a fashion type thing. Whereas up here, it's more, people know that you're sick or something, when you're up here. So it's just kind of, I see it on the same, but on a different level ... Body image more in Sydney and disclosure and the likes of that up here.*

For this reason, they generally believed it was easier to have lipodystrophy in the Northern Rivers than it would be if they lived in Sydney, citing what they saw as a strong emphasis in the urban gay community on a body ideal defined by 'healthy-looking' muscularity, fitness and youth. Stuart, who experienced fat loss from his face, buttocks and legs, said the following:

*I suppose I'm not so aware of it. I was very aware of it when I was in Sydney, because it's sort of—there's the whole image stuff and, yeah, it sort of—I got a bit depressed about it all down in Sydney. But I don't notice it so much here, people just, people treat you as you ... I don't think people are aware of it. I mean, the general community up here isn't aware of it. And I suppose that whole, you know, the whole image stuff is much stronger in Sydney than it is up here. I mean, a lot of the gay men up [here] aren't into going to the gym and looking beautiful. It's, you know, and a*

*lot of the guys who are up here are older guys anyway, so there's—It's just, it's just a very different scene really, compared to Sydney.*

This lesser concern with body image was often explained with reference to the supposed lack of emphasis on 'looks' and appearance in the local community in general and also with reference to the renowned 'alternative' culture in the region, which was seen by many as being more inclusive and more accepting of difference. As Alexander put it: 'Nobody gives a stuff what you look like. So, in that regard it's, you know, it's a great place.' Corey gave a description of his friends to illustrate the relaxed attitude to body image in the region:

*I know so many various types of people [laughs]. It's like, I've got hairy friends and fat friends and skinny friends and gorgeous friends and, you know, it doesn't bother me. Body image, here, doesn't seem to matter. Again, like I said, it's purely about a person.*

However, a couple of the men disputed this notion, saying that the emphasis on body image and a particular body type was not much different among gay men in Northern Rivers than it was in certain sections of Sydney gay community. Leroy was one of them:

*Sydney is really full-on, the 'body beautiful' thing, but, oh yeah, up here as well, yep. If you've got a good body, you're going to be paid more attention to. No two ways about that one. And if you're in shape and look like you're healthy and muscly, everyone wants to get to know you, it seems. But, you know, that's just part of the gay community, I think, very body conscious.*

On a more general note, Ike argued that any distinction between the Northern Rivers and Sydney was basically illusory because the local population of gay men was largely made up of expatriate urbanites:

*This is the upper, upper, upper north shore of Sydney ... This place is full of the champagne Buddhist set, the retiring boomers with money ... This is not the country.*

But most of the participants felt there was a distinct cultural difference. Many commented that common measures of social status in Sydney such as wealth, occupation, possessions and appearance were of much less importance in the Northern Rivers. 'People don't look at a person for what they do, what they wear, how they look', Corey said. 'It's about the person generally, which is so much more accepting.' While they did not dispute the obvious urban imprint on specific local expressions of lifestyle and attitude, they insisted that the generally tolerant and 'progressive' mind-set which partly defined the region was precisely a result of the fact that many urban people who moved there brought with them those kinds of values and sought an alternative life, as Max put it:

*I think people come here for a particular reason and they come here because, you know, it's that gentleness I spoke of before. I think people are more interested in you as a person as opposed to their projected view of what they like. So, they're more accepting. I think people generally have a gentler view of other individuals up here. A lot of people have come from larger cities. So, they're aware, for the most part, of wanting to live a different life, you know, that notion of alternate, alternate being anything that's not part of the dominant culture. So people have a vested interest, I suppose, in behaving and acting and thinking in a different way. You know, they've made significant choices in the move up here. Yeah, you know, I mean, I get quite surprised with comments that people make about the gay scene in Sydney and the willingness to write individuals off because of how they look.*

Yet, in many of the interviews, there was a tension between this emphasis on the relaxed and accepting attitude to body image in the Northern Rivers and the participants own experience of body shape change. Most were clearly troubled by their changing appearance and described lipodystrophy as 'unattractive' and 'horrible'. Concerns with the way they looked often had a negative impact on self-esteem and tended to be tied up with a dread of ageing, here expressed by Lewis who said his body shape changes included excess belly fat, 'definite' fat loss from legs and buttocks, and 'a little bit in the face':

*Suddenly, when your body distorts, it can have a significant emotional effect on you. 'Oh, God', you know, because it's particularly, how can I say it, it's reminiscent of men as they get older. It's accentuated and it has also accelerated it. And by doing both those things, you're sort of 'Oh, my god. I'm half way to the grave' ... It has an effect on the way that you feel about yourself, you know, in the sense that you don't feel as good about yourself.*

The participants grappled with this tension between their personal discomforts with lipodystrophy and not wanting to be, as Leroy expressed it, 'too caught up in vanity'. There was a sense that feeling bad about lipodystrophy or about one's inability to conform to a dominant body ideal was incongruous with the particular cultural milieu in which they lived. Denton described this dialogue with himself:

*You know, half of me says, you know, you can't possibly be so shallow as to have—to place such importance in your body image that you think that because you might be, you know, changing in some way that that's going to make you less a person. But I'm faced with the fact that I am discomforted.*

Some participants had tried to address lipodystrophy by changing or stopping their anti-retroviral medication. Some went to the gym regularly in an attempt to alleviate or stave off symptoms such as big bellies and to build up muscles to replace loss of fat from buttocks, arms and legs. They also went to maintain cardiovascular health, a common problem in lipodystrophy. Only one participant had had New-Fill treatment for facial fat loss and there was markedly less awareness of New-Fill among the Northern Rivers men than among the Sydney participants.

## SEX AND RELATIONSHIPS

In many of the interviews, lipodystrophy was construed as a sexual rather than a social issue. In contrast to their perception that the importance and anxieties of body image were mitigated by the 'alternative' local culture, it was in discussions of relationships that the notion of lipodystrophy as unattractive and problematic arose most regularly and most prominently in the participants' stories. For many of the men, the problem of relationships was compounded by ageing and the broader issue

of HIV stigma in gay community. Stuart, for example, said the much-talked-about 'acceptance' and relaxed attitude in the Northern Rivers did not commonly extend beyond friendships to include sexual relationships or sexual attraction:

*There's a level of acceptance as in friendships ... But in terms of wanting to have sex with you, might be different. And I think that's in terms of being older and HIV. There's a stigma around that. So you can go out and, you know, go home by yourself, most of the time, which happens ... I suppose [lipodystrophy] is a marker too, that people know that you're HIV ... I think there is a lot of stigma and discrimination within the gay community around being HIV still. Especially in terms of sexual, you know—people don't want to sleep with you if you're HIV—and around relationships. I don't think people really want to have—people are fearful that if they're with somebody who is HIV, then they'll get sick and die and that whole process ... I mean I sort of understand that. But, yeah, it's really difficult.*

On the whole, the participants believed that other gay men inevitably found lipodystrophy unattractive, a sentiment many candidly confessed they shared, though not without seeing the cutting irony of it, as Max pointed out:

*Well, I don't find someone with lipodystrophy attractive. I'm not saying this is good, bad or indifferent. If there was a particular chemistry, then that sort of surpasses, you know, necessarily how someone looks unless, you know, maybe they're grotesque. But to be really quite honest, if I was looking for a root and someone had pretty major lipodystrophy, I don't think I'd be feeling particularly attracted towards them. So, I guess that's what it comes down to really, doesn't it? What does that say about you, when you are that lipodystrophy?*

Those who were in a regular relationship mostly said that lipodystrophy had not been a major issue in the relationship and generally felt that their partner was sensitive and supportive. 'He loves me just the way I am', Alexander said. In some cases, the partner also had lipodystrophy and the two of them would continually support each other. Leroy commented:

*My partner's pretty understanding. He still thinks I look good ... And anyway, similar things are happening to him. So I don't feel quite as bad [laughs] ... So, we are sensitive to each other's needs, and that's why it hasn't been a big issue.*

Only Corey, one of the younger participants, expressed fears that his partner might find him unattractive if the fat loss in his legs progressed any further, reasoning that his partner was 'obsessed with his body' and had recently stopped his own antiretroviral therapy when the veins in his legs began to protrude. This sense of lipodystrophy posing a challenge to intimate relationships was a poignant theme among participants who were single but who wanted a partner. For some, the compounding effects of lipodystrophy with a range of issues around HIV and health had made them give up any attempt to find, or hope of finding, a partner. Vincent said the following:

*I think, well, it's all got to do with your self-image, confidence. Why would anyone like someone like me, who's, you know, co-infected with two viruses? All that goes through my head. I don't, at times, don't feel worthy, I suppose. Nor do I have, or have had, the inclination or the desire. And that's, that's basically a lot to do with the [hepatitis C] drug treatment. And it's been increased by the changes in the way I look, the feelings of unworthiness, no confidence, no libido, all those, all those together. So I just don't think about relationships. I mean, I lie. I fantasise about it, but I never consider looking.*

## KNOWLEDGE AND SILENCE

There was a shared sense among the participants that lipodystrophy was rarely talked about, either among friends or within the HIV sector, or indeed within relationships. 'No one ever has the guts to say anything', Walter stated. Some commented that lipodystrophy had been brought up in the peer support group on a few occasions, and some had spoken to a counsellor, but many told me they hadn't really talked about it in depth with anyone prior to the interview. As Max said:

*You know, I think there's discussion about it and then most probably in a lot of counselling*

*rooms there's discussion about it, and we talk about it happening, but we don't necessarily talk about how we feel about it happening ... I don't know, I haven't experienced a lot of discussion, really meaningful discussion.*

Some of the participants thought that lipodystrophy was less talked about in the region compared to the major cities. However, a sense of social silence around lipodystrophy was a common theme also among the Sydney participants. On the other hand, less access or exposure to information about body shape change might account for the fact that the Northern Rivers participants generally had less knowledge and understanding of lipodystrophy than did their Sydney counterparts. While this might have partly contributed to lipodystrophy being slightly less of a theme and less of a problem among the men in the Northern Rivers compared to the Sydney men, it also meant that they generally had less awareness of its causes and development and of ways to manage the condition physically and emotionally. There was a patent yearning for more information among some of the men, such as Ethan who was experiencing fat loss. Here he talks about how he reacts when he sees other people with more pronounced lipodystrophy:

*It makes me stop and say, you know, 'I know you've got the virus and how sick are you?' It makes me start questioning things. Is this going to happen to me now that I'm on the drugs that create it? How are they coping with it? Do they want to talk about it? ... There's all these things that I want to ask them and just, you know, questions I want to ask and everything but, like, whether they want to talk about it—so I don't ask or, you know, I do and then I just sense that I may have opened up a can of worms for them ... Yeah, so a lot of times I don't ask where I should ask, because it's things that I need to know at the moment. A lot of the time when I see someone that I know has got it, or looks like they have it, yeah, I just want to ask questions, you know, 'How do you cope with it? How do you feel about it?'*



## DISCUSSION: LIPODYSTROPHY

While there was a tension in the interviews between the emphasis on relaxed local attitudes on one hand and concrete personal implications on the other, to some extent lipodystrophy and body image tended to be less of a problem among the Northern Rivers participants. The particular cultural environment in which they live is one likely reason for this. Less access and exposure to information and discussions on lipodystrophy may also play a part. While these factors might mitigate some of the challenges that people with lipodystrophy may face in urban environments, there is also a sense among the men in Northern Rivers that the issue of lipodystrophy is bounded by social silence and taboo to a certain extent, a sense that they share with their Sydney counterparts.

