



## **CHALLENGING RESEARCH: METHODOLOGICAL BARRIERS TO INCLUSION OF LESBIAN AND BISEXUAL WOMEN IN AUSTRALIAN POPULATION-BASED HEALTH RESEARCH**

RUTH MCNAIR, MELANIE GLEITZMAN & LYNNE HILLIER

### **Abstract**

*Lesbian and bisexual women have particular health disparities compared with heterosexual women, largely due to their marginalised status and associated experiences of homophobia and discrimination. Australian health research is contributing to this marginalisation and to the ignorance of health care providers by failing to identify the sexual orientation of participants in population-based studies and therefore failing to highlight lesbian and bisexual health issues. Inclusion is hampered not only by systemic limitations, but also by ethical and methodological challenges. These include difficulty guaranteeing safety and developing trust with participants, not using a wide enough range of sexual orientation measures, and an inability to obtain samples that are truly representative. Suggestions are offered within the paper to enable inclusion of these women in population-based research including how to engage participants and sensitively disseminate research findings. Multiple sexual orientation measures are outlined, highlighting that sexual orientation is a multi-dimensional phenomenon. At the very least studies should include measures of sexual identity, sexual behaviour, sexual attraction, and at least one measure that addresses how sexuality impacts on social relationships. In parallel, lesbian and bisexual women should be recognised in Australian health policy as specific population subgroups that require attention.*

### **Introduction**

There are many challenges to researching lesbian and bisexual women's health<sup>2</sup>. The challenges have been identified by researchers in diverse fields including social work (Martin & Knox, 2000), public health (Sell, Wells, & Wypij, 1995; Boehmer, 2002), psychology (Rothblum, 1994), nursing (Roberts, 2001), and medicine (Council on Scientific Affairs, 1996). In this paper we will canvass the reasons to research this group of women, not the least of which is that many research gaps exist.

When referring to lesbian and bisexual women, we recognise the diversity within this group including women who identify as lesbian, gay or bisexual; are same-sex attracted; have a female partner; are emotionally connected with a woman; or are connected with lesbian or bisexual communities. We have chosen to focus specifically on inclusion in population-based studies, while recognising that qualitative methods are also very valuable in this field. We will then examine what we suggest are the three areas of challenge for lesbian and bisexual women's health research: systemic barriers, ethical dilemmas and methodological limitations. We have summarised key issues within each category in Table 1.

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<sup>2</sup> Where we use 'lesbian and bisexual women', we are referring to the group of women who are not exclusively heterosexual. We acknowledge that many of these women do not label themselves as lesbian or bisexual.

