

Literature Review and Survey Instruments

submitted to:

Ottawa-Carleton GLBT Wellness Task Group

by:

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A. Introduction

In August 2000, Social Data Research Limited was contracted by Pink Triangle Services to provide support to the Ottawa-Carleton GLBT Task Group in identifying the wellness needs of GLBT residents of Ottawa-Carleton. This Phase Two report summarizes the following:

- B. Literature Review that was conducted to aid in questionnaire design
- C. Survey Methodology

B. Literature Review

by Gordon Josephson and Anne Wright
for Social Data Research Limited

The following literature review focused on obtaining information of use in the preparation and administration of a wellness needs assessment survey in Ottawa's GLBT communities. The purpose of the literature review was to find information that would help establish "what to ask, how to ask, and who to ask" in conducting the needs assessment. Specifically information was sought on:

- 1) other surveys of wellness needs and strengths within GLBT communities,
- 2) descriptions of methodologies and sampling strategies, including how research in the GLBT communities has dealt with uncertain prevalence rates and ascertaining sexual orientation
- 3) summaries of trends in health behaviours, health beliefs, morbidity, and mortality in GLBT communities,
- 4) descriptions of health issues typically examined in GLBT wellness initiatives, and
- 5) examples of innovative programs and services and/or initiatives undertaken to support wellness in GLBT communities.

Information was sought through web based searches using the directory Yahoo and the search engine Alta Vista. Searches involved combinations of the terms gay, wellness, lesbian, survey, health, methodology, health needs, bisexual, and transgendered. Published literature was searched through the electronic databases PsychInfo, Medline, Eric (social sciences), AIDSline, Healthstar, and Sociofile. Search terms included combinations of, gay, lesbian, bisexual, gender identity, homosexuality, transsexualism, sexual orientation, with the terms health, "health beliefs", "health behaviour", questionnaire, survey, methodology, needs, assessment, wellness, mortality, and morbidity.

The results of the literature search are presented below using the categories listed above. The information best captured in category five, "examples of innovative programs, services or initiatives" is not reviewed here but has been compiled and is included in the resource materials accompanying this report.

1. Other Surveys Of Wellness Needs And Strengths Within GLBT Communities.

On-line reference was made to a "newly launched gay health survey" at **GayHealth.com**. The survey ranks the top health concerns of gay men and lesbians. The GayHealth.com survey was conducted by FlashFocus, a market Research company, and included more than 1,750 respondents. Questions appear to have included a ranking of the top health concerns for men and women. GayHealth.com was founded by gay and lesbian medical professionals to serve the health care needs of the lesbian,

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gay, bisexual and transgendered community. It is a website with health news, columns, Q & As, and searchable health care resource database.

Website information indicates "more than" 1,200 gay men and lesbians were surveyed in a **Community Health Survey sponsored by K-Y Brand personal lubricants**. The survey solicited participants at the millennium march on Washington this year. Questions appear to have included mental health, substance use, relationship to health care professional, partner abuse, and safer sex practices. Depression came out as a suggested major focus for gay and lesbian health organizations.

An on-line description speaks of a "**National Survey on Gay Men's Health**" being near completion in 1997. A researcher at the University of California at San Francisco interviewed more than 1,700 gay and bisexual men living in New York, San Francisco, Chicago and Los Angeles. Telephone interviewers randomly dialled households in selected neighbourhoods to identify men who have sex with men. The interview took up to an hour to complete and included questions on a range of topics including health care, discrimination and homophobia, sexual activities, emotional well being, alcohol and drug use, attitudes about their community, as well as the AIDS epidemic's impact on their lives.

According to an on-line description, the University of Florida's "**First national survey of gay and lesbian issues**" examined gay rights nation wide and published the findings in "**Private Lives, Public conflicts.**" The researchers found that gays and lesbians continue to experience an inordinate amount of hostility on a daily basis.

Lesbian Health Survey conducted by the Fenway Community Health Center in Boston, a self-report questionnaire that surveyed a national sample of lesbians. Five thousand questionnaires were distributed to 392 contacts in 49 states in the fall of 1987. The contact list was developed from personal contacts, names of organizations from gay and lesbian publications, and health care centers. The contacts included individuals, religious groups, college organizations, lesbian and gay organizations, women's centers, bookstores, bars, and health centers. The researchers attempted to distribute the questionnaire around the country to increase representativeness. To assist this proportional representation, a letter was sent to each contact asking how many questionnaires they felt they could distribute to women in their area. Once these requests were reviewed, varying numbers of questionnaires were mailed to the contacts for their distribution in their location. After obtaining feedback on a pilot questionnaire (100 people critiqued the survey) a 17 page questionnaire was developed that asked about:

1. demographics
2. personal health practices
3. health history of self and family
4. sexual activity and history
5. history of traditional women's health conditions
6. mental health practices and history (e.g. use of mental health services)
7. work and environmental influences
8. genetic attributions hypothesized by others to be related to homosexuality

Self-identity and labelling were measured using a Kinsey Scale by which respondents were asked to represent their sexual orientation along a 7-point continuum, with 7 being exclusively heterosexual and 1 being exclusively homosexual.

The National Lesbian Health Care Survey conducted by Ryan and Bradford through the National Lesbian and Gay Health Foundation (NGLHF) from 1983 to 1988. Full report was published in July 1998 by NLGHF. Purpose: expand the knowledge about health care needs and concerns of women. Approximately 100 individuals participated in the development of the questionnaire, three versions were piloted throughout the U.S. Health was defined holistically and incorporated the following aspects of lesbians lives:

- community and social life
- general health and health care
- gynaecological health and health care
- mental health and health care
- substance abuse and eating disorder
- physical and sexual abuse and help-seeking behaviours
- discrimination
- self-care
- outness
- demographic questions were also asked to assess representativeness of lesbians surveyed

The survey was mailed to gay and lesbian health care organizations. Efforts made to reach specific group such as the military, shelters, prisons, reservations. People were notified through bookstores and advertisements in gay newsletters and other publications. 4000 questionnaires were distributed approximately half (1,925) were completed and returned.

