



Women's Health Victoria

"facilitating access to quality women's health information"

Access to Women's Health Information

A Literature Review of Women as Information Seekers

Market Research 2002-2003 for Women's Health Victoria

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EXECUTIVE SUMMARY

Women's Health Victoria commissioned Market Access, an independent market research company, to undertake a review of literature regarding the health information needs of women.

The review of literature was conducted as the preliminary component of a comprehensive study of Victorian women's health information needs. Subsequent components of the study were conducted to include the needs and views of service providers and influencers in the field of women's health. The review was also intended to provide a basis for determining the needs for primary research with Victorian women in relation to accessing health information.

The objectives of this literature review focussed on identifying women's preferred channels for accessing health information, the critical times for accessing health information and any barriers that existed for women in their access to health information. A key aspect was related to the emerging trends in access to health information.

Channels for accessing health information

Two conceptual models are useful in the evaluation of health information channels. The first classifies health information sources in terms of the specificity and reach of the information. This can range from mass media, which delivers non-personalised information to the population, to health professionals, who deliver personalised information to the individual.

The second model classifies health information sources as either passive (eg. mass media and popular press) or active (eg. consultation with a general practitioner or other health professionals, telephone helplines, the internet and the like). This model classifies health information from the perspective of the consumer in terms of the involvement required of them in accessing health information.

Mass media and the popular press, specifically TV, newspapers and magazines, are the most commonly cited sources of health information for women and for the population generally.

Information from these passive sources is generally incorporated into women's body of knowledge about a particular health topic. It might also prompt women to actively seek more specific or detailed information. However, information from these passive sources alone is unlikely to prompt women into health-related behaviour change, and is not specifically relevant to women who are making decisions about investigations or treatments.

Information obtained via active seeking – specifically and most commonly from general practitioners (GPs) and other health professionals – is more effective in promoting health-related behaviour change, and in enhancing women's choices about tests and treatments. Women regard information delivered by the GP as the most credible.

The internet is being used increasingly by women, and the population generally, for obtaining health information. Current trends suggest that it is surpassing some other active sources, including telephone helplines and written resources. It is used for a variety of reasons, including self-education prior to consultation with a health professional; verifying and adding to information obtained from health professionals; and adding to women's overall health knowledge.

While the internet was seen in the past to be the domain of men, this is no longer the case. Current trends show that women are just as likely as men to use the internet. Indeed, once online, women are more likely than men to seek health information.

However the digital divide still means that specific groups of Australians have less access to web-based health information. This includes those of lower socio-economic status, those in rural and remote areas, where internet access is still limited, those with mental illness, those who are illiterate, people from Indigenous communities and the elderly.

Despite the increase in health information seeking on the internet, telephone helplines remain an effective and necessary information source at a time of crisis. Telephone helplines offer the advantage of being readily available, offering personalised service and being anonymous. These advantages apply particularly for women living in domestic violence situations.

Likewise, newsletters remain appropriate for isolated groups, especially women living in remote and rural areas, and for those with a chronic health condition. Already though, many organisations have posted web-based newsletters and it is likely that, over time, these will increasingly replace printed newsletter mailouts. Video conferencing has also been used successfully to provide health information and advice to those living in rural and remote areas.

Barriers to accessing health information

The major barriers for women in accessing health information relate to quality assurance (QA), concerns about confidentiality, and difficulties with comprehension. These barriers apply variously across the different information channels and the specific groups of women.

QA is most concerning in regard to internet-based health information and, to a lesser extent, popular women's magazines. QA by internet users is inhibited by the enormous quantity of information, and difficulties in verifying its source, currency and accuracy. Many filtering mechanisms and accreditation systems have been developed to optimise the quality of internet-based health information.

Confidentiality is most salient for young women, who are dealing with sensitive health issues such as sexually transmitted infections (STIs), contraception, pregnancy and drug-related concerns. Given that sensitive information is more easily shared amongst same-age peers, peer-education is particularly common and effective for informing young people about health issues.