Table 1: Challenges of researching lesbian and bisexual women's health

<b>Categories</b>	<b>Challenges</b>	<b>Recommended solutions</b>
<b>Systemic barriers</b>	<b>Stigma and homophobia:</b> <ul style="list-style-type: none"> <li>- Lack of support &amp; isolation of lesbian health researchers in research institutions</li> <li>- Fear of, or actual, negative impact on research career</li> </ul>	<ul style="list-style-type: none"> <li>- Build partnerships between researchers and lesbian/bisexual community</li> </ul>
	<b>Ignorance and silencing:</b> <ul style="list-style-type: none"> <li>- Lack of sexual orientation focus in national policy frameworks and population-based research</li> <li>- Lack of perceived need affecting funding and publication of research</li> </ul>	<ul style="list-style-type: none"> <li>- Add sexual orientation as a health determinant to policy frameworks</li> <li>- Submit papers to mainstream health journals</li> </ul>
<b>Ethical dilemmas</b>	<ul style="list-style-type: none"> <li>- Possibility of harm to participants including exploitation</li> <li>- Lack of trust by lesbian &amp; bisexual woman of the scientific community</li> <li>- Anonymity does not guarantee disclosure</li> </ul>	<ul style="list-style-type: none"> <li>- Ensure transparent processes for anonymity</li> <li>- Choice of location for completion of surveys</li> <li>- Sensitive dissemination of research findings</li> </ul>
<b>Methodological limitations</b>	<b>Differing theoretical frameworks</b> <ul style="list-style-type: none"> <li>- Determinants of sexual orientation: essentialist versus constructivist</li> <li>- Stages of sexual orientation: linear model of developmental stages versus situational model</li> </ul>	<ul style="list-style-type: none"> <li>- Research questions and data collection should be consistent with framework</li> <li>- Declaring theoretical framework in publications</li> </ul>
	<b>Sampling</b> <ul style="list-style-type: none"> <li>- Lesbian &amp; bisexual women are hard to reach if not connected with communities</li> <li>- Poor representation of diversity in many non-probability samples</li> <li>- Probability samples –lesbian and bisexual women are not evenly distributed geographically</li> </ul>	<ul style="list-style-type: none"> <li>- Include sexual orientation measures in population-based studies</li> <li>- The small proportion of lesbian/bi women requires large sample size to determine differences</li> </ul>
	<b>Defining the construct to be measured</b> <ul style="list-style-type: none"> <li>- Reliance on a single measure that is not inclusive enough</li> <li>- No universal agreement of measures, resulting in difficulty comparing results across studies</li> <li>- Language can alienate – multiple terms with different meanings for different individuals</li> </ul>	<ul style="list-style-type: none"> <li>- Use multiple measures for various dimensions of sexual orientation including social affiliation</li> <li>- Development of validated multi-dimensional scales</li> <li>- Use a breadth of language and terms within measures</li> </ul>

### **Why Include Sexual Orientation in Population-based Studies**

An increasing body of research indicates that sexual orientation can influence health and well-being. This influence is largely a result of experiences of sexual orientation based discrimination, marginalisation and violence (Meyer, 2001). The recent inclusion of sexual orientation measures in some population studies has revealed that sexuality-based discrimination is clearly linked to the physical (Krieger & Sidney, 1997; Smith, Rissel, Richters, Grulich, & de Visser, 2003), and mental (D'Augelli & Grossman, 2001) health disparities of lesbian and gay people.

There are many gaps in our knowledge of specific health disparities. While many studies have suggested possible specific issues, we need representative data that will tell us whether lesbian and bisexual women actually differ from heterosexual women with regard to the incidence of cancer and prevalence of cancer risk factors (Cochran, Mays, Bowen, Gage, Bybee, Roberts, Goldstein, Robison, Rankow, & White, 2001); cardiovascular risk factors and incidence (Solarz, 1999); access to health care (Diamant, Wold, Spritzer, & Gelberg, 2000; Saulnier, 2002); body image and weight differences (French, Story, Remafedi, Resnick, & Blum, 1996); and sexual health issues (Marrazzo, 2000).

Mental health research provides a good example of new knowledge that has been obtained from inclusive population-based research. Two recent Australian longitudinal population-based studies have confirmed that significantly higher levels of depression, anxiety and suicidality are seen amongst the non-heterosexual compared with heterosexual participants, particularly for the bisexual or mainly heterosexual groups (Jorm, Korten, Rodgers, Jacomb, & Christensen, 2002; Hillier, De Visser, Kavanagh, & McNair, 2003; McNair,

Kavanagh, Agius, & Tong, 2005). These differences appear to relate to social

isolation and experiences of homophobic abuse and violence. The Australian Longitudinal Women's Health study (ALWHS) has also shown much higher levels of illicit and licit drug use amongst non-heterosexual women (Hillier et al., 2003). These findings mirror those of population based studies in USA (Gilman, Cochran, Mays, Hughes, Ostrow, & Kessler, 2001), the Netherlands (Sandfort, de Graaf, Bijl, & Schnabel, 2001), and New Zealand (Fergusson, Horwood, & Beautrais, 1999).