The Coalition for Lesbian & Gay rights in Ontario (1997) conducted a survey on the experiences of sexual minorities in Ontario's Health Care and Social Services systems. Data was gathered through public forums, meetings, and other forms of personal contact, and (mostly) from their questionnaires. Six thousand of these were distributed and 1,233 were returned but it was unclear how many actually made it into people's hands (hence no response rate). Surveys were distributed through ads in gay newspapers, and flyers, through a tollfree phone line, through community groups, selected bars, social events, and dances. No attempt was made to randomize the sample. The actual questionnaire is not included in the final report, questions included use of health care professionals, an indication of how "problematic" that use was, amount of stress in life, occurrence of verbal harassment, physical assault, and use of welfare services. Separate discussions are provided for youth, francophones, elderly, the disabled and those living outside of urban areas. The report also included outreach to transgendered individuals through support groups, advertisements in transgendered publications, a notice distributed at the Gender Identity Clinic of the Clarke Institute of Psychiatry, contacts through social service agencies, word-of-mouth, direct outreach in bars and on the street and snowball sampling (total sampled were 33 individuals aged 20 to 60 years).

Catherine Browning (1998) conducted a survey on sexual assault in the GLBT community in Ottawa-Carleton. Questionnaires on sexual assault were distributed through GLBT groups in the city. A letter introducing the project was mailed or delivered to group facilitators or collectives, or directly included in mail-ready questionnaire packages. Surveys were also distributed from a table at an information fair. Seventy people completed the questionnaire.

A good deal of work on community health has been done in Vancouver, however, the results of this work have been reported in several different formats and pieces and the relationship of each report to each other is often unclear. One such report, "Lesbian, Gay, Bisexual and Transgendered Health Care Access: A LGBT Health Association Research Report" (1999) includes a description of a survey and a specific discussion on methodological issues around sampling. The survey (pg 33 and 34 of the report) consists of only 14 questions and focuses mostly on demographic information and the use of health care services. The discussion of method suggests that the study was conducted with very little methodological rigor and without a clear central procedure and reporting body.

The Gay, Lesbian, Bisexual and Transgendered Health Access Project is a collaborative community-based program funded by the Massachusetts Department of Public Health (MDPH). It has been involved in several surveys relating to GLBT health including the

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following as described at their website (listed below) :

1) Access and Use of Health Services by Lesbians and Gay men in the Greater Boston Area: An Exploratory Study.

Population - 425 self-identified gay and lesbian women: 123 women (29%) and 302 (71%) men. The overwhelming majority identified as Caucasian/White, and tended to be middle class and well-educated.

Methods - Self-administered anonymous surveys were distributed through mailing lists of gay, bisexual and lesbian identified organizations with a response rate of 46% (n=336). An additional 36 (66%) responses were collected through outreach to these organization's members, and the remaining 79 (100%) responses through outreach at bars and bookstores. Responses from bisexual or heterosexual identified individuals were excluded (n=26).

2) Boston Young Gay Men Study

Population - Five hundred and eight men, ages 18-29, who reported having sex with men or identified themselves as gay or bisexual, and were either enrolled in an accredited college in the Boston area or, if not in school, were ages 18-24.

Methods - Outreach efforts were targeted to the campuses of 17 Boston area colleges with 400 or more male students. Additional outreach sites included community health centers, and gay nightclubs. Advertisements were placed in the local media.

Participants were privately interviewed at the community health center using a standardized questionnaire to obtain demographics, history of STDs, substance use and sexual behaviour. Participants were tested for STDs. "Measures of self-acceptance of homosexuality (Fischer scale) and to identify depression (CES-D scale) were also used." Data was collected in 1994 by the Institute for Urban Health Policy and Research, Boston Department of Health and Hospital and by the Fenway Community Health Center.

3) Elder Needs Assessment Survey

Population - 164 gay, lesbian and bisexual respondents , aged 50-88 (mean = 60.5 years) living in the greater Boston area, 26% were women.

Methods - Requirements for participation included involvement in a same sex relationship during his or her lifetime, age (50 and older) and living in the greater Boston area. Researchers advertised in local newspapers, at bookstores, places of worship, and gyms, and through organizations known to the elder gay community. 222 surveys were distributed with a response rate of 74% (164). The survey included questions regarding basic demographic information, access to health care, and service needs from the community.

4)Lesbian, Gay Bisexual Young Adult Survey

Population - 218 lesbian, gay and bisexual young adults aged 14-25: males (57.3%) and 93 females (42.7%). Mean age was 22 years old.

Methods - Self-administered anonymous surveys were distributed during 1994 Gay Pride March, gay and lesbian identified bars and local newspapers, and through JRI outreach workers. Completed surveys were mailed to JRI Health in postage paid return envelopes.

The Access Project has also produced a report, Health Concerns of the Gay, Lesbian, Bisexual and Transgendered Community (which could not be located through library searches). The web site also briefly mentions a state wide survey with health care providers. More information on the project, as well as copies of above reports, can be obtained from JRI Health Boston MA 617-988-2605, fax 617-988-2629 or at www.glbthealth.org.

The Young Men's Survey - estimating HIV seroprevalence and risk factors among young men who have sex with men. The Center for Disease Control and Prevention, in collaboration with state and local health departments, has developed a venue-based probability survey of young men who have sex with men. Conducted in seven metropolitan areas in the U.S., the Young Men's Survey combines outreach techniques with standard methods of sample surveys to enumerate, sample, and estimate prevalence outcomes of a population of young men who frequent public venues and who have sex with other men.

- teams (a) identify all public venues within a defined area that are frequented by young men who have sex with men; (b) from this universe, build monthly sampling frames of venues that yield sufficient numbers of young men who have sex with men; and (c) sample young men from venues randomly selected from monthly sampling frames.

- Young men who agree to participate in the Young Men's Survey are interviewed, counselled, and tested for HIV, hep B, and syphilis in vans parked near sampled venues (MacKellar, Valleroy, Karon, Lemp, Janssen, 1996).