Indigenous women and those from diverse linguistic and cultural backgrounds appear to have poorer access to health information, either written or via GPs, hence their relatively low utilisation of screening and treatment services. Given language and cultural barriers facing both groups of women, written information materials are often seen as inappropriate. Indeed, even amongst the population generally, and regardless of reading level and cultural background, there is evidence that pictorial and graphical representations in pamphlets are more effective than text. While the internet is a relatively good channel for non-English speaking women, providing easy access to information in a range of languages, this is not the case for Indigenous women.

Some specific groups of women, including lesbian women, sex workers and women in domestic violence situations face many GP-related barriers which can act to inhibit disclosure of personal information. This either raises the reliance of these groups on other information sources or results in precluding their access to appropriate health information. For instance, lesbian women apparently rely most often on informal networks and lesbian newspapers and magazines for health information.

Concluding comments

The literature review highlighted some key areas that deserve attention in future research. These issues tended to be in relation to the use of new technologies, including the internet, as a medium for accessing health information and comparison of this medium with other channels of information access. Specific issues included:

- (a) the manner in which the internet is surpassing other active sources of health information, and in particular the manner in which information accessed via the internet is used to substitute health professional consultation;
- (b) the way in which women discuss with their GP information accessed via the internet, and the reasons why they might choose not to do so;
- (c) the mechanisms that women use for determining quality and reliability of health information accessed through the internet.

Future research regarding health seeking on the internet needs to take account of health information seeking for both oneself and on behalf of others. It was apparent that accessing health information for others is a primary value of this medium, especially given that women are the main decision-makers, family carers, and health-information-seekers in the family.

A range of questions also exists in relation to the access to and usefulness of the internet for health information for particular groups of women, including women from diverse linguistic and cultural backgrounds, indigenous women, those of lower socio-economic status, rural women, those with mental illness, those who are illiterate and the elderly.

BACKGROUND AND RATIONALE FOR THE PRESENT REVIEW

Women's Health Victoria (WHV) is a state-wide women's health information service that aims to provide high quality, independent and up-to-date information to women, health service providers, and policy makers. Market Access, an independent market research company, was commissioned to undertake a review of literature relevant to the health information needs of women. A second literature review relating to the health information needs of service providers was undertaken concurrently. These literature reviews are intended to provide a basis for further primary research to be undertaken with women, service providers, and policy makers and influencers as appropriate.

There are a number of reasons why it is important to understand women's health information channels and preferences. First, women are the main decision-makers in terms of medical and treatment decisions, they are the main family carers, and the driving force behind health-information-seeking in the family. A recent study of 924 gastroenterology outpatients, undertaken by researchers at Duke University Medical Centre, United States of America (USA), demonstrated that those who sought health information were typically women in their early fifties (O'Connor & Johanson 2000). An Australian study of general practice patients similarly highlighted women as the main health information seekers (Charlton 1997). Indeed, women have been referred to as "health brokers" as they act on behalf of others in seeking health information and subsequently making health-related decisions (SWH 199?, cited in Astbury & White 1998).

Second, women clearly want information. A study of 2,500 adults attending outpatient clinics, undertaken by the University of Kansas Medical Centre in USA, demonstrated that 76% wanted to be informed about all the possible adverse effects of medications, and this was particularly so for older women (Ziegler et al. 2001). The authors concluded that patients want to be fully informed and "do not favour physician discretion in these decisions" (p.706). Likewise, a study of staff and women at two urban hospitals in London demonstrated that pregnant women wanted to be informed about all advantages and disadvantages of prenatal screening, even though they found some of the statistical information shocking (Oliver et al. 1996). In contrast, ultrasonographers were concerned that information delivery to women might increase anxiety, reduce uptake of prenatal tests, and reinforce negative media messages, highlighting "the resistance of some health professionals to evidence-based health care" (1996; p.1252). A smaller qualitative Australian study conducted through St George Hospital in Sydney and involving 21 pregnant women demonstrated that women were "overwhelmingly in favour" of carrying their medical records during pregnancy (Phipps 2001). This study again highlights women's preference to be informed and involved in medical and health-related decision making.