### **Systemic Barriers**

One of the greatest threats to the health of lesbian, gay and bisexual (people) is the lack of scientific information about their health (Sell & Becker, 2001, p 876)

Multiple systemic barriers exist in lesbian and bisexual women's health research. We suggest there are two underlying issues creating these barriers, which are stigma and homophobia, and ignorance. Stigma creates particular difficulties for researchers, many of whom are working in isolation within their institution. They commonly face a lack of institutional support and fear negative impacts on their career if they pursue research in this area. Anecdotally, many researchers find they must maintain two streams of research, undertaking a mainstream and acceptable topic in their official time while pursuing lesbian health research largely in their own time.

Ignorance creates a much broader set of challenges. The widespread lack of awareness of the potential health disparities outlined above and incorrect assumptions that the health needs of lesbian and bisexual women are the same as any other woman create silence in health care policy. For example, the Australian Institute of Health and Welfare gathers biennial data on Australia's health. The 2004 report does not include sexual orientation within the lists of

health inequalities, special populations or health determinants (Australian Institute of Health and Welfare, 2004). Lesbian and bisexual women are referenced just once, in relation to sexually transmitted infections, although in the same sentence as gay men (p 161).

The lack of policy attention in turn leads to difficulty in attracting research funding and difficulty in having work accepted for publication in mainstream, high impact journals whose editors do not often see the relevance of such work for their readers. A review of all Medline listed publications over the past 20 years found only 0.1% included lesbian, gay, bisexual and transgender (LGBT) populations (Boehmer, 2002). Eighty percent of the LGBT articles focused on gay men, with only 28% including lesbian women and 9% including bisexual women (some studies included both genders). Over half of the articles focused on sexual health, and the only area in which lesbian women were addressed more than any other group was family-based research. It is no wonder that many health care professionals and women's health researchers have little awareness of the specific issues of this group. Ignorance leads to silence and marginalisation of lesbian and bisexual women's health research, just as these women are marginalised within Australian society (Pitts, Smith, Mitchell, & Patel, 2006).

#### *Omission of Sexual Orientation from Population-Based Study Demographics*

There is an almost universal failure to include sexual orientation measures in population-based studies in Australia. For example, there is no individual sexual orientation question on the five-yearly population census. Minimum demographic data collection for health related studies includes age, gender, socio-economic measures, geographical location of residence, and often race, ethnic and cultural measures, in recognition that all of these variables can influence health and

well-being. Failing to include a measure of Aboriginal/Torres Strait Islander status in any Australian health study would be deemed a major omission. By contrast, sexual orientation measures are rarely included unless sexuality is the specific focus of the research.

Sexual orientation is missing for many reasons. Some of these again relate to ignorance, where study designers have unconsciously omitted sexual orientation due to a heteronormative approach. That is they simply do not think of this population subgroup within their general assumptions of heterosexuality. Stigma also plays a role with researchers fearful of offending heterosexual participants therefore not including the questions. The ALWHS is a case in point, with sexual orientation questions not yet included in the older women's surveys, despite general agreement that the non-heterosexual women in this group are likely to be particularly marginalised. The ALWHS research team is concerned to protect the response rates for each survey and is not willing to compromise the trust of their older cohort by adding a sexual orientation question.

#### *Effects of Exclusion From Population-Based Studies*

One important problem resulting from the absence of population-based data is the lack of generalisability of our current lesbian and bisexual women's health knowledge. Lesbian and bisexual women's health research to date has largely been conducted using convenience sampling. These non-probability samples tend to include predominantly Anglo-Saxon, well-educated, middle-class, urban lesbian women and therefore do not represent specific issues for a more diverse range of women. For example, the Medline review mentioned above showed that 85% of the LGBT articles omitted any reference to race or ethnicity (Boehmer, 2002). Some studies over the last decade have recognised this lack of diversity and have purposively sampled ethnic minorities and rural lesbian

women in particular. However, older lesbian women continue to be missing from most studies (Wojciechowski, 1998).