An assessment of lesbians and gay men's health care was conducted by Ramirez in the U.K. using a questionnaire adapted from the Health of the Nation 1992 study in the UK. The study uses a convenience sample of lesbians and gay men attending three major gay events in London. A team of 10 trained field workers of both sexes were located with other health information exhibits at each event. Field workers actively targeted/approached a minority group member (e.g. visible minorities within the gay community) for participation. A total of 2,045 questionnaires were completed with 1,913 suitable for analysis: 1,260 men, 647 lesbians and 6

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transgendered (men to women) people. Health behaviours, top health concerns and service use was asked. There appears to be an attempt to measure stress and stress due to sexual orientation but it is not clear what the measure involved and is likely a single question.

Exploring the Health and Well-being of gay, lesbian, bisexual and two-spirit people in Canada, the McGill School of Social Work (Ryan, Brotman and Rowe, May 2000) conducted a literature review and five focus groups to "validate the literature review, provide a Canadian perspective and add the voices of aboriginal and rural citizens". It did not include a survey but it is recent and the authors could be contacted for the full report.

In an exploratory descriptive study of **lesbian and heterosexual women's health life-style activities and health histories**, Bunting (1992) distributed 200 questionnaires by "non-probability snowball sampling" through women's bookstores, community groups, and gay and lesbian organizations. Participation could be entirely anonymous. A sample of 79 women was obtained (52 heterosexual and 27 lesbian), the sample consisted of predominantly white middle class and college educated people. The questionnaire used fixed-alternative questions to gather demographic information, health history data, and self-reports of social interaction patterns and sexual partner preference. Health life-style activity data were obtained using questions that asked respondents to indicate the degree to which various health-related and illness-screening activities were a part of their life-style on a 4-point Likert scale, from not a part of my life-style (1) to a very central part of my life-style (4). Additional health history questions investigated participation in mental health counselling, birth control use, pregnancy history, and description of general health status.

Jones and Gabriel (1999) conducted a **survey of the psychotherapy histories of lesbians, gay men, and bisexuals**. The number, duration, and circumstances of each therapy episode, and respondents' view of their therapist and of therapy, were identified. Respondents were recruited through a variety of means: notices mailed to 23, 000 names obtained from national gay/lesbian mailing lists, posted on Internet bulletin boards and in gay/lesbian publications, and distributed at conferences and gatherings, and through informal networks. The variety of recruitment methods used made it impossible to report on the relative success of each method or to estimate response rates. Each person who requested a copy of the questionnaire received a packet that included a reply envelope and a postcard to request a summary of the findings. No follow-up reminders were sent. Six hundred useable questionnaires were returned: 63% from women and 37% from men.

- Respondents were offered a choice of characterizing their sexual orientation as

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"unconflicted gay or lesbian", "conflicted gay or lesbian", "unconflicted bisexual", "conflicted bisexual", "conflicted heterosexual" or "other".

Pisarski and Gallois (1996) conducted a **needs assessment of Brisbane Australia lesbians**. The study did not have a health focus but a description of its method is included here. Questionnaires were distributed to Brisbane organizations that were either known lesbian social or service groups or were women's organizations that provided services to lesbians. This was done in an attempt to contact as many lesbians as possible, including lesbians who were open about their sexuality and those who were closeted. The questionnaire was hand delivered to sixty participants, who were asked to return it in an attached pre-paid envelope; the rest were distributed to representatives of various organizations. Of the 250 questionnaires distributed 101 were returned. The questionnaire was in two parts, the first contained 23 questions seeking demographic information. Part two presented a series of 75 statements which were answered on a six-point scale, ranging from 1=disagree strongly to 6= agree strongly. The statements contained items aimed at identifying the needs of lesbians as individuals and the needs of specific groups.

Moran (1996) explored **lesbian health care needs through a survey administered at a Toronto softball league organizational meeting**. Midway through the meeting participants were informed of the survey and its purpose. Only surveys completed and returned on the night of the meeting were used for analysis. A questionnaire on the potential health care needs of lesbians was developed specifically for this study. The Health Status of Canadians; Report of the 1991 General Social Survey was used as a guide for the structure and wording of questions. The final questionnaire contained 61 yes-or-no and multiple-choice questions on demographics, health care use; preventive care; habits, diet, and exercise; mental health and physical health. Of 360 women invited to the meeting, 205 attended and 195 completed the survey. The questions used for analysis were the 186 in which the women answered yes to the question "Are you a lesbian"?

White and Dull (1997) describe a **study of health risk factors and health-seeking behaviour in lesbians conducted in Oregon**. The research involved a state wide self-administered survey of members of a lesbian community organization (324 respondents).

2. Descriptions Of Methodologies And Sampling Strategies, Including How Research In The GLBT Communities Has Dealt With Uncertain Prevalence Rates And Ascertaining Sexual Orientation

a) Methodological concerns

Kauth and Prejean (1997) express a concern with studies that combine bisexual and gay men's responses, suggesting that the two groups vary considerably on psychological variables. The authors further suggest that future research with gay people should strive for larger and less urban samples, more ethnic minorities and women, and comparison groups for matched heterosexuals. They suggest both "snowballing" sampling, a survey strategy which employs social networks to tap into hidden communities, and surveying from as many different sources as possible including non-gay identified agencies in order to increase the heterogeneity of the sample. Uncontrolled dissemination of questionnaires, however, prevents accurate estimates of response rates and prohibits data about non responders for inferences about potential sampling bias.

Solarz (1999) has written a book entitled Lesbian health: Current assessment and directions for the future. The book contains a thorough discussion of methodological challenges of doing work in this population.

b) Sampling Strategies

The use of focus groups for developing AIDS related health surveys is discussed by O'Brien (1993) who suggests it is helpful to ask focus group members for ideas on how to best reach people with a questionnaire. Suggestions by participants included, posting a notice on electronic bulletin boards, working with staff of businesses owned by members of the gay community, and advertising in the performance programs of the local gay men's chorus. Visible minority men in the focus group offered to recruit other such minority men.