Third, women continue to report that they receive inadequate health information. A random survey of 229 New South Wales (NSW) women diagnosed with breast cancer, undertaken by researchers at the University of Newcastle, NSW Australia, demonstrated that of the 15 highest unmet needs reported, ten related to health information (Girgis et al. 2000). Likewise, Australia's family carers, predominantly women, consistently report that they need more information about both their relative's condition and available services and supports (Schofield et al. 1998).

Fourth, access to appropriate health information enables women to access needed services, which is crucial in the promotion of the health of women and their families. Many research studies have demonstrated that having access to good quality and timely information enables women to access needed services and supports (Pullen et al. 2001a; Schofield et al. 1998).

At the same time though, good quality health information can successfully substitute for consultation with health professionals, thereby enhancing women's sense of autonomy and potentially having positive fiscal benefits. A random household survey of 1,812 parents (mostly mothers), co-ordinated through Stanford University USA, demonstrated that the provision of good quality health information decreased paediatric consultations with doctors in the following year (Wagner & Greenlick 2001).

Similarly, access to health information assists women in decision-making regarding medical tests and procedures. A randomised controlled trial (RCT) involving 1,692 women booking into antenatal care, explored the effects of information sessions on uptake of various antenatal screening procedures (Thornton et al. 1995). The study, undertaken by researchers at Leeds University in United Kingdom (UK), demonstrated that, compared to those receiving usual care, women who attended an information session demonstrated more considered uptake of screening tests. Specifically, Down's Syndrome screening, usually low, was increased amongst intervention women, whereas screening for Cystic Fibrosis, usually unnecessarily high, was lowered amongst intervention women.

Likewise, access to health information increases the likelihood that women will undertake positive lifestyle changes. A telephone study of 102 community-based rural women aged 65+, conducted by researchers at the University of Nebraska (USA), measured women's health-promoting behaviours, including physical activity, nutrition, and stress-management behaviours. The findings demonstrated that women with access to health information had more positive lifestyles and had made more attempts to make positive lifestyle changes.

Finally, having an understanding of the health information dissemination systems used and preferred by women is crucial to the continued improvement of such systems. Particularly given the current information explosion, mostly attributable to the increasing information on the world wide web (www), quality assurance has become a priority (Rhodes 2000; Timmons 2001; Best & Bedi 2001; Trevitt et al. 2001). For example, researchers from the University of Florida, USA, estimate that 70,000 websites disseminate health information (Cline & Haynes 2001), and many cite information which is inaccurate (Allen et al. 2002; Cline & Haynes 2001; Latthe et al. 2000). Alongside this, there is a burgeoning research literature regarding the implications of internet use and methods of quality assurance.

DEFINING WOMEN'S HEALTH INFORMATION

In defining women's health information, several key issues or dimensions need to be considered. First, the health status of the information-recipient or information-seeker. For example, preventative health information is most relevant to well women, whereas information about diagnoses and treatments is most relevant to those who are ill and their families (Rees & Bath 2000). More specifically for the latter, the nature of the illness and the timing of information acquisition becomes important. In regard to an acute illness, for example, information needs to be gathered quickly, prior to or at diagnosis. In contrast, the information needs of those with a chronic condition, or who are undergoing long term treatment, change over time (Harrison et al. 1999; Luker et al. 1996). Specific information obtained before a consultation, investigation or treatment is particularly relevant in enhancing women's choice about their health (Ziegler et al. 2001; Hallowell 2000; Oliver et al. 1996).