Despite justified criticism of the lack of diversity and non-inclusion of more isolated women, Rothblum defends such community samples as being very useful in helping to increase the visibility of community issues (Rothblum, 1994). Australian convenience studies have provided valuable health information about women who attend community events or support groups and therefore have access to participate in the research. New knowledge from these studies has included issues of sexual health and behaviour (Richters, Bergin, Lubowitz, & Prestage, 2002), substance use (Murnane, Smith, Crompton, Snow, & Munro, 2000), cervical screening (Brown, Hassard, Fernbach, Szabo, & Wakefield, 2003), parenting (McNair, Dempsey, Wise, & Perlesz, 2002) and same-sex attracted youth issues (Hillier, Dempsey, Harrison, Beale, Matthews, & Rosenthal, 1998; Hillier, Turner, & Mitchell, 2005).

A further problem with the current reliance on non-probability studies is that they might actually be providing misleading information. Kirsti Malterud (2004) recently highlighted that the current level of knowledge, can create "epidemiological myths about the health of lesbian women", and argued strongly for representative studies to resolve these myths (Malterud, 2004, p. 463). For example, the prevailing understanding is that lesbian women are at higher risk of heavy alcohol intake. This has arisen from multiple studies that derived their sample from lesbian women attending community events at which alcohol was often an integral component. However, a recent population-based Dutch study showed that alcohol intake was similar between heterosexual and non-heterosexual women (Sandfort, Bakker, Schellevis, & Vanwesenbeeck, 2006).

Finally, another negative impact of the lack of representative data is the consequent

lack of knowledge transfer about lesbian and bisexual women to health care providers via education. Health care providers do not learn about the specific health issues, and are therefore largely unaware that there are health disparities that need to be addressed. Many knowledge gaps cannot be addressed without access to large studies, for example whether lesbian and bisexual women have a higher prevalence of ovarian cancer. This prevalence is suggested by a higher likelihood of ovarian cancer risk factors such as smoking, reduced childbearing and obesity (Dibble, Roberts, Robertson, & Paul, 2002), however has not yet been proven. The largest ovarian cancer study in the world is currently underway in Australia, which could answer this question, however study investigators have not included a sexual orientation question (personal communication with Chief Investigator Dr Anna de Fazio).

### **Ethical Dilemmas**

The ethical concern of any scientific research involving human participants is to prevent or minimise harm to those who participate in the research study. Ethical codes of practice for researchers in the health, behavioural and social sciences emphasise the importance of ensuring participants' privacy, dignity, and self-determination (Martin & Knox, 2000). When participants are members of stigmatised minority groups such as lesbian and bisexual women, researchers must take special care to ensure that the research process: (i) respects participants' rights to anonymity and confidentiality; (ii) is transparent and does not exploit participants; and (iii) has relevance for lesbian and bisexual women's lives, with study outcomes that provide some benefit.

In Australia, health care professional bodies have been slow to provide specific ethical guidelines related to research with lesbian or bisexual women. The Australian Psychological Society (APS) produced guidelines for psychological practice with lesbian, gay and bisexual clients in 2000,

however these do not discuss research at all (Australian Psychological Society, 2000). The general NHMRC guidelines on ethical conduct of research state that the guiding ethical principle is "respect for persons which is expressed as regard for the welfare, rights, beliefs, perceptions, customs and cultural heritage of persons involved in research" (NHMRC, 1999, p. 11). We believe that this is an appropriate framework for research with lesbian and bisexual women, particularly if researchers apply the concept of culture to include customs and beliefs relating to sexual orientation and behaviour (McNair, 2003). The NHMRC Human Research Ethics Handbook does have a section on research involving gay men and lesbians (NHMRC, 2001). This examines the research impact of stigmatisation and marginalisation, and in particular highlights issues of community involvement; the appropriateness of the language used; the appropriateness of the methodology; confidentiality and disclosure of sexual orientation; and respect for cultural difference. These recommendations will be incorporated into the discussion that follows.