It should be emphasised that people experience and deal with lipodystrophy in different ways depending on their personal biography, their disease history, their social situation, and indeed the cultural and geographical environment in which they live. But, in light of the ongoing stigma of HIV, and a highly body-conscious society that shows little tolerance of body types that happen to fall outside the cultural ideal, it is no surprise that lipodystrophy is a socially and sexually isolating experience for many people affected by it, including people who might live in a cultural environment that is comparatively accepting and alternative such as the Northern Rivers. Yet, this often distressing effect of HIV therapy receives relatively little community attention. There are occasional articles in the HIV media discussing the potential causes of lipodystrophy or possible treatments for it (or lack thereof). And there are periodic reports from Australian and overseas conferences about the attempts by medical science to solve this conundrum. Or, in more rare and awkward instances, graphic images of lipodystrophy are used to scare young gay men into safe sex, as in a recent HIV prevention campaign by the Stop AIDS Project in San Francisco<sup>16</sup> which received some attention in Australia (e.g. Slavin, 2003; Persson, in press).

But, apart from these sporadic media or scientific commentaries, there is a curious silence around

body shape change, perhaps most poignantly in regional areas with less access to information and to a relatively cohesive and organised gay community. While lipodystrophy may be talked about among friends and partners, in peer support groups or privately with counsellors, there is an absence of broader debate that addresses what lipodystrophy means, not just for individuals affected by it but for the affected community as a whole. For something so visible, lipodystrophy is strangely invisible. 'It doesn't seem to be widely acknowledged, but yet you see everyone walking around with it', commented Adam, a 36-year-old Sydney participant who recently started HIV treatment and who was concerned that he might be developing lipodystrophy:

*I think there is all this avoidance about it. You don't have any role models and positive people with 'lipo' coming out and saying, you know, 'I have lipo and this is the effect it's had on me.' There's no educating younger people about what it's like to have lipo, you know. You hear about what it's like to be positive and all that stuff. But you don't hear about what it's like to have lipo ... There is a silence around it.*

Why this silence? Some study participants argued that they didn't want to make an issue of it or give lipodystrophy more attention than it deserved. Others speculated that lipodystrophy simply brought up too many difficult issues to deal with. Whatever the reason for this silence, it has a certain impact. Participants in both Sydney and Northern Rivers argued that finding support or people with whom to share their experience was generally quite difficult. Many hesitated to approach others with lipodystrophy, fearing that they might 'touch a raw nerve' or acknowledge its visibility, which was precisely what concerned people the most. For others, their own lack of support or unresolved issues around lipodystrophy made it difficult for them to reach out to their peers, despite the fact that they wanted to. One Northern Rivers participant, José, talked about this dilemma:

*I feel I should go up and say 'Hi', you know, 'How are you going?' I feel as though I should put my hand around them as though it's a shared experience. And I don't. I usually look the other way. I don't like it when I do, but I think it's because I haven't come to terms*

<sup>16</sup> Go to: [www.stopaids.org/about\\_us/archive/hiv\\_no\\_picnic.html](http://www.stopaids.org/about_us/archive/hiv_no_picnic.html)

*with it myself [that] I can't reach out to other people.*

In contrast to this silence, there is a flurry of activity around lipodystrophy in the medical domain. For a community that has long and actively resisted medicalisation, it is peculiar to note that both the problem of lipodystrophy and its solution have more or less been handed over to the medical profession. No doubt this entrustment of lipodystrophy to medicine lends it certain legitimacy as a serious problem deserving of scientific attention, perhaps offering a rightful sense of vindication after years of having body shape change dismissed as a mere 'cosmetic' concern.

But is this enough? Considering that body shape change is not only a medical problem but also a social issue, it might deserve some genuine community attention and soul-searching as well. Lipodystrophy is more than the sum of its metabolic complications. It is also about body image and sexuality, it's about HIV stigma and HIV survival, it's about the practices of pharmaceutical companies, it's about community, health, ageing, gender, and much more. Passing the problem on, wholesale, to medical science in effect depoliticises lipodystrophy and obscures the social factors that contribute to its significant impact on people's lives. Moreover, widely adopted medical terminology, such as 'abnormal', has a tendency to pathologise lipodystrophy and unnecessarily reinforce its already negative image. Representations of lipodystrophy as 'disfiguring' or 'bizarre' affect how it is experienced and perceived and thus limit the community's ability to forge alternative ways of understanding and seeing lipodystrophy, ways that do not marginalise people, rely on fears of HIV or ignore the realities of HIV treatments. As Alf, a Sydney participant, stated:

*People actually construe lipodystrophy as always negative, you know. It's not always negative ... It can actually be really nice sometimes.*

Referring to a sense of brotherhood in survival, he explained:

*To be, you know, on the dance floor at Mardi Gras or the Inquisition party and there's a whole heap of guys you're dancing with and*

*you look around and you think, 'They're all positive.' You know, that's great. Yeah, you can see it.*

In order to reclaim body shape change as something the community lives and deals with in constructive and supportive ways, there is a clear need to rethink and demystify lipodystrophy, for example, through education campaigns or projects that address and challenge the social issues at the heart of lipodystrophy and, indeed, HIV. Talking about lipodystrophy should be part of a wider need to talk about HIV in a time of a changing epidemic and rising infections, not in order to further stigmatise or demonise, but to truly (or truthfully) give HIV 'a face'. This kind of approach would build on, and revitalise, past achievements. While the work is far from complete, community activism has nevertheless been successful in gradually turning around perceptions and representations of HIV/AIDS in society at large. Why not lipodystrophy within its own domain? Lipodystrophy offers an opportunity for collective discussion, not only about body image but about HIV in general, and can serve as a catalyst for lifting silences around a range of issues (Persson, 2003b). This is particularly vital in regional areas where people with HIV do not have ready access to the kinds of social spaces and discussions that may encourage alternative ways of seeing lipodystrophy, as was related, for example, by Alf (above).

While this part of the report is partly intended as an overview of some of the issues facing people who move to, and live in, the Northern Rivers region, one major aim of the study was to address a gap in the research on lipodystrophy. The personal and social impact of lipodystrophy is extremely under-researched. Hopefully, the findings of this study will go some way towards providing much-needed understanding of the complex issues facing people who experience body shape changes and the ways in which social and cultural environments shape and mediate those issues. It is hoped that educators, health promoters and other service providers in the HIV sector will take up this kind of research to gain a different insight into the impact and experience of lipodystrophy. It is also hoped that some of the themes and issues around lipodystrophy high-lighted here will provide a basis for further research and for future health promotion programs.

## SUMMARY OF FINDINGS

### MOVING TO NORTHERN RIVERS

Almost all of the participants in this study had moved from an urban environment to the Northern Rivers region in search of a better, more relaxed lifestyle. Most were happy with their decision and had no intention of moving back to the city. The weather, the beautiful environment, the lack of stress, traffic and pollution, and the friendly, relaxed country ambience were seen as major advantages of living in the region, while the most frequently cited disadvantages included the lack of public transport, lack of employment opportunities, a shortage of health services and HIV expertise, the risk of social isolation and the difficulties of finding a relationship.

### GAY COMMUNITY AND SOCIALITY

The idea of a local gay community varied among the participants. There was a feeling among some that there was no 'gay community' as such in the Northern Rivers, while others described what they saw as either a 'fragmented' and 'disjointed' gay community, or relatively cohesive queer collectives or gay groups. Most said that their social networks consisted of a mixture of gay and straight friends, neighbours and peers. There was a definite tendency for those relationships to be with other urban expatriates, rather than with local people. While many agreed that building social networks took a long time because of the need to travel long distances and the difficulties of gaining access to established social groups, some also commented that friendships tended to be strong and genuine because people had more time and were more reliant on each other than in the cities.

### DISCLOSURE AND DISCRIMINATION

Disclosure was generally seen as a significant issue because of the perceived level of stigma and discrimination associated with HIV in regional areas. There was a tendency among the participants to become more cautious in their interactions with the local population and with various government and health services than they had been when living in a city. However, most instances of discrimination relayed by the participants were in relation to their own social community or group and to sexual situations involving local gay men.

### HIV AND HEALTH SERVICES

One of the most frequently raised issues in the interviews was that of regional services. Most participants agreed that there was a lack of HIV-related services. The limited choice of doctors and the lack of local GPs with HIV experience were major concerns, as was the lack of specialist expertise and home care in the event of declining health. However, the participants were divided over the issue of insufficient services. Some argued that this was to be expected in a regional area, or that available services were fairly good all things considered, while others felt that more money and resources should be allocated taking into account the growing population of people with HIV. This inadequacy of health services is similar to the situation in regional areas generally.

### LIPODYSTROPHY

Between the regional and urban arms of the Side Effects and Lipodystrophy Project there were both similarities and differences in how lipodystrophy was experienced. Concerns that body shape changes would be seen as a physical 'sign' of HIV and sickness were common to both groups. For the Sydney participants, this sense of forced disclosure was primarily a concern in relation to gay community because of a widespread perception that lipodystrophy was well known in that social domain. For the men in the Northern Rivers, however, forced disclosure was an issue both in relation to other gay men *and* to the broader community. While the Sydney participants believed they 'stood out' by virtue of living in a 'knowing' community, the men in the Northern Rivers arm of the study believed they stood out because living in a smaller community went hand in hand with a higher degree of visibility and 'talk' generally.

Anxiety around body image and loss of 'looks' and sexual desirability were major themes among the Sydney participants, primarily within the context of gay community. Body image was generally seen as *less* of an issue among the men in the Northern Rivers. They tended to explain this with reference to the supposed lack of emphasis on 'looks' and appearance in the local community in general, and also with reference to the renowned 'alternative' culture in the region, seen by many as being more inclusive and more accepting of difference. For this reason, they generally believed

it was *different* and *easier* to have lipodystrophy in the Northern Rivers than it would be if they lived in Sydney, citing what they saw as a strong emphasis on body image in the urban gay community. Nevertheless, many Northern Rivers participants talked about the negative effect of lipodystrophy on their self-esteem in ways that were similar to those of their Sydney counterparts. Concerns around body image and appearance, particularly, came to the fore in sexual situations or in the context of finding a relationship.

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## **APPENDIX: ACON NORTHERN RIVERS**

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Several changes have occurred since the writing of the report. This update was provided by the ACON Northern Rivers branch.

### **Client satisfaction survey**

See summary of results on page 39. Eighty-seven per cent rated their 'overall satisfaction' with the service as 'satisfied'/'very satisfied'.

Stakeholder, PLWHA and service provider feedback now forms part of the annual review of HIV services. Surveys will be completed by June 2005.

### **Gay Men's Advisory Group**

An advisory committee was established to ensure feedback from community members, both HIV-negative and HIV-positive, into program development.

### **PLWHA Consultative Committee**

The Branch continues to support the PLWHA Consultative Committee and has one seat on the Committee.

### **HIV peer support groups**

The Branch continues to offer a monthly HIV peer support group.

### **Redesign of care and support role**

The previous position of Care and Support was redesigned in April 2004 to more adequately reflect the needs of local PLWHA. A driver's licence is an essential requirement of the position. The incumbent will be forming a steering committee of PLWHA, service providers and stakeholders to inform the development of a coordinated three-year HIV Health Promotion Plan. Feedback from community members has already commenced.