Martin and Dean (1990) offer a discussion of sampling challenges with AIDS studies involving gay men. After considering other options they adopted an approach which employed a combination of (a) recruitment from diverse channels and sources within the gay community, and (b) personal referral into the sample by those individuals recruited through these sources. In order to establish one segment of the sample as a probability sample, in the traditional statistical sense, gay organizations were selected

as one of the recruitment sources, since a reasonably complete sampling frame of gay organization members could be constructed. Participants were recruited through five sources: Gay Organization Members, Unsolicited Volunteers, Pilot Sample Referrals, Gay Pride Festival Participants, and Sexually Transmitted Disease Clinic clients.

- A community-based sample of 746 20-70 yr old men who identified as homosexual was constructed. The participants were comparable to randomly drawn San Francisco samples with respect to age, race, and degree of "being out". The authors of this study of AIDS noted that although conventional probability techniques are the method of choice, a reasonably representative sample appears to have been assembled in the absence of a citywide sampling frame, a door-to-door enumeration, or a random-digit dialling screening procedure.

Fish (1999) explores issues relevant to getting lesbians to complete a questionnaire on perceptions of health-related issues. The author discusses 6 issues that affect likelihood of participation: budget and incentives, topic, time taken to complete a questionnaire, the nature of the sample, publicity, and anonymity, confidentiality, and reminders.

The difficulties with non-random sampling strategies are highlighted in a discussion of research into the economic status of gay and lesbian households (Lee Badgett, 1998). Non-random samples at events likely to attract more economically stable and mobile individuals show higher income levels. The author reviews 3 more statistically appropriate samples (that used random sampling in the broader population). Sampling results suggested rates of homosexuality based on adult sexual behaviour of 4.6% of females and 4.9 % of males and found that gay or bisexual men earned as much as 27% less than heterosexual men; lesbian and bisexual women earned less (but not statistically significantly so) than heterosexual women. In a second study 5.7% of people identified as gay lesbian or bisexual (it involved a face to face survey); household incomes for these men and women were indistinguishable from the incomes of heterosexual households. The third random selection study reviewed found that 3% of participants identified as gay and lesbian and comparison of incomes showed gay and lesbian people to be in lower family income categories.

c) Particulars Around Measuring Certain Concepts in this Population & Particular Measures

DiPlacido (1998) reviews the literature on the stress experienced by lesbian, gay men and bisexuals as a result of their minority status and recommends that both external and internal stressors be examined with this population. It is suggested that gay related external stressors (discrimination and antigay violence) will be more apparent in

the out individual and internal stresses (emotional inhibition, self-concealment, internalized homophobia) more apparent in the less out individual. The author reports initial findings from a study of stress and well-being involving 17 lesbians in which a positive correlation was found between internal stressors and wellbeing. She reports beginning a study to extend this analysis to a survey of 500 racially mixed lesbian and bisexual women in New York City.

Coyle (1993) used a 30-item scale called the General Health Questionnaire (GHQ-30) to examine the psychological well-being of 140 gay men in the U.K.

Measures as identified in e-mail to Bruce by Brad Buxton:

- Quality of Life Index, Generic version III by Ferrans & Powers, 1984 and 1998
- Subjective Quality of Life Profile, (SQLP) copyright: Apret, Script-Inserm
- Quality of Life Profile, copyright Centre for Health Promotion

A Well-being index has been recently developed. It consists of 11 items and assesses general satisfaction with life and particular satisfaction with specific roles. Participants respond on a three point scale ranging from "dissatisfied" to "satisfying" regarding how they found their leisure time, work in and around the home, work on the job, sexual relationships, friendships, and other items. The measure looks interesting; it was newly created by Frable, Wortman and Joseph (1997) who also used the Rosenberg Self-Esteem Scale (10 statements) and the Hopkins Symptom Checklist (58 items) to measure participant functioning.

Shidlo (1994) reviews the measurement of internalized homophobia and suggests it is better called internalized homonegativity. The author suggests the use of, and conduct studies using, the Nungesser Homosexuality Attitudes Inventory (NHA) (created by Nungesser, 1983). The measure consists of three subscales and is a 34 item instrument. The subscales are: (1) attitudes towards the fact of one's own homosexuality (Self); (2) attitudes towards homosexuality in general and toward other gay persons (Other); and (3) reactions toward others knowing about one's homosexuality (Disclosure). The tool obtained good measures of internal consistency ($\alpha = .94$).

d) Estimating Prevalence Rates and Ascertaining Sexual Orientation

Self assessment is the most typical method for the assessment of sexual orientation in research published in the Journal of Homosexuality 1974-93 (Chung & Katayama, 1996).

A 1994 University of Chicago survey of adults estimated prevalence of homosexuality among males at 2.8% and among females at 1.4%. Cameron and Cameron (1998) claim these are inaccurate due to the exclusion of adults over the age of 59 from the study. They corrected the estimates to 2.3% (males) and 1.2 % (females).

Michaels (1996) offers an extensive discussion of the measurements of the prevalence of homosexuality in the United States. Michales describes results from the National Health and Social Life Survey "the most comprehensive probability based survey of sexual behaviour in the U.S.". Questions pertaining to homosexuality covered three dimensions: behaviour, desire, and identity. Behaviour mainly refers to same-gender sexual experience or partners since age 18 years. Desire was measured by combining responses to two items in the survey: sexual attraction to same-gender individuals and appeal of having sex with someone of the same gender. In the NHSLs study, homosexuality referred simply to a self-definition as homosexual or bisexual (or a variant such as gay or lesbian). Desire and identity were asked about in the present tense, in a global way. In the study 9% of women and 10% of men reported any homosexual behaviour, desire, or identity as adults. Thirteen percent of women and 6% of men reported both same-gender sexual experience and some level of same-gender desire but did not self-identify as homosexual or bisexual; most considered themselves heterosexual with a small number identifying as something else.