#### *Generating Trust*

Historically lesbian women, gay men and bisexuals have been mistrustful of the scientific community and wary of researchers' motivations for obtaining sexual orientation information. Whilst changes in public opinion have seen a greater proportion of the public endorsing civil rights for lesbian women and gay men (Herek, 2002), lesbian and bisexual women are well aware of negative attitudes held by the public in general and also by health and mental health professionals (Rothblum, 1994). For this reason, many lesbian and bisexual women may be reluctant to participate in research that targets their sexual orientation, regardless of whether it is an anonymous survey or not. They may, however, be more willing to participate in research when investigators are part of their community, or when the research process involves consultation with community

representatives. The NHMRC recommends consultation with lesbian and gay agencies during the research design stage to be sure that language used is appropriate and non-judgemental. Making participants aware that research protocols and survey materials have been developed in such a way that respects their lives and gives lesbian and bisexual women a voice will encourage them to believe in the integrity of the research process and feel more comfortable about disclosing potentially sensitive information.

#### *Ensuring Anonymity and Confidentiality*

Allowing for anonymous participation and ensuring confidentiality of any information obtained is of primary ethical importance for lesbian and bisexual research participants. While population-based research largely involves anonymous data collection, research teams may still need to take extra steps to ensure that participants are aware of the process involved in anonymising data. Lesbian or bisexual researchers may face particular ethical dilemmas involving anonymity, confidentiality, and professional boundaries when participants are other lesbian or bisexual women from the same community (Woodman, Tully, & Barranti, 1995). Where participants and researchers share social situations, participants may assume (incorrectly in the case of population research) that researchers know confidential information about them and feel uncomfortable about this. Special care must be taken to keep researcher/friend roles separate and it may even be inappropriate for a researcher's friends to be in her research sample.

#### *Disclosure of Sexual Orientation*

We cannot guarantee that all lesbian and bisexual women involved as participants in population-based research will disclose their sexual orientation. For some participants the threat of discrimination, harassment and social ostracism, and even violence, following disclosure of non-heterosexual identities is very real and assurances of anonymity may

not totally overcome this. Bradford et al suggest that willingness to disclose to researchers also varies according to cultural and personal factors including age, religion and education level (Bradford, White, Honnold, Ryan, & Rothblum, 2001). For example, older non-heterosexual women are known to deliberately conceal their sexual orientation to protect their family, for religious reasons, or as a survival strategy; and tend to avoid defining themselves with any sexual identity (Wojciechowski, 1998). Perceived social desirability of non-heterosexual sexual orientation also plays a role, with some women choosing not to disclose their sexual orientation in order to create a 'better' impression to the researcher (Meston, Heiman, Trapnell, & Paulhus, 1998).

The place in which a questionnaire is completed (at home, at work, in person, researcher-completed) may also impact on the degree of disclosure (Boynton, Wood, & Greenhalgh, 2004), and so giving participants a choice as to where they complete a survey is important. In recent research with same sex attracted young Australians, many of whom had not disclosed their sexual orientation to their parents, young people could fill out the survey on the net or in hard copy which could be obtained by phone or through the post. In this way young people could choose the option that they felt most comfortable with (Hillier et al., 2005).

#### *Respect for Cultural Difference*

Reporting research findings to both the health care provider and the lesbian and bisexual communities is important. This can be difficult if results are sensitive or potentially pathologising. The NHMRC guidelines recommend being sure to avoid comparisons with heterosexual populations that might imply inadequacy or blame on the part of the lesbian or bisexual group (NHMRC, 2001). We also assert from our personal experience that making an effort to report findings to lesbian and bisexual

community is a further sign for the community that researchers are trustworthy and truly interested in the wellbeing of the participants. We suggest that this will help to increase lesbian and bisexual women's trust in the scientific community.