### **Richmond Interagency**

The HIV Services Officer represents ACON on the above interagency. The interagency consists of Home and Community Care (HACC) services and services from other non-government organisations.

### **Outreach services**

All project positions within the Branch have an outreach responsibility. The previous incumbent of the Care and Support role did not have a driver's licence. This was addressed in the redesign of the position in April 2004.

An HIV Treatments Outreach service operates from Clinic 145, Tweed Heads.

### **HIV-Positive Gay Men's Health Retreat**

The Branch facilitates an annual health retreat for HIV-positive gay men. One of the aims of this retreat is to seek feedback from community members regarding branch program and services.

### **Community feedback**

The Branch produces a monthly publication entitled Rainbow News (distribution 600+). Each edition of the newsletter covers a single topic, e.g. PLWHA Health. The Manager, via his monthly column, invites community feedback and input into branch programs/services.

### **Complaints procedure**

All clients are advised of their rights and of the procedure for making a complaint about services/programs, etc.

### **Memoranda of Understanding**

The Branch now has formalised memoranda of understanding with both sexual health services in the area, with the objective of improving service delivery for PLWHA, gay men, lesbians and transgender persons.

## ACON NORTHERN RIVERS: 2003 CLIENT SATISFACTION SURVEY RESULTS

### Summary

Note: All percentages are rounded.

- 21 responses were provided for 23 service contacts.
- Respondents were aged between 18 and 56+ with 43% being in the age range 36 to 55.
- 81% of respondents were male.
- 62% of respondents identified as gay.
- No Aboriginal and Torres Strait Islander data was identified.
- 43% of respondents were new to the service.
- 19% of respondents had received the 'Information for New Clients' sheet with 100% of those indicating that the sheet was useful.
- 87% rated their overall satisfaction with the service as satisfied/very satisfied.
- 74% were satisfied/very satisfied with the waiting time for the service. 86% rated this as an important factor.
- 78% were satisfied/very satisfied with the competence of staff in their service delivery. 86% rated this as an important factor.
- 87% were satisfied/very satisfied with the fairness and equity in which the service was provided. 82% rated this as an important factor.
- 86% were satisfied/very satisfied with the information obtained. 82% rated this as an important factor.
- 96% were satisfied/very satisfied with the accessibility of the service. 76% rated this as an important factor.

- 83% said that they had got what they needed from the service. 7% of respondents (2 individuals) indicated that they did not get what they needed and a further 2 individuals indicated that their needs were only partially met.

### Satisfaction vs. Importance indicators

Issue	Satisfaction rating <sup>i</sup> (%)	Importance rating <sup>ii</sup> (%)
Timeliness	74	86
Competence	78	86
Fairness	87	82
Information	86	82
Accessibility – location	96	76

<sup>i</sup> Percentage who indicated satisfaction as 'satisfied/very satisfied'

<sup>ii</sup> Percentage who indicated importance as 'important/very important'

### Recommendations

Overall service satisfaction was high (87%), but as with any quality improvement initiative there are always areas and options for further improvement. It is suggested that service delivery should be a continuous area of review for the Branch. The following recommendations are general recommendations rather than specific service delivery recommendations.

It is recommended that:

- 1 the results of this survey are used as a benchmark for the 2004 client satisfaction survey
- 2 the 'Information for New Clients' information sheet be continued to be used and that all team members be reminded that all new clients to the service are to be provided with a copy of the information sheet on their first visit to the service.





## PART 2

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Positive Health in the Northern Rivers: an analysis of  
Northern Rivers data from the Positive Health study

Andrea Fogarty  
Patrick Rawstone  
Garrett Prestage

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### NSW Project Coordinator

Hédimo Santana

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## INTRODUCTION

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### POSITIVE HEALTH STUDY

The data presented in this report are drawn from the Positive Health study, a longitudinal cohort study of people living with HIV/AIDS (PLWHA) in New South Wales and Victoria, Australia. The major aims of Positive Health are to explore decisions regarding the uptake of treatments, the use of services, and experience of health over time by people living with HIV/AIDS.

### Recruitment

Participants were and are recruited from a range of sources including advertisements in HIV or gay-related media, flyers distributed at events, newsletters, through other studies or community organisations, networking, 'snowballing' (in which new participants are recruited by existing participants through word of mouth) and direct referrals. The cohort is an open cohort, which allows new participants to be recruited each year in addition to the longitudinal sample. To date, there have been four rounds of data collection: 1998/1999, 2000/2001, 2002/2003, and 2004.

### Funding and administration

The project is funded by the Commonwealth Department of Ageing, and the NSW Department of Health and the Positive Living Centre and is jointly administered through the National Centre in HIV Social Research (NCHSR), the National Centre in HIV Epidemiology and Clinical Research (NCHECR), the Australian Research Centre in Sex, Health and Society (ARCSHS), the National Association of People Living with HIV/AIDS (NAPWA) and the Australian Federation of AIDS Organisations (AFAO).

### Questionnaire

The study uses face-to-face, structured quantitative interviews. Interviews occur annually and generally last one to one and a half hours. The interview addresses the following areas:

- contact with HIV-positive people and organisations

- disclosure of HIV serostatus
- use of services
- personal health and serological testing
- use of complementary or alternative therapies
- use of antiretrovirals and other medical treatments
- recreational drug use
- clinical trials
- beliefs about medicine and HIV.

All data used in this report come from 2002/2003 and focus mainly on experiences of health, access to HIV/AIDS-related services and use of various treatments.

### RATIONALE FOR COMPARING THE EXPERIENCES OF PARTICIPANTS FROM THE NORTHERN RIVERS AND SYDNEY

There are an estimated 300 people living with HIV/AIDS in the Northern Rivers region of NSW. The area for which the Northern Rivers Area Health Service (NRAHS) is responsible has experienced an increase in the number of people newly diagnosed with HIV such that the Northern Rivers represents 2% of newly diagnosed infections between the years 1998 and 2002 (Hardwick & Cotton, 2004). Of all area health services that provide Level 4 HIV/AIDS care, in 2001/02 NRAHS had the largest number of people living with HIV/AIDS who required admission to hospital and the biggest outflow of patients to other states (Hardwick & Cotton, 2004).

This report is a comparison of the experiences of people living with HIV/AIDS in the Northern Rivers district of NSW with those of their counterparts living in Sydney to find out if any of the issues they faced were significantly different from those faced by their Sydney counterparts. In conducting these analyses, we are wary of the fact that participants in the study are not necessarily representative of people living with HIV/AIDS who live in both regions. As such, we recommend caution in generalising the results in this report to the larger population of people living with HIV/AIDS in both regions.

## DEMOGRAPHIC PROFILE

What follows is a comparison of the demographic profiles of those living in the Northern Rivers and those who live in Sydney City.

### SAMPLE

A subsample of respondents was drawn from the main Positive Health study of more than 600 participants. The subsample was predominantly male (98.4%) and was made up of 24 people living with HIV/AIDS from the Northern Rivers region of NSW and 228 residing in the city of Sydney. For the purposes of this report, we used the Northern Rivers Area Health Service's definition of the Northern Rivers prior to 2005: that is, the area encompassing towns and regions of NSW with the postcodes 2460–2490. Sydney City is defined as the areas encompassed by postcodes 2000–2009, 2010–2012, 2014–2020, 2021–2036, 2037–2050, 2130–2141 and 2203–2204.

### LENGTH OF TIME LIVING WITH DIAGNOSIS

At baseline interviews, subsample participants were asked in what year they were diagnosed as HIV-positive. Figure 1 shows the range of years in which all participants were diagnosed with HIV.

There is considerable range in the years in which participants tested HIV-positive, from as early as 1982 to as recently as 2003. All Northern Rivers participants were diagnosed prior to 1999 (range = 1983–1998), while Sydney participants were diagnosed as recently as 2003 (range = 1982–2003).

In the case of each participant, the length of time since diagnosis was calculated (in years) and the mean length of diagnosis for each group was compared. On average, Northern Rivers participants reported a significantly longer length of time spent with their HIV-positive diagnosis (mean = 13.65 years) than participants from Sydney (mean = 10.98 years,  $t = 2.125$ , 248 df,  $p = .035$ ).

### SEXUAL IDENTITY

Table 1 shows the sexual identity of participants. The majority of participants identified as gay, lesbian or homosexual, with no significant differences between participants in the Northern Rivers and Sydney. None of the Northern Rivers participants identified as bisexual or queer.

### AGE

Participants ranged in age from 21 to 68 years, with a mean age of 43.4 years (median = 43). Northern Rivers participants reported an average age of 48.04 years, which was significantly older than participants from Sydney, whose average age was 42.93 years ( $t_{248} = 3.03$ ,  $p = .003$ ).

### EMPLOYMENT

Participants were asked about their current work situation and significant differences in employment status were evidenced between those in the Northern Rivers and Sydney (see Figure 2). The majority of Northern Rivers respondents reported being on pensions and a significantly higher proportion of respondents from Sydney reported working full-time compared with those in the Northern Rivers ( $p < .001$ ).

### INCOME

Participants from the Northern Rivers were significantly more likely to have reported incomes of less than \$15 000 than Sydney respondents ( $p = .001$ ). In keeping with this, a higher proportion of Sydney respondents reported incomes equal to or in excess of \$50 000 than did those living in the Northern Rivers region (see Table 2).

Nearly two-thirds of Northern Rivers participants reported incomes of \$15 000 or less, yet only 26.2% of the general population living in the same geographical area reported similar incomes (NSW Health, 2000).

### EDUCATION

Table 3 shows the highest level of education reported by participants. The majority of Sydney participants reported having attended university, while the majority of participants from the Northern Rivers region reported having achieved a tertiary diploma or trade certificate. However, these differences were not statistically significant.

### LIVING SITUATION

There were no significant differences in living arrangements between the Northern Rivers and Sydney participants. Around a third of participants reported owning their own homes. The majority of people lived in rental accommodation that was government-assisted or private (see Table 4).

**Table 1: Sexual identity**

	Northern Rivers		Sydney City	
	<i>n</i>	%	<i>n</i>	%
Heterosexual	2**	8.3	5	2.2
Bisexual	-	-	8	3.5
Gay/Lesbian	19	79.2	160*	70.2
Queer	-	-	9	3.9
Homosexual	3	12.5	32	14.0
Other	-	-	14*	6.1
<b>Total</b>	<b>24</b>	<b>100.0</b>	<b>228</b>	<b>100.0</b>

\*There is one woman in each of these categories.

\*\*There are two women in this category.