A U.S. national probability sample of males interviewed by telephone and asked their sexual orientation found 3.7% reported they were homosexual or bisexual. When compared to the usual samples drawn from the gay world, the sample produced larger numbers of men with little education, married men, older men, minorities, and those living in small towns (Harry, 1990). Respondents were asked "Would you say that you are sexually attracted to members of the opposite sex or members of your own sex?"

3. Summaries of trends in health behaviours, beliefs, and morbidity and mortality in GLBT communities.

For the methodological reasons described above very few solid epidemiology studies have been conducted with the GLBT population. A further difficulty for Canadian communities is that the overwhelming majority of statistics on rates and prevalence for the various health issues examined are based on U.S. samples.

Some general trends are presented in the literature but arguments are also made that sampling bias is responsible for many of the findings. For example some studies have shown higher rates of alcoholism in lesbian women and some authors attribute this to sampling from bars and social venues. An excellent review of the literature on this

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particular issue can be in VanScoy (1997).

Other trends include the following, several of which are discussed further in the literature reviewed in section four below:

a) Youth Needs:

GLBT youth have significant mental health needs associated with coming out and society's response to their sexuality. Children learn at an early age that "fag" and "queer" are insults. Coming to terms with GLBT sexuality is still a challenge even though gains have been made in a few schools in the region and within some families towards more support and acceptance. With cut-backs to the education system, the number of alternatives available to youth who don't feel welcome within the mainstream schools is becoming even more limited. Fisher (1999) identifies lack of preparedness on the part of educators, counsellors and mentors dealing with youth as a significant gap in our system of supports for youth.

Floyd et al. (2000) discuss the importance of asking about parent-youth relationships in assessing the well being of GLBT youth. East and El Rayess (1998) found that there is a need and desire for further training of pediatricians about the health care of homosexual youth and that open discussion of sexual orientation and sex is difficult even for well-trained pediatricians.

In an study of Australian youth Smith, Lindsay and Rosenthal (1999) found adolescents attracted to members of the same-sex report engaging in elevated levels of health-limiting behaviours. Health risks of GLBT youth include social and emotional isolation, running away, dropping out of school, prostitution, violence, and STDs (Dempsey, 1994).

More than 50% of LGB youth experience suicidal thoughts (Bagley and Tremblay, 1997). It's estimated that 30% of all youth suicide are gays and lesbians (U.S. Health and Human Services, 1989). There is debate around studies which have identified increased rates of suicide ideation and attempts in GLBT people especially youth. Examples of studies identifying higher rates include Hershberger, Pilkington & D'Augelli, (1997) and Saulnier (1998).

GLBT youth likely have a higher rate of incompleteness of secondary school. One US study found that 28% of lesbian and gay youth drop out of school due to discomfort in the school environment (U.S. Health and Human Services, 1989). They also are likely to have a higher rate of homelessness and unstable housing related to not being welcome or at ease to be who they are within the family home (ABC News 20/20,

1999).. Up to 50% of LGB youth report negative parental responses when their sexual identity is revealed or discovered (Hunter and Schaecher, 1987) and up to 25% are disowned or forced to leave home (Remafedi, 1987). Those who are struggling to support themselves sometimes turn to the sex trade for income. There are few support services, particularly for young male sex trade workers. Within an education system which is homophobic, and which treads gingerly and ineffectively into the area of sexual health, access to safe sex education for GLBT youth is very limited (Fisher, 1999).

Trans-gendered youth, in particular, live the inner turmoil of feeling that they are in the wrong body. They have few positive role models. Additional issues related to the Trans gendered communit (Namaste, 1995) include: barriers to access to hormones and treatment; discrimination from health professionals; police; shelters; and substance abuse.

Based on a press release from Human Resources Development Canada, GLBT youth are thought to represent 25-40% of street youth.

b) Health Practitioners' Skills -- Health Organizations' Practices:

All people within the community need health services and practitioners who they trust to understand, accept their lifestyle and who are skilled in working with issues related to GLBT sexuality, lifestyle, family and community. Many GLBT people are not out to health and social service practitioners from whom they are seeking care. They fear discrimination. Lesbians have been shown to underutilize health services (Carroll,1999). There is some evidence that lesbians delay seeking health care until the need constitutes a medical crisis or emergency (VanScoy, 1997 p. 149). Research has shown that medical and allied health practitioners receive very little education on GLBT health issues. Negative attitudes towards lesbian, gay, bisexual and Trans gendered clients tend to be directly translated into the quality of medical and nursing care (Morrissey and Rivers, 1998).

c) Visible and Ethnic Minorities:

GLBT people of colour face a double discrimination in this society. Those from ethnic minorities in which same sex orientation is strictly taboo face alienation from their family and their community of origin. Having been raised within a society in which they are a minority, cultural community and family become a haven for identity. Often claiming one's sexual orientation results in an estrangement from family and community. Within the GLBT community, there may be a feeling of isolation and invisibility as a minority within a minority (Greene, 1994).

d) HIV+ and PHA's:

The needs of those who are HIV+ and who have AIDS are well-documented both locally and nationally. Those needs are changing with the availability of pharmaceutical treatments which enable those who are HIV+ to thrive. HIV levels in young men in the U.S. are increasing and several studies were identified that are trying to identify the health beliefs relating to this increase in young men's HIV infection and measure accurate morbidity rates (MacKellar et al, 1996; www.caps.ucsf.edu/YGMtext.html).

e) Cancer:

Some articles discussed higher rates of cancers in women. Haas (1994, p. 343) cites research indicating lesbians have a one-in-three lifetime risk of developing breast cancer, two to three times the risk for heterosexual women. Some research discusses higher rates of anal cancer in gay men.

f) Lesbian Health Issues:

No gynaecological diseases are unique to lesbians or occur more frequently for lesbians. Instead issues such as assault, loss of employment, stress, self harm, alcohol use, and attitudes of health care providers are what creates a health risk (Banks & Gartrell, 1996). Lesbian health issues include: higher rates of breast cancer; stress related illness such as ulcers, allergies, and hypertension; more limited social support networks; depression; alcohol abuse; and suicidal ideation may be of more concern (Haas, 1994).

g) Frail and Differently-Abled:

For those who are differently-abled, frail and/or need support with activities of daily living, isolation is a problem. The mainstream services may not be a place where GLBT seniors can feel safe to be out to their peers. There are few local facilities which offer supportive housing, or various stages of nursing care which identify themselves as GLBT positive (a retirement home has recently been established).

h) Seniors:

Seniors are less likely to be out to a number of people in their lives. A survey of senior gays and lesbians in Winnipeg found that 53% of respondents feel that the fact that they are lesbian or gay does not act as a barrier to their use of seniors' services or programs other than housing (Sum Quod Sum Foundation, 1997). Most (88%) believe there is a need for greater awareness/education of providers of seniors' services about the needs of gays and lesbians. Twenty-four per cent rejected the need for separate services and programs for older gays and lesbians. In a discussion of issues of particular concern to GLBT elders, the fear of losing housing has been identified as an issue that might be important to explore.

i) Mental Health:

GLBT people appear to access mental health counselling more often and are more satisfied with their services than non-GLBT people (Jones & Gabriel, 1999). Rates of depression may be higher in GLBT people (gayhealth.com survey and K-Y Health Survey as described above). It is a common myth that within this community it is likely that the rate of sexual-related trauma such as childhood sexual abuse, rape, and other forms of coercion/violence in the context of sexuality is higher than in mainstream society. However, the National Lesbian Health Care Survey (Bradford et al, 1994) in the US found that rates of childhood sexual abuse, and incest were comparable to rates within the general female population (www.glbthealth.org/mhealth.html). The same survey found that depression rates among lesbians were as high as they are among heterosexual women.

j) Substance Abuse:

Substance abuse rates are also high among many parts of the community – the bars are still one of the few places to go to meet people, particularly if you are not connected to many people who are part of the community. Substance abuse is correlated with risk of unsafe sex. Although there are some resources in Ottawa-Carleton related to recovery which are GLBT-positive, people who are GLBT often seek help from mainstream services and organizations and do not feel free to be out to peers in treatment and support settings. Nitrite ("poppers") use was explored by French and Power (1999) who found differing patterns of use according to sexual orientation.

k) Violence:

Hate crimes and violence towards people who are GLBT affects every member of the community. Fear of being out at night and, when crimes occur, fear of reporting the crime is common. The Ottawa-Carleton police force has worked actively with the GLBT community to deal more appropriately with hate crimes and with concerns that community members have about police attitudes towards members of the community.

Violence does occur within GLBT relationships, but women may be reluctant to access mainstream supports, fearing censure for their sexuality. There are no mainstream supports for men in violent relationships.

l) GLBT-Headed Families:

Families headed by people who are GLBT have unique needs. Most children of gay or lesbian parents were born within heterosexual relationships and the parent subsequently identified as gay (Patterson, 1995). More and more lesbians are

choosing to have children, and are seeking help through reproductive technology or through adoption. Gay men who want to father have more limited options. Discrimination is a barrier to adoption and to secure custody arrangements.

4. Descriptions of health issues typically examined in GLBT wellness initiatives (i.e. the scope)

In a well written review of the health behaviour of lesbians VanScoy (1997, p. 141) describes that "although the health behaviour of lesbians has only recently begun to gain recognition and acceptance as unique, a number of themes and issues have already begun to be identified". The author notes the importance of identity, and the multiple ways it is constructed, when thinking about lesbian perspectives on health. The importance of identity is discussed in the context of both the individual identifying as lesbian and in efforts to change the behaviour of health care professionals (i.e. the importance of helping them understand the multifaceted nature of the "lesbian community"). This reference also discussed the theme of perceived (and real) patriarchy in the health care system as a barrier for lesbian women.

VanScoy also discusses the importance of considering individual characteristics in survey participants such as age, race, linguistic background, economic resources, occupational status, experience with (or desire to experience) pregnancy and parenting, and particular health or wellness concerns. The author discusses six specific actions taken by lesbians which have received the greatest attention in the literature through the mid-90s:

- 1) avoiding the traditional health care system altogether (with the exception of mental health services)
- 2) relying on any or all of alternative health care providers, partners, friends, and self for broadly based, holistic health care
- 3) delaying health care
- 4) not disclosing lesbian identity to health care providers
- 5) selecting lesbian or other female providers when available
- 6) seeking and using substance abuse and mental health services, programs, or support groups

VanScoy reviews this literature and illustrates how the research indicates lesbian women pursue these six approaches to health care (the research reviewed is based on studies of U.S. women).

In an assessment of health needs in New York City based solely on a literature review, the New York City Department of Health (1999 or 2000) found that gay men

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and lesbians face particular health issues that relate to "the social environment in which they live, to the ongoing pervasiveness of homophobia and hostility in many quarters, to unique developmental issues related to discovery and acceptance of a "minority " sexual orientation, and to patterns of sexual behaviour and socialization that are different from those in society at large". The report focuses on six areas of health concern in which gays and lesbians "have the most distinctive patterns of needs:"

- 1) HIV/AIDS
- 2) other sexually transmitted diseases
- 3) breast cancer
- 4) substance abuse
- 5) mental health
- 6) violence

The report was obtained at www.ci.nyc.us/html/doh/html/ah/glreport.html.

The McGill Centre for Applied Family Studies conducted an examination of health care access issues facing gay, lesbian bisexual and two-spirit people. The report is entitled [Access to Care: Exploring the Health and Well-Being of Gay, Lesbian, Bisexual and Two-Spirit People in Canada](#) (Ryan, Brotman, and Rowe, 2000). Although the title says Canada the focus groups only involved one major city and surrounding rural area and it is therefore not a national study. The report reviews literature which documents the "current knowledge base in glbt health and health care" with a focus on "health care and social service needs and access issues in health care and social services". In addition, five focus groups were conducted, two among Two-Spirit people, two in an urban environment (one with men, one with women), and one with men and women in a rural setting. The focus groups explored various topics related to people's perceptions of good health and good care, the barriers that exist to health and care, issues related to services, and how glb & two-spirit people identify appropriate caregivers and quality care. Starting on page 8 of this document is an extensive listing of health problems experienced by lesbians, gay men, with special sections relating to the elderly, youth, two-spirit people, and those living in rural areas. Some of the "health problems" seem somewhat obscure but others are unique observations. None of the problems identified are referenced and thus their validity is questionable. The report contains an extensive review of the literature and is recent but it lacks methodological rigor.