### **Methodological Limitations**

#### *Theoretical framework*

The theory of sexual orientation that underpins the study is important to the whole research design, from formulation of research questions to interpretation of results. A review of 152 public health research papers including lesbian women and gay men found that only 4 papers reported the study's conceptual framework or how researchers had defined sexual orientation (Sell & Petrulio, 1996). For example, two divergent approaches to understanding sexual orientation are that sexual orientation is an individual characteristic, present from birth or early childhood (essentialist approach, which tends to be more favoured by gay men); and that sexual orientation is a choice, determined in part by social context (constructivist approach, more favoured by lesbian women) (Martin & Knox, 2000). Each theory can lead to different sexual orientation measures being used. So while an essentialist researcher would ask participants to label their lifetime sexual orientation, a constructivist would take fluidity of sexual expression into account, and therefore include questions regarding whether the sexual orientation of participants has changed over time.

Similarly, linear models of developmental stages of sexual orientation, which are still popular amongst some psychologists and researchers, suggest that the final stage of integration into the mainstream is the ultimate goal (Cass, 1979). Other researchers would subscribe to a situational model, where different stages might occur in different situations, and where a sexual orientation that is submerged in lesbian

culture is a legitimate goal. These different frameworks again would generate different questions regarding social interactions.

### *Sampling in Population-Based Studies*

The limitations of convenience sampling have been outlined above. Theoretically, population-based sampling should overcome some of the issues such as poor representation of diversity and inability to find women who are connected to the lesbian or bisexual communities. However, population-based sampling also has limitations. The sample size within these studies needs to be large to generate enough power to find statistically significant differences between lesbian, bisexual and heterosexual women, if they exist, given the small proportion of non-heterosexual women. Also, the sampling framework must take into account the uneven geographic distribution of non-heterosexual women, many of whom are known to prefer an urban environment.

### *Measuring the Multiple Dimensions of Women's Sexual Orientation*

Homosexuality is a complex, multi-dimensional phenomenon whose salient features are related to one another in highly contingent and diverse ways. (Laumann, Gagnon, Michael, & Michaels, 1994, p. 320)

There are many dimensions of sexual orientation that can be measured. These include:

- sexual identity – a self-defined label
- sexual behaviour or experience
- sexual attraction
- emotional attraction
- social connection and participation with other lesbian/ bisexual women/communities
- romantic attraction
- degree of disclosure of sexual orientation to others
- time since self-identity as lesbian/bisexual
- degree of fluidity of sexual orientation

Typically, less than 2% of women in population-based studies identify as lesbian or gay, whereas sexual behaviour or sexual attraction tend to reveal a larger proportion of people. For example, in a large telephone interview study of Australians (Sex in Australia study), 0.8% of the women identified as lesbian and 1.4% as bisexual, while 15.1% of women reported same-sex attraction or experience (Smith et al., 2003). A USA study found that 1.4% of women identified as lesbian or bisexual, 4.3% had been involved in same-sex sexual behaviour since puberty, and 7.5% same-sex attraction (Laumann et al., 1994).

Many lesbian and bisexual women, in particular, have been shown to display little congruence between different dimensions of sexual orientation. When comparing women and men in the Sex in Australia study, the male respondents displayed more congruence between their identity, behaviour and attraction than did female respondents (Smith et al., 2003). Morris and Rothblum (1999) found that amongst lesbian women, there were no strong correlations between the dimensions of sexual identity, sexual experience, years out, disclosure and lesbian community participation. Only sexual experience and identity were moderately correlated. The authors concluded that we "can't assume that lesbian identified women behave in predictable ways" (p. 555). What this finding tells us is that different measures of women's sexual orientation will most likely identify quite different populations which will of course not be comparable. Establishing reliable and consistent measures of sexual orientation is therefore one of the first challenges when inserting sexual orientation items into population based samples.