**Table 3: Highest level of education achieved**

	Northern Rivers		Sydney City	
	<i>n</i>	%	<i>n</i>	%
Primary and up to three years of high school	2	8.3	9	3.9
School Certificate	6	25.0	30	13.2
HSC	3	12.5	38	16.7
Tertiary diploma or trade certificate	9	37.5	56	24.6
University degree	4	16.7	95	41.7
<b>Total</b>	<b>24</b>	<b>100.0</b>	<b>228</b>	<b>100.0</b>

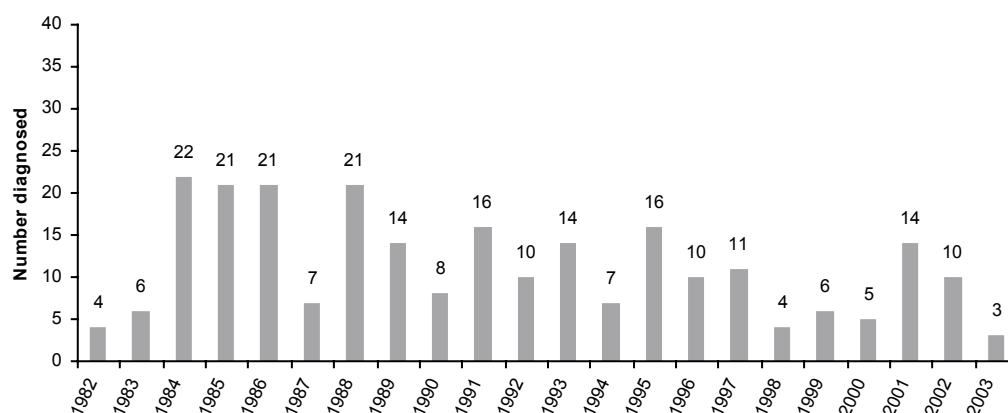
**Table 2: Average income**

	Northern Rivers		Sydney City	
	<i>n</i>	%	<i>n</i>	%
\$0 to \$15 000	16	66.7	56	25.2
\$15 001 to \$26 000	3	12.5	44	19.8
\$26 001 to \$50 000	4	16.7	52	23.4
\$50 000 or more	1	4.2	70	31.5
<b>Total</b>	<b>24</b>	<b>100</b>	<b>222*</b>	<b>100</b>

\*missing data (*n* = 6)

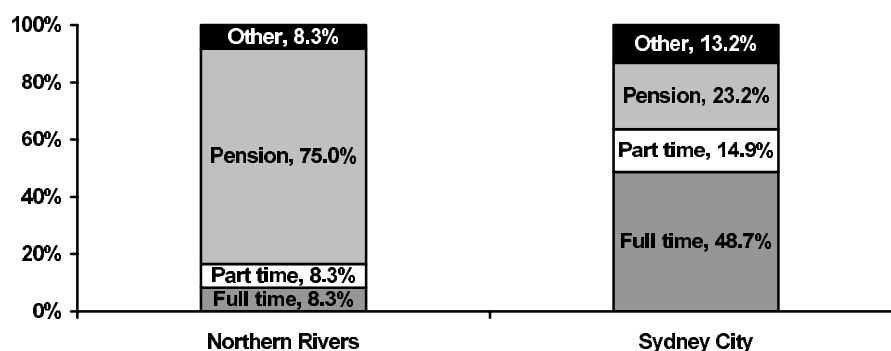
**Table 4: Current living arrangements**

	Northern Rivers		Sydney City	
	<i>n</i>	%	<i>n</i>	%
Owens own home	8	33.3	71	31.1
Rents	14	58.3	144	63.2
Other	2	8.3	13	5.7
<b>Total</b>	<b>24</b>	<b>100.0</b>	<b>228</b>	<b>100.0</b>



**Figure 1: Year of diagnosis**

\*missing data (*n* = 2)



**Figure 2: Employment**

In the Northern Rivers region, about 33.3% of participants reported living alone, which was not significantly different from the 41.7% of Sydney City participants who reported living on their own.

Figure 3 shows the proportion of respondents who said they lived with partners, family and/or friends. Of those who reported living with someone ( $n = 149$ ), there were no significant differences between Northern Rivers and Sydney participants in the categories of housemates with whom they lived.

## CHILDREN

A minority of participants had children; only 10.1% of Sydney City participants and 12.5% of Northern Rivers participants reported having children. These proportions are not surprising given that the sample was made up of predominantly homosexual men and it has been estimated that around 10% of gay men are parents (Millbank, 2002). These results are similar to those reported in other Australian samples (Grierson et al., 2000; Prestage et al., 2000). What is unknown, however, is whether or not the participants who reported having children were the main caregivers or custodians.

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## COMMUNITY

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### INVOLVEMENT WITH SUPPORT GROUPS OR ORGANISATIONS FOR PEOPLE LIVING WITH HIV/AIDS

Participants were asked whether or not they were members of or participants in certain HIV/AIDS-related organisations, including support groups, social groups, and community or political groups.

Although it would appear that a higher proportion of Northern Rivers than Sydney City participants were associated with support groups for people living with HIV/AIDS, these differences were not statistically significant (see Figure 4).

### ATTITUDE TO POSITIVE COMMUNITY

Participants were shown a list of statements relating to participation in the HIV-positive community and were asked to indicate to what degree each of the statements applied to them.

Since we supplied no definition of 'positive community' to participants, these results should be interpreted with caution as 'positive community' could have meant different things to different people.

A majority of Northern Rivers participants reported that they felt part of a positive community and actively took part in it. This was similarly observed among Sydney City participants, of whom a slightly lesser majority reported some involvement in a positive community (see Figure 5).

However, it should be noted that almost a third of Sydney City participants reported that they did not think there was a positive community and even more stated that they were not interested in a positive community. This was different from respondents in the Northern Rivers, less than 5% of whom reported 'no interest' in the positive community and approximately 10% of whom did not think a positive community existed.

When asked how many of their close friends were HIV-positive, 28 Sydneysiders reported 'none', but no Northern Rivers person reported this.

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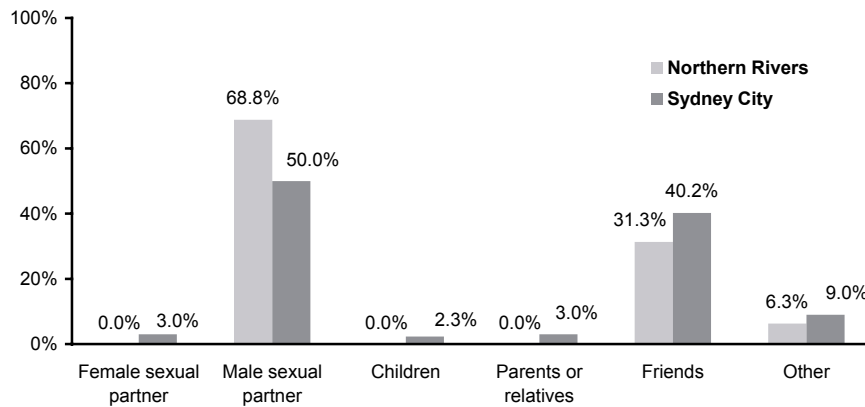
## SOURCES OF EMOTIONAL SUPPORT

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Participants were shown a list of potential sources of emotional support in their lives (e.g. gay male friends, parents, other relatives, doctor, etc.) and were asked to rate how much emotional support they received around HIV-related issues from each category of person (e.g. 'a lot', 'some' or 'none').

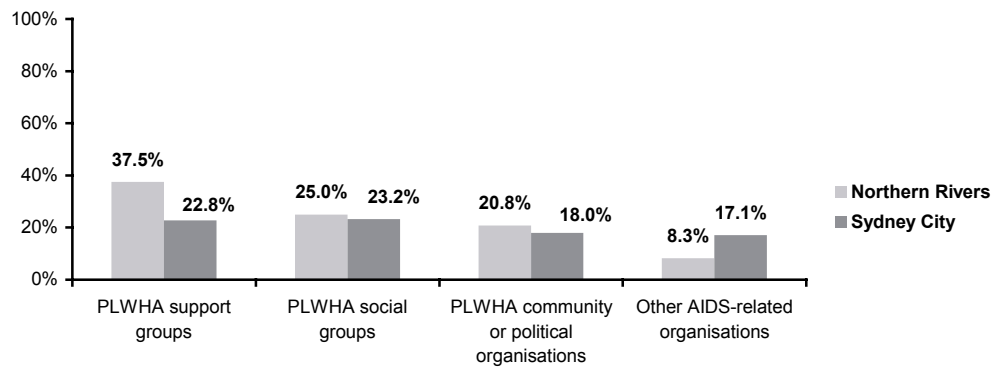
There were no statistically significant differences between the Northern Rivers and Sydney City participants in how much emotional support they received from different categories of people. Given that not all sources of support were relevant to each participant (e.g. a person's mother might not have been alive), proportions were calculated only for those participants for whom each type of support person was applicable.

For participants in the Northern Rivers, the five most commonly nominated sources of 'a lot' of emotional support included: regular partners (68.8%,  $n = 16$ ), pets (66.7%,  $n = 18$ ), doctors (41.7%,  $n = 24$ ), straight female friends (40.9%,

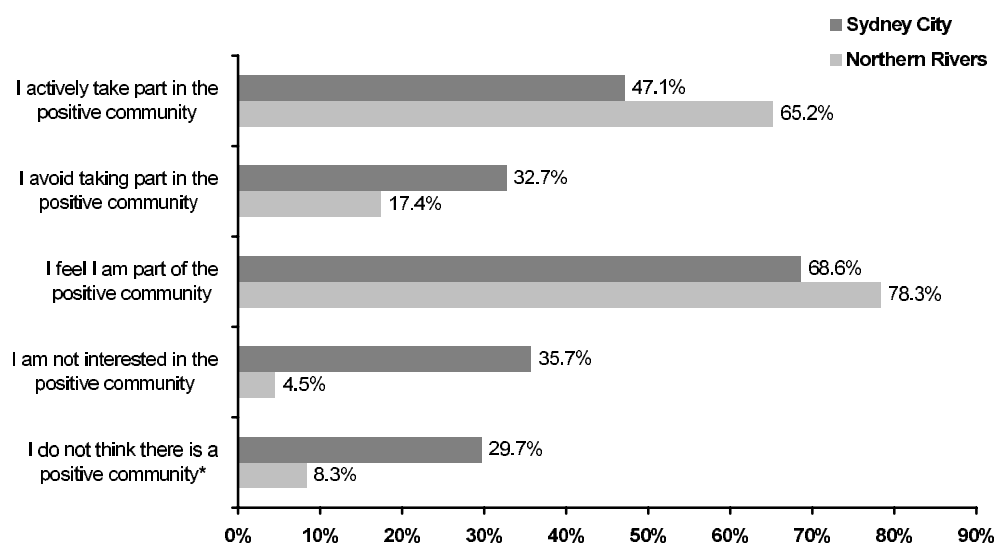


**Figure 3: Accommodation arrangements**

Note: Includes only those who reported living with someone ( $n = 149$ ).



**Figure 4: Association with PLWHA organisations**



**Figure 5: Contact with positive community**

Note: These categories are not mutually exclusive.

\*significant difference



$n = 22$ ) and parents (38.9%,  $n = 18$ ). For those in Sydney City, common sources of 'a lot' of emotional support were regular partners (72.4%,  $n = 127$ ), doctors (48.0%,  $n = 227$ ), pets (39.3%,  $n = 135$ ), gay male friends (37.3%,  $n = 228$ ) and positive people (35.6%,  $n = 225$ ).

Interestingly, 14.7% of Sydney City participants reported that they did not receive any emotional support from other HIV-positive people, while nobody from the Northern Rivers reported this.

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## DISCLOSURE

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Participants were asked to whom they had disclosed their HIV-positive status. On the whole, there were not many differences in patterns of disclosure between Northern Rivers and Sydney participants, with similar proportions reporting that they had disclosed their status to a number of people, usually their doctors, friends and families. There was one exception, however. Participants from the Northern Rivers were, on average, more likely to have disclosed their HIV-positive status to their mothers (88.2%) than Sydney City participants (59.7%,  $\chi^2 = 5.40$ ,  $p = .02$ ).