So what are women's major health concerns? Astbury and White (1998) identified six key themes relevant to women's health information needs. These themes, based on a review of research findings, policy documents, and the content of women's common requests to health information services, were:

- Age-related issues
- Emotional and mental health
- Reproductive health
- Violence and women
- Women as carers
- Emerging health issues (including women and alcohol; older women and breast cancer; younger women and abnormal pap test results; lesbian women and reproductive health; older women and reproductive health; and older women and low income).

These six themes are used to guide the present review both in terms of the health issues covered and the identification of specific-needs groups of women. These groupings are particularly relevant to Section 4 of the present review with regard to information access needs for particular target groups of women.

Astbury and White emphasise that "the health issues facing women are complex and diverse" (1998; p.39), and that women are heterogenous in nature. Even within specific subgroups defined, for example, by age, geographic location, ethnicity, or education level, there is much heterogeneity. As noted, this "demands modes of information dissemination which are flexible enough to address individual women's circumstances and preferences" (Astbury & White 1998, p.40).

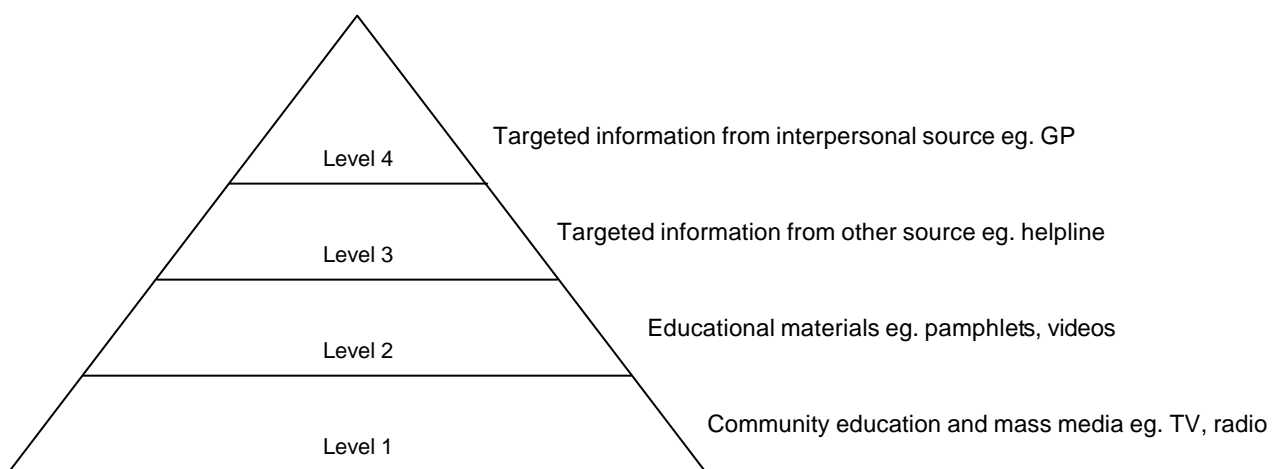
Indeed, the heterogeneity of women, both broadly and within specific subgroups, must be borne in mind in reviewing women's current methods and preferences for accessing health information. Clearly some methods of information dissemination are designed to reach large numbers of women but, in doing so, are potentially limited in the extent to which they can provide specific, detailed or personalised information. For each of the dissemination options along the continuum from population-based education through to targeted resource material or personalised advice, women's current utilisation and preferences are likely to vary. Thus frameworks for considering health information dissemination channels also need to be considered.

FRAMEWORKS FOR HEALTH INFORMATION DISSEMINATION SYSTEMS

Two frameworks or models are useful for considering health information dissemination systems. The first is based around the specificity and personalisation of the information provided. The second is based around the involvement required in obtaining the information.