### *Limitations of the Use of a Sole Measure of Sexual Orientation*

Studies have tended to include a self-identification measure, usually as the only measure. This is often based on the original scale developed by Kinsey, in which participants rate themselves according to a

six-point scale from exclusively heterosexual to exclusively homosexual (Kinsey & Institute for Sex Research., 1953). Many researchers use this as a continuous variable as Kinsey intended and ask participants to mark where they sit on a line with no numbers, and then use a template to categorise the identity with a number (Morris & Rothblum, 1999). This measure has also been used as a discrete variable, in which participants select one of five identities. For example, the ALWHS asked women to indicate which of the following five categories best described their sexual identity: 'I am exclusively heterosexual', 'I am mainly heterosexual', 'I am bisexual', 'I am mainly homosexual (lesbian)', or 'I am exclusively homosexual (lesbian)'. Participants could also select 'I don't know' or 'I don't want to answer'.

There are several limitations to using identity as the sole measure of sexual orientation. Many non-heterosexuals may reject the use of labels for themselves or not identify with the particular labels used in the study, despite having a same-sex partner, or being part of the lesbian community. The language used within such a sole measure may alienate participants if they don't apply the particular labels presented to themselves. Also, it is by no means clear what participants mean if they select 'mainly heterosexual' or 'mainly homosexual/lesbian' if no opportunity is given for them to describe their attraction and behaviour. Some may be selecting this category on the basis of sexual activity, or attraction rather than identity. This becomes problematic when attempting to interpret results. For example, the mental health status of 'mainly heterosexual' women in the ALWHS was found to be significantly worse than that of the lesbian or heterosexual women, particularly in the mid-aged cohort, and associated with lower levels of social support (McNair et al., 2005). However, we do not know who this group regarded their social group to be or whether any of them have a same-sex partner.

Other studies have used sexual behaviour as the main measure. For example, a Dutch population-based study of over 7,000 people used self-reported sexual behaviour in the preceding year as the only sexual orientation measure (Sandfort et al., 2001). The 1.4% of women with same-sex partners had a higher prevalence of substance use disorders and mood disorders than the women with male partners, however without sexual identity or social affiliation measures the study cannot attempt to comment on the reasons for this.

Sexual attraction has become a useful measure in Australian studies concerning the sexual health and well being of young people (Rosenthal, Smith, & Lindsay, 1998; Smith et al., 2003). This measure is appropriate for a number of reasons. First, young people tend to experience sexual attractions long before they assign themselves with a sexual identity and so by using attractions as a criterion the size of the potential research population is maximised.

Second, unlike the terms 'gay' and 'lesbian', 'same sex attracted' is more user friendly for organisations and for young people. For example, Hillier, Warr, and Haste (1998) were given permission to distribute a rural survey through education departments using a question about attraction rather than one that used the terms gay or lesbian (Hillier et al., 1998).

Third, use of the term 'same sex attraction' does not foreclose on young people's sexual futures. Young people who are same sex attracted today may or may not become the gay and lesbian adults of the future. When carrying out research with same sex attracted young people however, it is even more revealing to use several items to measure sexual orientation including quantitative measures of identity, behaviour, attraction and qualitative explanations of these, gender of last partner and relationship status (Hillier et al., 1998).

### *A Multi-Dimensional Approach*

The Sex in Australia study provides an example of a population-based study that has used multiple measures (Smith et al., 2003). Having included measures on identity, experience and attraction, the study was able to demonstrate the incongruence between measures, particularly for women. The fact that there is often little overlap between sexual orientation measures among women is very good reason to include a range of sexual orientation measures. We suggest that studies should aim for a high level of inclusiveness by using a multi-dimensional set of measures. Ideally, as a minimum, sexual identity, behaviour and attraction should be measured (Sell et al., 1995). Adding attraction and behaviour is important not only to increase the proportion of non-heterosexual women identified. Women with same-sex attraction and/or behaviour are found to display different health outcomes to heterosexual women, regardless of identity.