It is important to note that time and place of disclosure cannot be determined in these analyses. When Northern Rivers participants reported that they had disclosed their HIV status to an employer, it was not clear whether this was an employer in the Northern Rivers region or an employer from a previous job in a different area.

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## HEALTH AND HEALTH MANAGEMENT

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For the most part, participants in Northern Rivers and Sydney reported similar experiences of health and illness in relation to HIV/AIDS. The following section is a brief description of choice of key doctor, self-rated health, clinical markers, HIV/AIDS-related illness and decisions regarding care.

### KEY DOCTOR

Participants were asked to describe the key doctor whom they saw for HIV/AIDS-related care and advice (Table 5).

There were statistically significant differences between the Northern Rivers and Sydney city participants in how they described their key doctor. The majority of Sydney participants said their key doctor was an 'HIV GP': that is, a GP who had a high caseload of HIV-positive clients. One in five Sydney participants reported seeing a specialist with HIV expertise. This was considerably different from the case in the Northern Rivers, where half of the respondents saw a specialist ( $\chi^2 = 11.71$ ,  $p = .003$ ).

Participants were also asked if they consulted a different medical doctor for non-HIV-related issues. A majority of Northern Rivers participants (75%) reported that they saw a different medical doctor for non-HIV-related issues compared with participants in Sydney (33.8%,  $\chi^2 = 15.71$ ,  $p < .001$ ). This was a significant difference.

### SELF-RATED HEALTH

Figure 6 shows participants' ratings of their health over the previous 12 months, from 'fair or poor' to 'excellent'. There were no significant differences between Sydney and the Northern Rivers participants in this regard, with almost 80% of participants reporting at least 'good' health in the previous year.

### VIRAL LOAD

Participants were asked for an approximation of their most recent viral load test results which were classified as 'undetectable', 'low', 'moderate', 'high' or 'unknown' (see Table 6).

In both the Northern Rivers and Sydney City, the majority of participants reported an undetectable viral load. Less than 10% of Sydney respondents and less than 15% of Northern Rivers respondents reported high viral load. There were no significant differences between the two groups.

### CD4/T-CELLS

As well as being asked about their viral load results, participants were also asked about their most recent CD4/T-cell count test results. Table 7 shows the T-cell counts of Northern Rivers participants compared with those of participants in Sydney City.

There was a broad range of responses in both groups, with similar proportions reporting low,

**Table 5: Key doctor**

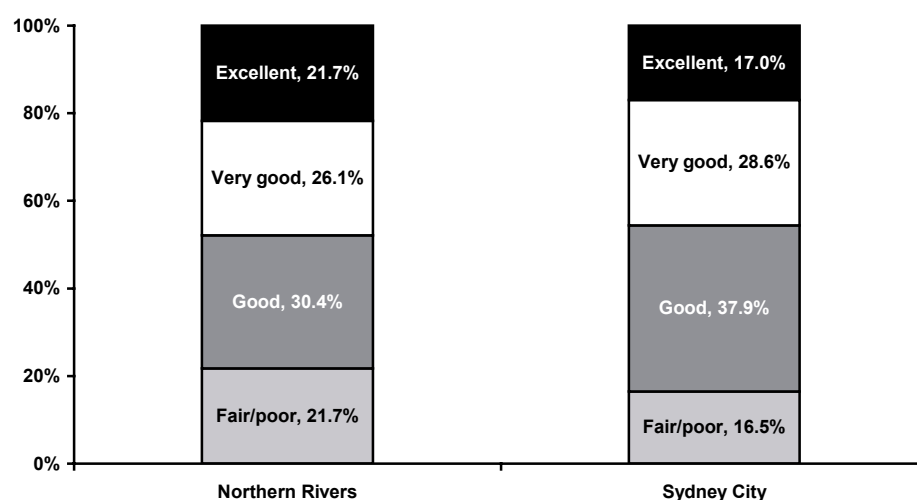
	Northern Rivers		Sydney City	
	<i>n</i>	%	<i>n</i>	%
GP	2	8.3	14	6.1
HIV GP	10	41.7	168	73.7
Specialist with HIV expertise	12	50.0	46	20.2
<b>Total</b>	<b>24</b>	<b>100.0</b>	<b>228</b>	<b>100.0</b>

**Table 6: Self-reported viral load approximation**

	Northern Rivers		Sydney City	
	<i>n</i>	%	<i>n</i>	%
Undetectable	14	58.3	122	53.5
Low (< 10 000)	4	16.7	41	18.0
Moderate (10 000–50 000)	3	12.5	34	14.9
High (> 50 000)	3	12.5	16	7.0
Other/Don't know	-	-	15	6.6
<b>Total</b>	<b>24</b>	<b>100.0</b>	<b>228</b>	<b>100.0</b>

**Table 7: Most recent CD4/T-cell count test results**

	Northern Rivers		Sydney City	
	<i>n</i>	%	<i>n</i>	%
0–350	8	33.3	52	22.8
351–500	6	25.0	44	19.3
501–750	6	25.0	66	28.9
750+	3	12.5	48	21.1
Don't know	1	4.2	18	7.9
<b>Total</b>	<b>24</b>	<b>100.0</b>	<b>228</b>	<b>100.0</b>

**Figure 6: Self-rated health**

moderate and high CD4/T-cell counts. As was the case with viral load, there were no significant differences observed between the CD4/T-cell counts of Northern Rivers and Sydney respondents.

### HIV/AIDS-RELATED ILLNESSES

Participants were presented with a list of opportunistic infections and HIV/AIDS-related illnesses and asked whether they had experienced any of these in the preceding year. The results are shown in Table 8.

Very few participants reported having experienced any HIV/AIDS-related illnesses in the previous year, particularly in the Northern Rivers. This is perhaps surprising given that participants from the Northern Rivers reported having lived significantly longer with HIV. However, given that there were no significant differences in important clinical markers like CD4/T-cells and viral load, there is no particular cause for concern.

### HEALTH DECISIONS

When asked to describe their key doctor, people living with HIV/AIDS were also asked how they made major decisions regarding their health and use of treatments (see Table 9).

There were no significant differences between the Northern Rivers and Sydney participants in this regard, with the majority indicating that decisions about their health were made in conjunction with their doctor after joint discussion.

### USE OF STRATEGIES TO IMPROVE OR PROTECT HEALTH

Participants were asked a range of questions about their use of lifestyle strategies to improve or protect their health. Questions were asked about strategies such as use of massage, exercise, increased sleep, vitamin supplements, meditation and changes in philosophy/spirituality.

Figure 7 shows the use of various lifestyle strategies by people living with HIV/AIDS in both regions.

There were similar rates of uptake for both regions, with diet, exercise and the reduction of stress being the most popular strategies. However, Sydney participants were more likely than Northern Rivers participants to report the uptake of a special diet to improve their health.

## COMPLEMENTARY AND ALTERNATIVE MEDICINES AND THERAPIES

In addition to lifestyle strategies used to protect health, participants were also asked if they had used a number of complementary and alternative medicines in response to their HIV infection. For example, they were asked about their use of homeopathic remedies, acupuncture, antioxidants and marijuana for medicinal purposes.

Participants' responses are shown in Figure 8.

**Table 8: Experience of HIV/AIDS-related illnesses and infections**

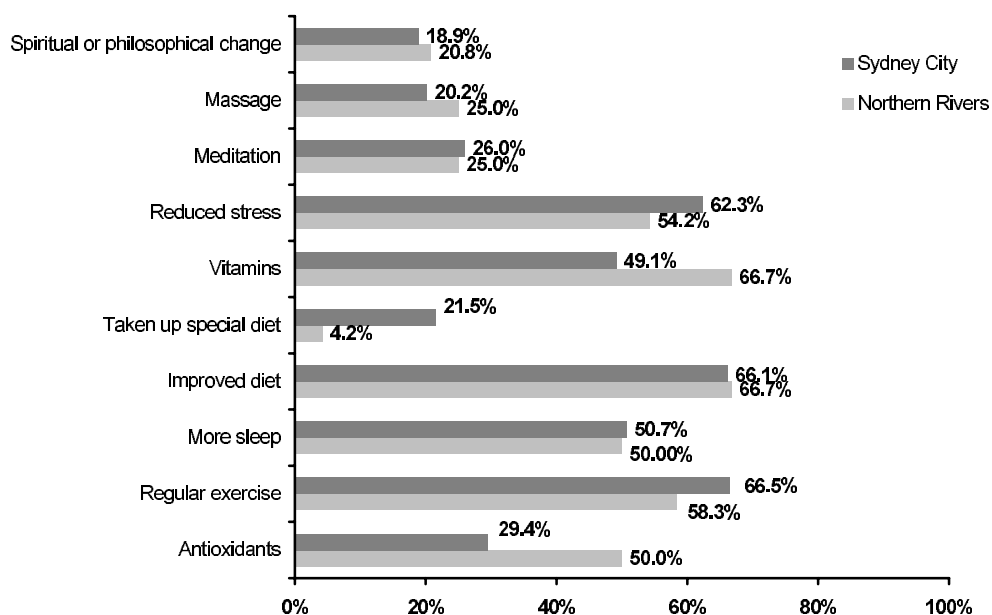
	Northern Rivers		Sydney City	
	<i>n</i>	%	<i>n</i>	%
Fungal infection	6	25.0	63	27.6
Oral hairy leukoplakia	2	8.3	7	3.1
Dementia	2	8.3	10	4.4
Viral pneumonia	1	4.2	4	1.8
Cytomegalovirus	1	4.2	-	-
Mouth candida	1	4.2	27	11.8
Shingles	-	-	15	6.6
Oesophageal candida	-	-	10	4.4
Herpes that lasted longer than one month	-	-	10	4.4
Kaposi's Sarcoma	-	-	4	1.8
Pneumocystis carinii pneumonia	-	-	2	0.9
Lymphoma	-	-	2	0.9
Cryptosporidiosis	-	-	2	0.9
Toxoplasmosis	-	-	1	0.4
Mycobacterium avium complex	-	-	1	0.4
Tuberculosis	-	-	1	0.4
Meningitis	-	-	1	0.4

Note: Categories are not mutually exclusive.