A) THE SPECIFICITY MODEL

This framework, originally conceived by Associate Professor Anna Howe (personal communication) and adapted from a review of services, programs and policies relevant to Australian carers (Murphy 1999), is presented below:



The lowest level (Level 1) is largely concerned with community education and mass media strategies. This level comprises all population-based strategies designed to reach all women and/or members of the community; broad reaching but not intensive or personalised. This applies to mass media, such as television (TV) advertising and, to a lesser extent, TV, radio, newspaper and magazine reporting. For example, TV advertising is commonly used to convey broad-based health messages, such as the benefits of smoking cessation and road safety. The strategies become progressively more intense and more specifically oriented toward specific groups of women at each progressive level.

Level 2 comprises information oriented towards specific subgroups of women, but still not in a personalised way, and not in response to personal or situational factors. Written or video materials developed to address a specific health concern of a sub-group of women are designed to be highly informative for the specific target group, but not broad-reaching. While targeted, these resources are not personalised to the individual. This applies to resources such as a pamphlet on the risks of ultrasound in pregnancy (Oliver et al. 1996) or an educational video designed to teach older women about breast-self examination (Wood 1996).

Level 3 comprises information specifically oriented towards the individual women, such as that offered via a telephone helpline. The information is personalised to an extent, but the degree of personalisation is limited by the medium itself. Generally the information exchange does not occur within the context of an established relationship. Internet information belongs at this third level, but the tailoring of the information is done actively by the information-seeker herself during the search.

The top level (Level 4) comprises targeted strategies for any specific woman, most notably specific information requested of and delivered by an individual service provider such as a general practitioner (GP). Personalised information provided in the context of an established relationship is considered the most intensive.

The linkage between the different levels of information is important. Regardless of where resources are allocated, the system falls down when there is either (a) good information at a population level (level 1) but inadequate discussion of those issues at a more personal level or in the context of a trusted relationship (level 4); or (b) health professionals specialised in a specific women's health issue (level 4; eg. sexual health in young women), but a lack of easily accessible, broad-based information to raise awareness about that issue and/or the availability of such specialists (level 1 or 2).

B) THE ACTIVE/PASSIVE MODEL

This model is based around the intention behind the acquisition of information. This model has been used by a number of contemporary health researchers to classify information dissemination methods (eg. Wilson & Walsh 1996; Carlsson 2000). Passive information channels include TV, radio, newspapers, and informal networks (family and friends). Information acquisition via these channels is relatively non-intentional on the part of the individual. It is often incidental and tends to require relatively little energy. Active information channels include medical books, telephone helplines, pamphlets and brochures, the internet, and consultation with health professionals. Information acquisition via these channels is relatively more deliberate or intentional on the part of the individual.

OBJECTIVES

This review addresses a number of objectives, namely:

1. To identify women's current and preferred channels for accessing health information.
2. To identify the critical times at which women access health information.
3. To identify the barriers that exist for women in their access to health information.
4. To identify the emerging trends in relation to women's access to health information.
5. To identify the specific information needs of women in relation to accessing health information.
6. To identify the group or segment differences that exist in relation to the way health information is accessed.

In this document, objectives 1, 2 and 3 have been addressed specifically and in turn, in Sections 1, 2, and 3 of the Detailed Findings of the report. Objectives 4 and 5 have been subsumed within all sections of the Detailed Findings. In addressing Objective 6, literature relevant to several key groups of women has been collated separately in Section 4. In addition the needs of specific groups have also been discussed throughout other sections of the Detailed Findings as appropriate.

BOUNDARIES FOR THE PRESENT REVIEW

A review of literature relating to women's health information needs, the availability of health information, and the efficacy of available information dissemination methods was undertaken by the Key Centre for Women's Health in Society (Astbury & White, 1998). Their review incorporated literature from 1986 to 1998. The review was comprehensive and detailed, and addressed each of the objectives of the present literature review. In order to avoid duplication, the present review covered literature published or produced since 1998. An overview of sections of the Astbury and White review has been provided as a starting point to the present review where appropriate.