The three measures of identity, behaviour and attraction are not enough for health research that incorporates a social perspective, as they do not recognise sexual orientation as a cultural and social phenomenon (Boehmer, 2002). Important measures that relate to the social context of sexual orientation are the length of time since coming out, the level of disclosure of sexual orientation to others (outness) and the degree of participation in the lesbian or bisexual community. These are all relevant when considering the effect of social connectedness on health and levels of support available. For example, the likelihood of experiencing discrimination and victimisation including violence is increased with time since coming out and with increasing levels of disclosure to others (D'Augelli & Grossman, 2001). Conversely, the psychological health of lesbian women is found to be more positive with more years of self-identification as lesbian, and more involvement in the lesbian/bisexual

community (Morris, Waldo, & Rothblum, 2001).

### **Recommendations for Research and Implications for Health Policy**

We have developed a series of recommendations focusing on the inclusion of lesbian and bisexual women in population-based studies. These recommendations address some of the systemic, ethical and methodological challenges that we have outlined, in order to maximise inclusiveness, participant engagement, levels of trust, and sense of safety in the research process. Some of these have already been presented in the body of the paper and all are presented in Table 1.

The inclusion of sexual orientation measures will produce benefits that far outweigh the risks associated with the unproven fear of offending heterosexual participants. Also, all non-exclusively heterosexual women warrant attention, not just those who may respond to a single identity or behaviour question. We recommend that a broad range of measures is included. The sexual identity measure would preferably use a wide array of terms from which participants can select, including 'lesbian', 'gay woman', 'queer', 'bisexual', 'non-heterosexual', 'other', and add an open-ended question for participants to explain their identity further if they choose. Ideally in the future we can work towards multi-dimensional scales that measure all of these factors, however there is much empirical research to be done first to validate the use of such scales in large representative samples.

Engagement of lesbian and bisexual participants in the research process is important to build trust and increase the likelihood that they will disclose their sexual orientation. This has been demonstrated by the successful national HIV/AIDS strategies since 1989 (Australian National Council on AIDS and Related Diseases, 1998), which involved grass-roots health workers, volunteers and consumers in partnership

with government and non-government agencies. This approach enabled effective health promotion and harm-minimisation approaches and avoided stigmatisation of sexual orientation. Research teams need to raise their own awareness of the social pressures, levels of discrimination and impact of marginalisation faced by lesbian and bisexual women. In parallel, building partnerships between researchers and lesbian and bisexual community can reduce the isolation faced by individual researchers. Trust is further developed if there is a commitment to making the results accessible to the participants and wider lesbian and bisexual communities.

Addressing the systemic silence with regard to lesbian and bisexual women's health is a pressing need. While research evidence from representative studies will emerge over coming years, lesbian and bisexual women's health requires policy attention now to build research capacity and community confidence. Sexual orientation should be added as a health determinant to Australian health policy frameworks to enable a mainstream approach for this population. Australia has demonstrated its capacity to do this, with national policies that incorporate a sexual orientation indicator including the National Suicide Prevention, Mental Health, Drug, and Homeless Strategies. Funding for research has started to trickle down from some of these policies for specific lesbian and gay initiatives, however to date most have targeted young people. Conversely, the National Women's Health Policy includes sexual orientation only in the context of women's reproductive health (Leonard, 2003), and Australian aged care policy is completely silent on sexual orientation (Harrison, 2005). Lobbying for adequate funding of research that focuses on lesbian and bisexual women's health is also crucial, as is repeated attempts to publish research findings in mainstream health journals.

Only when we have a real commitment to inclusion of the diversity of women's sexual

orientation in Australian policy and research will we start to fully understand the specific health issues that these women face. Then we will have a chance to reduce their marginalisation and adequately meet their health care needs.

### Author Notes

Ruth McNair (corresponding author), MBBS, FRACGP, Senior Lecturer and PhD Candidate. The Department of General Practice, University of Melbourne, 200 Berkeley St, Carlton, Vic, 3053. Email: [r.mcnair@unimelb.edu.au](mailto:r.mcnair@unimelb.edu.au)

Melanie Gleitzman, PhD, Lecturer. School of Psychology, University of New South Wales, Sydney, NSW, 2052.

Lynne Hillier, PhD, Senior Research Fellow. Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, 3000.

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