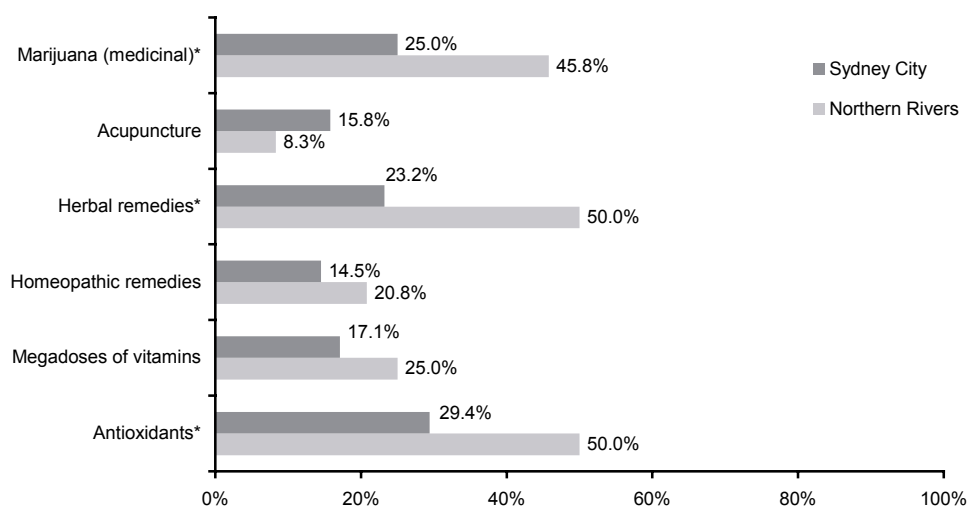
**Table 9: Decisions regarding treatments and health**

	Northern Rivers		Sydney City	
	<i>n</i>	%	<i>n</i>	%
My doctor gives me a range of options and I decide	3	12.5	44	19.4
I decide and tell my doctor what I want	0	0	8	3.5
My doctor and I discuss then we decide jointly	17	70.8	152	67.0
My doctor decides	4	16.7	23	10.1
<b>Total</b>	<b>24</b>	<b>100.0</b>	<b>227*</b>	<b>100.0</b>

\*missing data (*n* = 1)



**Figure 7: Use of lifestyle strategies**



**Figure 8: Use of complementary and alternative medicine**

\*significant difference

A significantly higher proportion of Northern Rivers participants reported using antioxidants ( $\chi^2 = 4.29$ ,  $p = .038$ ), herbal remedies ( $\chi^2 = 8.12$ ,  $p = .004$ ) and marijuana for therapeutic purposes ( $\chi^2 = 4.78$ ,  $p = .029$ ) compared with Sydney City participants. There were no significant differences in the use of homeopathic remedies, megadoses of vitamins or acupuncture.

## MENTAL HEALTH

Participants were asked a range of questions about mental health and well-being.

There were no statistically significant differences in a range of factors associated with depression between Northern Rivers and Sydney participants, whether self-reported or clinically diagnosed. It is worth noting that around 40% of participants reported clinically diagnosed depression (see Table 10).

On the whole, there were no significant differences between the Northern Rivers and Sydney participants with regard to the various aspects of mental health about which we inquired, with one exception. A higher proportion of Northern Rivers participants than Sydney participants reported a psychological illness other than depression. However, we did not ask about the specific nature of the psychological illnesses.

Closer investigation of people living with HIV/AIDS who were on antiretroviral treatment showed that Northern Rivers participants reported anxiety at a higher rate (60.0%) than Sydney participants (38.0%), a difference which approached statistical significance. Note that only participants on treatment were asked about their experiences of anxiety.

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## ANTIRETROVIRAL TREATMENT

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### OPINIONS ABOUT ANTIRETROVIRAL THERAPY

Participants were asked their opinion about the long-term effects of antiretroviral therapy (see Table 11).

Participants in both the Northern Rivers and Sydney had varied opinions about the long-term effects on their health of antiretroviral medication. There were no statistically significant differences. Around a third of participants in each group thought the medication would have mixed effects and roughly a quarter believed most long-term effects would be beneficial. Conversely, 8% to 15% of respondents thought that antiretroviral therapy would have harmful long-term consequences for their health.

### CURRENT TREATMENT

Only a small proportion of participants reported that they had *never* taken any antiretroviral therapy; in the Northern Rivers the figure was 16.7% compared with 10.1% of Sydney respondents. These differences were not statistically significant. The majority of participants had either taken treatment in the past, or were currently on antiretroviral medication (see Table 12).

Almost 70% of Northern Rivers participants and just over 60% of Sydney participants reported being on combination therapy. These proportions were similar to those in other samples of Australians living with HIV/AIDS; for example, in *HIV Futures 3*, 71.7% of respondents reported current use of antiretroviral treatments (Grierson et al., 2002).

### TREATMENT BREAKS

This section refers *only* to those people in the combined Northern Rivers and Sydney sample who had ever been on treatment ( $n = 221$ ).

There was a statistically significant difference between Northern Rivers and Sydney participants with regard to treatment breaks; 80.0% of people living with HIV/AIDS in the Northern Rivers reported that they had ever been on a treatment break compared with 56.7% of Sydney participants ( $\chi^2 = 4.07$ ,  $p = .044$ ).

Those participants who reported ever taking a treatment break ( $n = 130$ ) were given a range of options and asked if any these contributed to their decision to take a treatment break. Both lifestyle reasons (e.g. special event) and clinical reasons (e.g. resistance) featured prominently in their responses (see Figures 9 and 10).

**Table 10: Mental health and emotional well-being**

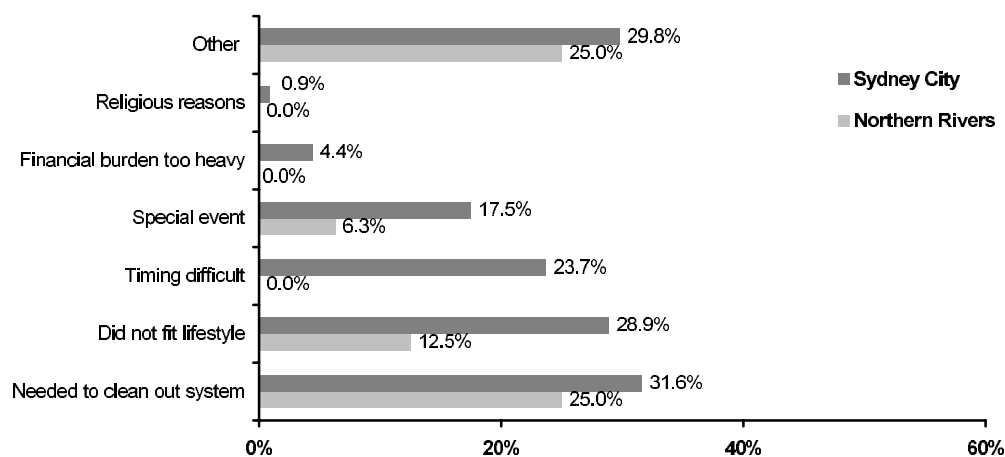
	Northern Rivers		Sydney City	
	<i>n</i>	%	<i>n</i>	%
Depression	5	41.7	52	39.1
Another psychological illness	3	25.0	10	7.6
Sought counselling	7	29.2	85	37.3
Sought treatment for appetite	4	16.7	48	21.1
Sought treatment for sleep	8	33.3	70	30.7
Sought treatment for concentration	3	12.5	37	16.2
Sought treatment for libido	9	37.5	50	22.1
Sought treatment for mood	7	29.2	84	36.8

**Table 11: Opinion about the long-term effects of antiretroviral therapy**

	Northern Rivers		Sydney City	
	<i>n</i>	%	<i>n</i>	%
No long-term effect	0	0.0	3	1.3
Beneficial	7	29.2	58	25.4
Mixed	8	33.3	79	34.6
Harmful	2	8.3	34	14.9
Unsure	7	29.2	54	23.7
<b>Total</b>	<b>24</b>	<b>100.0</b>	<b>228</b>	<b>100.0</b>

**Table 12: Antiretroviral treatment status**

	Northern Rivers		Sydney City	
	<i>n</i>	%	<i>n</i>	%
No antiretrovirals	6	25.0	73	32.0
1–2 antiretrovirals	2	8.4	15	6.6
HAART/Combination therapy	16	66.7	140	61.4
<b>Total</b>	<b>24</b>	<b>100.0</b>	<b>228</b>	<b>100.0</b>



**Figure 9: Lifestyle reasons that contributed to treatment break**

On the whole, similar proportions of respondents from both the Northern Rivers and Sydney reported that a range of lifestyle reasons had contributed to their decision to take a break. However, there was one exception, with Sydney participants more likely to report that they found taking medication at the right time too difficult and that this contributed to their decision.

Again, similar proportions of participants from the Northern Rivers and Sydney were likely to have reported that a range of clinical issues contributed to their decision to take a treatment break. The most common clinical issues were side effects from treatment and a doctor's recommendation to take a break.

## ACCESS TO SERVICES AND THERAPIES

Access to and use of services by people living with HIV/AIDS are areas of interest to many community groups, policy makers, researchers, health-care workers and HIV-positive people themselves. A recent NSW government report identified problems with access to services and retention of qualified GPs in rural areas (Hardwick & Cotton, 2004), problems that make the consideration of services in the Northern Rivers region vital.

Participants were asked whether they used a range of services to manage their HIV infection (Table 13). There were several significant differences in the use of services by people living with HIV/AIDS in the Northern Rivers and Sydney. Northern Rivers participants were significantly more likely to have reported using sexual health clinics, non-hospital AIDS clinics, naturopaths and health centres specifically aimed at HIV-positive people.

### OUT-OF-POCKET EXPENSES

Participants were asked how much money they spent on average each month on out-of-pocket expenses for consultations with doctors, specialists, alternative-health practitioners, dentists, dieticians and psychologists.

Figure 11 shows the proportion of people who reported spending money each month on a range of service providers and therapists. Relatively small proportions of respondents from both regions

reported spending extra money on service providers and therapists each month. Participants from the Northern Rivers were significantly more likely to have reported spending money each month on alternative practitioners than participants from Sydney ( $\chi^2 = 4.90, p = .027$ ). Sydney participants, on the other hand, were significantly more likely to have reported out-of-pocket dental expenses than Northern Rivers participants ( $\chi^2 = 4.04, p = .044$ ).

Respondents were also asked how much money they spent on antiretroviral drugs, other prescriptions, vitamins and natural therapies (see Figure 12, page 57).

Northern Rivers participants were significantly more likely to have reported spending money on complementary therapies each month than Sydney participants ( $\chi^2 = 7.17, p = .007$ ). Otherwise, there were no significant differences.