The current review has focussed on the health information needs of women. However, it must be noted that many of the studies cited in this review were not gender specific studies. In such instances gender differences have been noted whenever applicable and when no such differences have been observed between men and women, the population based findings have been reported.

The increasing accessibility of computers and, in turn, the internet also underscores the need for the present review to focus on contemporary research findings. Use of the internet is rapidly increasing, and researchers predict that it will continue to do so (eg. Bessell et al. 2002; O'Connor & Johanson 2000; ACNielsen 2001; Lathey & Hodge 2001; Institute for the Future 2000a; 2000b). Indeed, the internet appears to be superseding other media as a source of health information, particularly other active sources such as pamphlets, newsletters, telephone helplines and the like (ACNielsen et al. 2001; Carlsson 2000). As such, comparative prevalence rates rapidly become outdated and redundant. This highlights the need to restrict the present review to the last 3-4 years.

RESEARCH APPROACH AND METHOD

METHODOLOGY

A two-step methodology was used to identify and access material to be reviewed. First, relevant reports, literature reviews and other publications were accessed from the Women's Health Victoria (WHV) library, on the advice of the WHV librarian. Given its role as a clearinghouse for health information, WHV has a large collection of such material. Second, systematic literature searches were undertaken to identify relevant articles published in refereed journals. In order to ensure over-inclusion, searches were restricted to publications from 1996 onwards. All searches were restricted to English language and human research. Specific searches were specified as follows:

An online search of Medline using the key words "health information" and "women" identified 189 references. A second search using the key words "health information" and "access OR uses OR preferences" identified 152 references. There was some duplication. After checking all references for relevance, a total of 82 references were seen as relevant to the aims of the literature review and were accessed for review.

Once all relevant articles had been reviewed, some additional specific medline searches were conducted to ensure the comprehensiveness of the review. These searches used the key words: "helpline", "peer", "rural" and "domestic violence", each entered with the key word "information". On this basis, a total of 40 references were seen as relevant and were accessed for review.

DETAILED FINDINGS

This report is divided into sections to address each of the stated objectives as outlined. Where appropriate, reference is made to the relevant type of health information. Within each objective, issues are divided into sections in terms of either (a) the information source (eg. newspaper, internet, health provider) or (b) specific groups of women (eg. younger women, rural women, Indigenous women).

1 – WOMEN’S CURRENT AND PREFERRED CHANNELS FOR ACCESSING HEALTH INFORMATION

This section is divided into two parts. The first provides an overview of some key women’s health information dissemination services currently operating in Victoria, Australia. This section is restricted to generic information services for women: the broader range of information strategies currently available to specific groups of women are discussed in relevant sections throughout the report. This is not purporting to be a comprehensive coverage or evaluation of all existing women’s health information services. Instead, it provides a sketch of the types of services available, and a broad comparison of utilisation of the different media. The second draws on a range of published and unpublished research studies, both local and overseas, to identify and discuss women’s current and preferred methods for accessing health information.

1.1 – EXISTING SERVICES

The following is presented as a snapshot of existing services that provide health information for Victorian women. This is not intended to be a complete documentation of all of the relevant organisations, rather an overview of some of the key organisations in the field.

Several existing organisations currently provide health information to Victorian women via telephone information services, websites, resource centres and related services. These include: the Women’s Information and Referral Exchange (WIRE); the Royal Women’s Hospital Well Women’s Service (WWS), and Women’s Health Information Centre (WHIC); and Women’s Health Victoria’s (WHV) Health Information Line and related services. Several regional women’s health services also operate telephone information lines, websites and/or resource centres. Using recent Annual Reports, these services were reviewed in terms of uptake of the service by women and, where evaluation data was available, women’s attitudes to the services and the information received.