Solarz's 1999 reports on the meeting of a **committee on lesbian health research priorities** convened a workshop (as referred to above in discussion of methodology). The executive summary of the committee's work indicates that they "did not find that

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lesbians are at higher risk for any particular health problem simply because they have a lesbian sexual orientation". Rather, differential risks may arise, for example, because some risk or protective factors may be more common among lesbians (e.g. higher rates of nulliparity, which is associated with increased risk of breast cancer) they may experience differential access to health care services (e.g. because of fear of coming out the professionals) and they are exposed to stress effects of homophobia. The author adds that "little is known, however, about the specific impact of these risk factors on lesbian health" (p. 15 from the web <http://stills.nap.edu/html/leshealth/>).

In a discussion of a **research agenda for homosexually active men of colour in the U.S.**, Icard, Longres, and Williams (1996) indicated there is no one type of research that is appropriate to men of colour and that it is more a question of being sure that men of colour are heard in the various questions asked. The authors outline a framework for an applied research agenda which identifies the need for research in three areas: (1) needs and strengths (health and mental health issues, basic and higher order needs and resources); (2) service delivery themes (help-seeking behaviours, service help-giving behaviours, client help-accepting issues); and (3) outcome studies (client satisfaction, effectiveness of intervention).

Workplace issues for the GLBT population include topics such as, pervasiveness of discrimination in the workplace, formal and informal discrimination, fear of discrimination, interior and exterior barriers to career choice, and variability in workplace openness about sexual orientation (Croteau, 1996; Lonborg & Phillips, 1996). A review of 9 articles relating to workplace issues reveals a mix of methodologies including quantitative and qualitative surveys and phenomenological approaches (Croteau, 1996).

The relationship between **internalized homophobia and health issues** is discussed by Williamson (2000) in a critical review of the research on this topic. The author concludes the topic has a role to play in health promotion work with gay men and lesbians but as a construct it requires further discussion and development.

It appears that a needs assessment should ask about **participation in screening exams and utilization of health care** as there is evidence from survey data from the lesbian community that social identity and lesbian sexual behaviour have an important negative impact on health care by affecting these two factors (from the abstract, O'Hanlan, 2000).

If asking about **participation in community** it may be important to differentiate between sexualized (e.g. bath houses) and non-sexualized participation (e.g. volunteer

service) in community as Boies (1998) found a difference with the latter being associated with significantly greater wellbeing.

Commenting on their recent and thorough review of research on health behaviours of gay men Kauth and Prejean (1997, p. 134) state that "it is unclear from the literature what factors contribute to good adjustment and a sense of fulfilment among gay men. The bulk of psychosocial research has focused on problems experienced by gay men and has failed to examine how most gay people cope adaptively".

5. Additional Issues

For GLBT individuals in general other things to consider asking about in a wellness needs assessment include: regular exercise, use of meditation, monthly breast examination, religious or spiritual activities, have they discussed sexual orientation with health care provider, their coming out process and support services that would be (or might have been) of use during the process, present diet and knowledge of healthy diets, frequency of blood pressure checks and of pap smears (Moran, 1996), sexual dysfunctions, concerns regarding anal cancer or difficulties with bowel functioning, caffeine use, smoking, drug use, quality of intimate relationship(s), use of counselling services and for what issue(s), levels of distress, depression, suicidal ideation, violence, battering in relationships, disordered eating, social isolation, safe places to socialize (especially for youth), support networks, risky sexual practices and/or sexual practices they later worry or feel guilty about, rates and concerns regarding STDs and AIDS including testing services for these, immunization (e.g. hepatitis A and B), prostitution, physical or mental handicap, rejection from family, access to hormone therapy, concerns about and accessibility to sex reassignment surgery, repeated mourning, self-esteem.

C. Ottawa Carleton GLBT Wellness Study Methodology

The GLBT Wellness Study is designed to identify the wellness needs and strengths of GLBT residents of Ottawa-Carleton. Wellness is defined broadly to include physical, mental, social, emotional and spiritual dimensions of the individual. Factors that influence wellness include all the factors and facets that influence an individual's well-being. They include health and social services, and go beyond these services to include: employment, housing, social opportunities, friends and support networks, education, recreation, attitudes towards diversity, race, sexual and gender orientation and other formal and informal community services, opportunities, and characteristics. The GLBT Wellness Study includes the following methods of collecting information

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about wellness:

- 1) Community Needs Survey
- 2) Service Provider Needs and Gaps Questionnaire
- 3) Service Provider Inventory
- 4) Organization Questionnaire
- 5) Focus Groups.

These are described below.

1. Community Needs Survey

a. Questionnaire Design

An iterative process was used to arrive at the final instrument for the community needs survey. The goal was to develop an instrument which would take no longer than 30 minutes to complete, be comparable to studies conducted in other jurisdictions where appropriate, and include some standard questions from Statistics Canada to benchmark the results. The steps used to arrive at the final instrument included:

- a literature scan to identify key content areas from other studies
- examination of survey instruments from similar studies conducted elsewhere
- selected key informant interviews including researchers from Statistics Canada
- development of a survey content outline
- outline brainstorm session with Project Management Committee
- development of draft questionnaire
- internal and external review of draft questionnaire with revisions made prior to community workshop
- questionnaire pretest workshop with 38 community members (results presented under separate cover)
- revised questionnaire based on results of workshop
- final review and formatting of questionnaire

Although somewhat broader in scope, the community needs questionnaire follows the general framework of Statistic Canada's Canadian Community Health Survey (CCHS) and includes a number of comparative health and wellness questions. The CCHS is being conducted in major communities across Canada including the city of Ottawa at the same time as the Ottawa-Carleton GLBT Wellness Study. This leaves open the opportunity for comparative "benchmarking" analysis between the two survey samples at some point in the future. The community needs questionnaire also contains comparative questions from a number of surveys conducted in other jurisdictions within the same population groups including:

- The Ontario GLBT Study

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- The Vancouver LGBT Health Care Access Study
- The Winnipeg Seniors Study
- The Northern California Men’s Health Study

The final community needs survey instrument includes 61 questions which cover the following areas:

- demographic background
- housing and living arrangements
- issues related to “coming out” and sexual and gender identity
- general health and wellness and use of services
- experiences accessing needed services
- self-care approaches used to improve wellness
- health and wellness related concerns
- available community and social support
- sexual health and relationships
- crime and harrasment
- socio-economic background

Sampling and Distribution

A “snowball” non-probability sampling approach will be used for the community needs survey. Four thousand hard copy questionnaires will be distributed through various predefined distribution points including GLBT organizations, establishments and events. A distribution plan for the community needs survey was developed with the help of the Project Management Team and a committee of outreach volunteers who will be responsible for the distribution of the questionnaires. The plan lists the range of formally and informally-organized groups within the GLBT community that were known to the outreach committee. It indicates what sub-groups of the population are known to be represented in each of these organizations. The sub-groups the group wanted to make sure it reached included:

- gay men
- lesbians
- bisexual men
- bisexual women
- transgendered
- male to female
- female to male
- intersex
- differently-abled
- youth aged less than 25

- seniors aged 65 and over
- rural
- those with health issues (psychiatric, HIV/AIDS, Hep C)
- Aboriginal
- GLBT parents with children
- visible minority/ethnocultural.

The questionnaires will also be available at all Community Health Centres, at a major downtown book store, and on-line through the internet. The distribution points and the numbers to be distributed at each point were finalized with the volunteer outreach committee based on population estimates and the literature. The goal is to reach up to 800 respondents across the sample target groups with a minimum target set at 400 survey completions. The survey will be widely promoted through various channels in the media including a month long “AD Campaign” on all OC Transpo buses just prior to and during the survey field period.

A volunteer orientation meeting will be held at the start of the field period. At this meeting each volunteer will be given their designated survey package including the number of questionnaires for distribution. To protect anonymity the questionnaires will be distributed in a self-addressed return envelope which can also be used to return the questionnaire to the study office. The number of questionnaires distributed through each channel will be recorded. As well, respondents are asked to indicate where they “picked up” the questionnaire. This will allow the consultants to calculate the response rate to the survey and monitor response bias.

Throughout the six week study field period a confidential survey “hotline” will be established for survey respondents who require assistance completing the survey or those with questions about the study.

2. Service Provider Needs and Gaps Questionnaire

The Service Provider Needs and Gaps Questionnaire (see Appendix B) is designed to be filled in by service providers who are identified by GLBT residents as providing GLBT-appropriate services. The questionnaire is anonymous. It asks service providers what they think the needs and strengths of the GLBT residents are, and what they need in order to continue to practice in a way which is appropriate to GLBT clients. The questionnaire will be distributed in two ways:

- Snowball Method:** People who receive the survey will be given a service provider questionnaire and invited to give it to a service provide who has provided them with appropriate services
- Advertisers’ Method:** Those service providers who advertise in the GLBT media

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(*In the Pink* and *Capital Xtra*) will be mailed the questionnaire and inventory and asked to fill it in.

Service providers who do fill in the questionnaire will be invited to pass it on to other service providers who they believe provide GLBT-appropriate services.

One hundred responses will be analysed. In the event that more than 100 questionnaires are completed, the consultants will randomly select 100 from among the returned questionnaires.

3. Service Provider Inventory

The Service Provider Inventory (see Appendix C) is designed to be filled in by any service provider who is targetting GLBT residents as clients and would like to be listed on a list which will be distributed to other service providers who are also on the list. The list can be used for referral and for networking. Those who register to be on the list will be given the option of having their name and contact information published in a directory of service providers.

The Inventory questionnaire will be distributed with the Service Provider Needs and Gaps Questionnaire. All responses will be analysed and provided to the GLBT Wellness Task Group.

4. Organization Questionnaire

The Organization Questionnaire (see Appendix D) is designed to ask mainstream organizations that are used by GLBT residents about any GLBT-specific programs they are offering, and to ask them what practices and policies they have in place to improve access for GLBT clients. The questionnaire is listed in Appendix D. It will be distributed to the following types of organizations:

- Hospitals
- Community Health And Resource Centres
- Police Services
- School Boards
- Social Services
- Children's Aid Society
- Recreation Departments
- Public Health Department
- Homes for the Aged
- Community Care Access Centre
- Family Service Centres
- Crisis Services

- Housing services
- Corrections Services
- Chronic Hospitals.

Volunteers will be sought through the outreach committee to:

- establish a final list for distribution of the organization questionnaire
- obtain contact information
- contact the CEO's office and explain questionnaire -- identify who in the organization should be asked to respond on behalf of the organization
- contact the respondent for the organization, explain questionnaire, send it to respondent
- follow up with respondent within one week
- provide summary statistics on response rates and contact lists.

5. Focus Groups

Up to ten focus groups will be conducted with community members who live in particular circumstances and who may have special needs which may not be picked up in the survey. They may be under-represented in the survey, or they may be a small population with unique needs that may be lost in the overall survey because of its lack of specificity for sub-populations. The particular focus of each focus groups will be decided by the Management Committee based on analysis of early returns of the survey. In this analysis, the consultants will be examining returns from the following groups to see whether focus groups would be warranted:

- transgendered, possibly with breakouts for M to F, F to M, and intersex
- lesbians
- bisexual men
- bisexual women
- GLBTQ youth
- street-oriented youth
- GLBT people with extensive experience with the psychiatric/mental health system
- differently-abled GLBT people
- service providers
- seniors aged 65 and over
- those with health issues (HIV/AIDS, Hep C)
- Aboriginal GLBT people
- GLBT parents with children
- visible minority/ethnocultural.

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