### DIFFICULTIES OF ACCESS TO SERVICES

Northern Rivers participants (54.2%) were significantly more likely to have reported difficulties in accessing at least one service compared with

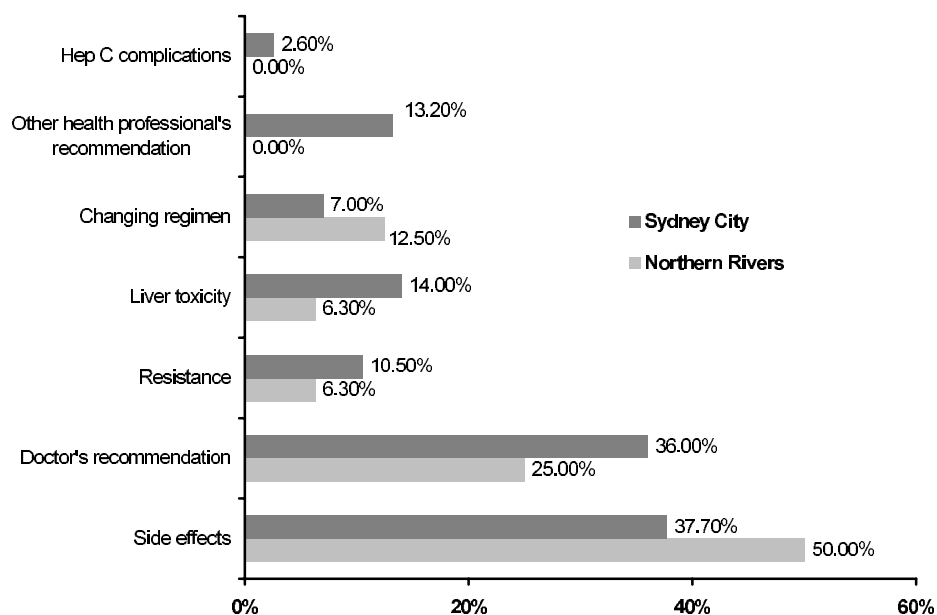
**Table 13: Services for management of HIV infection**

	Northern Rivers		Sydney City		
	<i>n</i>	%	<i>n</i>	%	
Hospital (clinic or outpatient)	7	29.2	77	33.8	ns
Hospice*	0	0	3	1.3	–
Sexual health clinic	22	91.7	31	13.6	$p < .001$
Community health centre	5	20.8	23	10.1	ns
Non-hospital AIDS clinic	6	25.0	22	9.6	$p = .023$
Naturopath	11	45.8	45	19.7	$p = .003$
Health centre for positive people	6	25.0	21	9.2	$p = .017$
Nowhere. Only my doctor*	2	8.3	112	49.1	–
Nowhere. I manage my own health	0	0	14	6.2	–

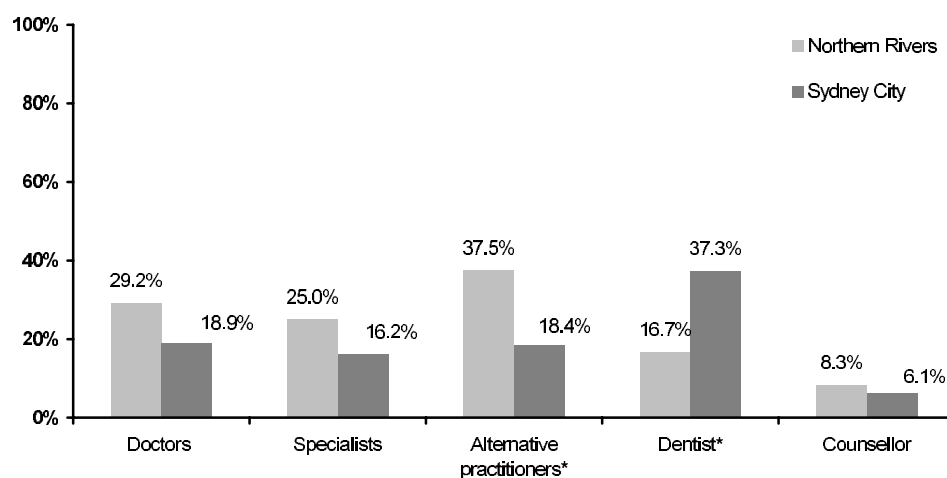
Note: Categories not mutually exclusive.

ns = non-significant

\*Too few people reported this service to be able to conduct statistical comparisons.



**Figure 10: Clinical reasons for taking treatment breaks**



**Figure 11: Percentage who incurred out-of-pocket expenses each month for service providers and therapists**

\* significant difference



Sydney City participants (22.8%,  $\chi^2 = 11.16$ ,  $p = .001$ ). Figure 13 shows the proportion who reported difficulties gaining access to specific services, such as to doctors who had experience in the management of HIV.

There were considerable differences between the two groups of participants in the number and type of difficulties they reported in gaining access to particular HIV/AIDS-related services. Northern Rivers participants were significantly more likely than their Sydney counterparts to have reported problems of access to doctors with experience in the management of HIV ( $n = 247$ ,  $\chi^2 = 46.03$ ,  $p < .001$ ), doctors who were able to prescribe antiretrovirals ( $n = 232$ ,  $\chi^2 = 37.32$ ,  $p < .001$ ), community-based pharmacies ( $n = 217$ ,  $\chi^2 = 22.16$ ,  $p < .001$ ) and also psychological counsellors ( $n = 175$ ,  $\chi^2 = 5.06$ ,  $p = .025$ ).

Of those who reported at least one problem with access ( $n = 65$ ), Northern Rivers participants were significantly more likely to have nominated problems related to distance (84.6%) than Sydney participants (26.9%,  $\chi^2 = 14.63$ ,  $p < .001$ ). In contrast, a higher proportion of Sydney participants (53.8%) than Northern Rivers participants (15.4%,  $\chi^2 = 6.19$ ,  $p = .013$ ) suggested that their difficulties of access to services were because of the inconvenient opening hours of those services.

## SEX AND RELATIONSHIPS

*Positive Health* also explores sexual practice. Although this section of the questionnaire was optional, of the 252 participants on whom this report is based, 234 (92.9%) agreed to answer the optional booklet. As there were not enough women nor heterosexually identified participants to enable statistical comparisons, these analyses include homosexually active or identified men only. As such, the following section presents data based on the 225 homosexually active or identified men from the Northern Rivers and Sydney who answered questions about their sexual practice. Most of the analyses in this section included too few Northern Rivers participants to conduct statistical comparisons. In these instances, the data are presented descriptively.

## RELATIONSHIP STATUS

Participants were asked about the status of their relationships and whether they had regular or had casual relationships.

Figure 14 shows the proportion of respondents who reported having a regular partner or having had a casual partner or both in the previous six months. Participants from the Northern Rivers and Sydney were equally likely to have reported being in a regular relationship. However, Sydney participants were significantly more likely to have reported having had a casual partner ( $\chi^2 = 5.34$ ,  $p = .021$ ). There were no significant differences in the proportions of people who reported having both a regular partner and a casual partner.

## SEROCONCORDANCE

Participants were asked the HIV serostatus of their current regular partner (see Table 14). They were also asked how many casual partners of varying HIV serostatus they had had sex with in the previous six months (see Table 15).

**Table 14: Seroconcordance in regular relationships**

	Northern Rivers		Sydney City	
	<i>n</i>	%	<i>n</i>	%
Concordant	6	46.2	38	30.4
Discordant	5	38.5	56	44.8
Status unknown	2	15.4	31	24.8
	<b>13</b>	<b>100.0</b>	<b>125</b>	<b>100.0</b>

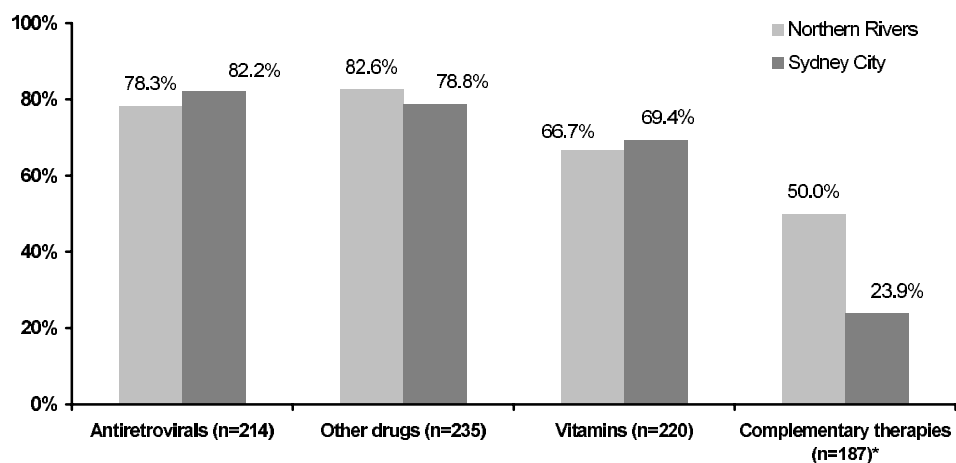
Note: 'Status unknown' includes participants who did not know their partner's HIV status, as well as participants who did not provide information about their partner's serostatus.

**Table 15: Proportion who reported a casual partner of positive, negative or unknown serostatus in the previous six months**

	Northern Rivers		Sydney City		
	<i>n</i>	%	<i>n</i>	%	
Concordant	7	63.6	88	53.0	ns
Discordant	3	27.3	50	30.1	ns
Unknown	6	54.5	145	87.3	$p = .003$

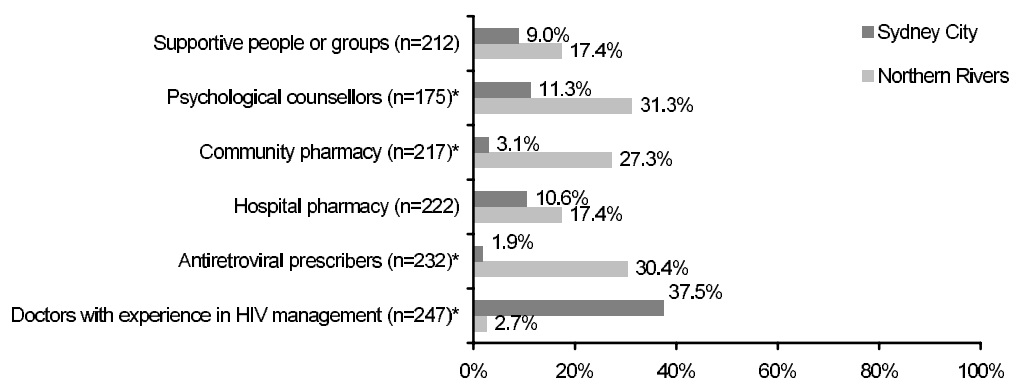
Note: Categories are not mutually exclusive.

ns = non-significant



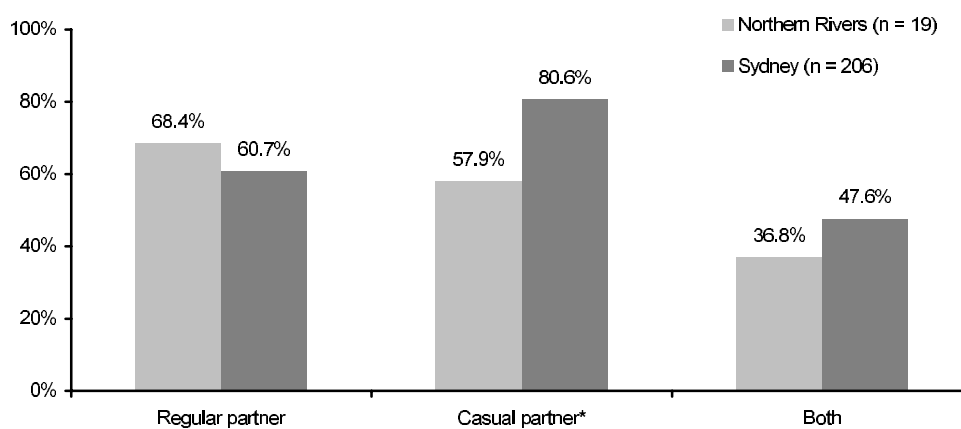
**Figure 12: Percentage who incurred out-of-pocket expenses each month for treatments**

Note: Proportions refer only to those PLWHA who reported wanting to use the treatments.  
\* significant difference



**Figure 13: Reported difficulties of access to services**

Note: Includes only participants who wanted to use each service.  
\* significant difference



**Figure 14: Relationship status**

Note: Categories are not mutually exclusive.  
\*significant difference

## DISCUSSION

This report provides a brief comparison of some of the experiences of people living with HIV/AIDS in the Northern Rivers region of New South Wales and in Sydney City.

A subsample of respondents was drawn from the main Positive Health cohort study of more than 600 people. The 252 respondents in the subsample were interviewed between August 2002 and July 2003. On the basis of the interviews, the respondents were categorised according to geographic location of residence and compared on a number of key study variables. Our aim was to establish a preliminary understanding of the similarities in and differences between the experiences of people living with HIV/AIDS who lived in these two regions. However, this report only states differences observed between the two groups. It does not explore the causes of these differences nor associations between factors that may have led to participants' different experiences of living with HIV. These issues will be further explored in issues papers and journal articles.

Generalising the results in this report to the wider population of people living with HIV/AIDS in Sydney and the Northern Rivers should be done with caution. This is because study participants were recruited through a convenience sample method and not randomly. As such, any differences between the two groups, as reported here, might be attributable to differences caused by the sampling method rather than to actual differences between the two populations. However, there is some corroboration of the findings in this report with a publication by NSW Health (Hardwick & Cotton, 2004).

Notwithstanding the caveat mentioned in the previous paragraph, the findings reported here paint an interesting picture of the similarities in and differences between the experiences of people living with HIV/AIDS in the Northern Rivers and Sydney. On the whole, the two groups reported similar experiences of living with HIV/AIDS. However, there were clearly some areas of disparity; for example, in the use of and access to services. The similarities and differences between the two groups can be interpreted in a number of ways and are further discussed below.

People living with HIV/AIDS in the Northern Rivers region were more likely than Sydney

participants to have reported that they were receiving a pension and not working. This could reflect a number of things. One possibility is that Northern Rivers respondents were more ill than their Sydney counterparts and that this impacted upon their ability to work. Given that Northern Rivers participants also reported having been diagnosed longer than Sydney participants, this interpretation is not entirely unlikely. Alternatively, it is possible that finding employment in the Northern Rivers region presented more of a problem than it did in Sydney. Given that in 1996 the Northern Rivers area reported the second highest rate of unemployment (15.3%) of all the area health services (NSW Health, 2000), this interpretation is plausible. The employment needs of people living with HIV/AIDS in the Northern Rivers may be more difficult to satisfy, given that there are fewer jobs in a narrower range than in Sydney. As participants from both regions reported similar states of health as indicated by clinical markers such as CD/T-cell counts and viral load tests, perhaps it is more feasible to attribute differences in employment status to the difficulty of finding employment rather than to differences in health.

Most participants agreed with the notion of a 'positive community' and had some level of involvement with this community. However, it is worth noting that what 'positive community' meant for people living with HIV/AIDS in the Northern Rivers might have been considerably different from what it meant for their Sydney counterparts. Even within each group, it is possible that attending support groups and participating in HIV-positive organisations was central to one person's notion of community, while another person might have experienced community in simple day-to-day contact with other HIV-positive people. It would appear that Northern Rivers participants and Sydney participants had similar contact with positive organisations and spent a similar amount of time with their positive friends, both of which are taken to be indicators of positive-community attachment (Rawstorne et al., in press).

Both Northern Rivers and Sydney participants reported having received 'a lot' of emotional support from a markedly similar range of sources: regular partners, doctors, friends, family and pets. A higher proportion of participants in the Northern Rivers reported their pets as a source of emotional support than Sydney participants. It is possible that

this reflects the availability of space—people living with HIV/AIDS in Sydney may have wished to have pets but may have been prevented from doing so by lack of space in their homes. It is also possible that, in the Northern Rivers, isolation may have been a more common experience and reliance upon pets became necessary rather than simply preferable. Unlike Sydney participants, no Northern Rivers participants reported that they did not receive any support from other HIV-positive people. This may indicate that Northern Rivers participants rely on positive friends in a small community where stigma and disclosure are major issues.

Given that Persson's report (first in this publication) reveals confidentiality as a major concern for people living with HIV/AIDS in the Northern Rivers, it is perhaps surprising that participants in both areas reported having disclosed their HIV status to similar groups of people. However, it has been noted that the location of people to whom Northern Rivers participants had disclosed was unknown and therefore it cannot be assumed that Northern Rivers participants were referring to friends or employers *in the region* when they spoke about disclosure. It is also unclear *when* participants had disclosed their HIV status; it may have been six months previously, the day before or five years previously when they lived in a different area.

With regard to experiences of illness and health, people living with HIV/AIDS in the Northern Rivers were markedly similar to their counterparts in Sydney. There were no obvious significant differences between the two groups in self-rated health or clinical markers such as CD4/T-cell counts and viral load approximations. As would be expected from this (since CD4/T-cell counts are often good indicators of the onset of opportunistic infections), there were also no significant differences in the incidences of HIV/AIDS-related illnesses and opportunistic infections. This is perhaps surprising given that Northern Rivers participants reported having been diagnosed for longer than Sydney participants and could have been expected to report more opportunistic infections.

One area of clear difference between the two groups concerned not the participants overall health status but the strategies used to improve, maintain or protect health. Northern Rivers partici-

ants were more likely than Sydney participants to have reported using antioxidants, herbal remedies and medicinal marijuana in response to their HIV infection. It could be that people living with HIV/AIDS in the Northern Rivers area are more open to complementary and alternative medicines, or that positive people with similar attitudes have moved to the area. It is also possible that these therapies are more readily available in the Northern Rivers region than in Sydney and that people living with HIV/AIDS in Sydney would have reported using these strategies had they had easier access to them.

Another area of difference was in the type of doctor on whom participants relied for the management of their HIV infection. Northern Rivers participants were more likely to have reported seeing a specialist with knowledge of HIV than an 'HIV GP' (defined as a GP with a high caseload of HIV-infected patients). Given that Northern Rivers participants also reported having had problems finding a GP who was experienced in HIV/AIDS management or could prescribe antiretroviral medication, this finding may reflect their need to accept what was available rather than having a choice of key doctor.

In addition, participants from the Northern Rivers were more likely to have reported that they saw a different doctor for health issues unrelated to HIV/AIDS. This finding is likely understood in light of the fact that there is only one service specifically dedicated to HIV/AIDS in the Northern Rivers area: the Sexual Health and AIDS Service (SHAIDS). The fact that this clinic deals strictly with HIV/AIDS and sexual health, and not with other health problems, creates a situation in which people living with HIV/AIDS in the Northern Rivers need to engage in dual tracks of health care; the doctor they see for HIV/AIDS does not deal with other health problems and their second doctor is unlikely to have the necessary experience or knowledge to manage HIV. Clearly, participants in Sydney do not face the same difficulties, with the majority having access to an HIV GP as their key doctor and none reporting the need to go elsewhere with other health issues.

There were no clear differences between the two groups with regard to current antiretroviral treatment. Northern Rivers participants were more likely to have reported ever having taken a treatment break in the past.

Issues of access to and use of services were experienced considerably differently by Northern Rivers and Sydney participants. While each group was likely to have reported similar experiences of health or made similar decisions regarding treatment, there were differences between the groups in their access to services, use of services, and money spent on therapies. It is unclear, however, whether Northern Rivers participants were accessing services located in the region or services located outside of the region, so results should be interpreted with caution.<sup>1</sup>

Northern Rivers participants were significantly more likely than Sydney participants to have reported using sexual health clinics for the management of HIV infection. On the surface this could suggest a greater need for sexual health advice in the Northern Rivers region than in Sydney. However, closer examination shows that this is likely to have resulted from the fact that the HIV/AIDS services are situated within the sexual health clinic in Lismore. The fact that a majority of Northern Rivers participants reported using a sexual health clinic may not necessarily be representative of their ideal care arrangements or personal choice; rather it may reflect the lack of choice available to people living with HIV/AIDS in the area. The same can be said of the fact that Northern Rivers participants were significantly more likely than Sydney participants to have reported attending non-hospital AIDS clinics or centres specifically for positive people; all three descriptions (sexual health clinic, non-hospital AIDS clinic and centre for positive people) may in fact refer to the one service.

By contrast, Sydney participants were particularly likely to have reported seeing only their key doctor to manage their health. It could be that participants in Sydney simply did not need to use a range of services for the management of their infection whereas Northern Rivers respondents did. However, it is more likely that Sydney participants had better access to a higher number and broader range of HIV GPs than people living with HIV/AIDS in the Northern Rivers. Sydney

participants may not have been forced to seek alternative services in the way that Northern Rivers participants were.

There were no significant differences in the percentages of participants from each region who reported incurring out-of-pocket expenses each month for seeing specialists, doctors and counsellors. The same was true in the case of monthly spending on antiretrovirals, other medications and vitamins. There were some differences, however. Northern Rivers participants were significantly more likely than Sydney participants to have reported incurring expenses for using complementary therapies and seeing alternative health practitioners. Sydney participants were more likely to have incurred dental expenses. One possible explanation could be that Northern Rivers participants did not have private health insurance and therefore had to pay for treatments that Sydney people living with HIV/AIDS might have been able to claim on private health insurance. However, there were no differences between the two groups in the uptake of private health insurance.

On the whole, Northern Rivers participants were more likely than participants from Sydney to have reported difficulties of access to certain services, specifically services related to HIV/AIDS care. It is clear that Northern Rivers participants felt there were genuine problems not only of access to GPs with experience relevant to the management of HIV and who could prescribe antiretroviral medication, but also of access to antiretroviral medication through community pharmacies. These reported difficulties are supported by a NSW Health report that identified only one part-time S100 prescriber not located within the SHAIDS clinic and two former S100 prescribers who had stopped prescribing after describing a lack of support (Hardwick and Cotton, 2004).

When asked about the nature of their difficulties with access, Northern Rivers participants were significantly more likely than Sydney participants to have reported issues of geography, including the distance they were required to travel to access services. Given that participants lived in a fairly spread-out region with just the one HIV/AIDS-related service in Lismore, this was understandable. Participants may have had to travel long distances simply for routine check-ups and the monitoring of

<sup>1</sup> At least 55 people living with HIV/AIDS have been identified who seek care outside of the Northern Rivers area. The Sydney-based AIDS Dementia and Psychiatry Team report that 10% of their clients are from the Northern Rivers area (Hardwick & Cotton, 2004).

clinical markers, something that may not have been much of an issue for Sydney participants. Sydney participants were more likely to have nominated the inconvenient opening hours of services as a problem. This was also understandable, given that more Sydney participants than Northern Rivers participants were working and required flexibility of opening hours. Or it may have been that Sydney people were used to a 24-hour city and expected services to be available most of the time.

Given that participants in the Northern Rivers were not experiencing marked ill health in comparison with their Sydney counterparts, does the issue of differences in services need to be addressed?

In this report, viral load and CD4/T-cell test results were the markers used to indicate health. These were not found to be significantly different between the two groups. However, overall health cannot simply be judged from an examination of clinical markers or from a person's experience of

illness; it is also about quality of life, a factor that is not measured comprehensively here. It may be that both groups of participants experienced a similar level of physical health, but different levels of mental health and emotional well-being. For example, it may be that Sydney participants had greater access to entertainment and leisure than Northern Rivers participants, or because they were working were more able to afford entertainment or travel, factors which are not always explored when participants are asked to rate their health yet may impact upon it nevertheless.

Clearly, people living with HIV/AIDS in the Northern Rivers felt that access to services was a problem, and so denying services on the basis of clinical markers would not be justified nor equitable. Given the findings of this report and the fact that health is a multifaceted issue that cannot be measured simply by clinical markers, it is essential that the imbalance in service provision between Sydney and the Northern Rivers region be addressed.

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