1.11 – Women’s Information and Referral Exchange (WIRE)

Women’s Information Referral Exchange Inc. (WIRE) has provided a telephone information service to women since 1984. During 1999-2000, WIRE expanded to include a Women’s Information Centre (WIC) and online facilities (WIRE 2000). The service operates in a feminist framework, a service for women run by women. The WIRE website contains information sheets relating to a range of key women’s issues, a calendar of events, and a news page, which points to the bi-annual WIRE newsletter 'HotWire' (WIRE 2001). The WIC has a broad range of pamphlets and other printed materials, as well as enabling visitors to access a database of services and the internet.

In 1999-2000, 12,058 women contacted WIRE and were given information. The majority used the telephone information service (n=7,717; 64%), although a substantial 30%

(n=3,658) accessed information from the WIRE website. Relatively fewer contacted the WIC (5%) or made email contact (1%) (WIRE 2000).

By 2000-2001, a larger 22,375 women contacted the WIRE services (WIRE 2001), an increase of 86% on the previous year. Online access increased to 12,578, a rise of 245% on the previous year. In contrast, contacts to the telephone helpline dropped to 6,244, a 20% decrease on the previous year.

For telephone callers, online users and visitors to the WIC, domestic violence is the most common reason for contact. In 1999-2000, the top ten telephone call issues were: family/domestic violence (13%), separation/divorce/relationship dissolution (10%), anxiety/fear/stress (10%), isolation/loneliness/lack of support (9%), housing (8%), parenting/children (8%), depression (7%), confidence/self-esteem/self-assertion (6%), other emotional states (6%), and legal separation/divorce matters (5%). For online contacts in 2000, 18% were related to sexual assault and 16% to domestic violence. A further 13% related to separation and children, and 13% to leaving a partner (WIRE 2000).

While not amongst the main reasons for contact, health was addressed in 1,342 (17%) telephone calls. The major health-issues discussed were general health, reproductive health, pregnancy/birth, abortion, disability (physical/intellectual/psychiatric), sexual health and STIs, body image/eating disorders, grievances with the health system, and breast cancer and screening.

The telephone information service appears to appeal to a variety of women, and to be a particularly good medium for some harder-to-reach groups. In 1999-2000, most callers were earning less than \$20,000 per year, almost 20% were calling from rural Victoria, and about 10% spoke a language other than English (WIRE 2000). By 2001, a higher 25% of women were calling from non-metropolitan or rural regions (WIRE 2001). In both years, the majority of callers were making first-time contact.

In their 2000 Annual Report, WIRE stated that their major objective remains the delivery of personalised information, tailored to the expressed needs of each individual woman. Despite good utilisation of the online services, the WIRE Annual Report (2000) stated that the technology "is limited in its capacity to explore and communicate major life concerns such as the impact of violence, isolation or depression. This means WIRE's key role remains to encourage women to take the next step to talk about their experiences" (p.5). The substantial increase in the number of women accessing the WIRE website during the following year (2000-2001), however, highlights the increasing use of the internet for women's information. Indeed, the concomitant decline in utilisation of the telephone information service suggests that the internet might be superseding the telephone service to some extent.

1.12 – Royal Women's Hospital Women's Health Information Centre (WHIC) and the Well Women's Service (WWS)

The Well Women's Service at the RWH has recently launched a free Women's Health Information telephone service for rural women, and a website for women to access immediate health advice. The website (www.rwh.org.au/wellwomens) contains a wide range of health information, a timetable of seminars and workshops, and offers an email question and answer service with direct access to a women's health nurse (HSN 2002). The site also contains fact sheets for women from non-English speaking backgrounds (HSN 2002).

1.13 –WHV health information line and related services

WHV offers a health information line, which is supported by Quality Information Health Issues Resources (QIHIRs), a library, a web site and a quarterly newsletter. The Health Information Line offers a freecall 1800 number. The 2000-01 Annual Report showed that, in the 12

months to June 2001, 1,740 callers contacted the health information line, the majority calling from metropolitan Melbourne (WHV 2001). Almost 50% were mailed printed information material subsequent to the call. Around 25% of calls were classified as complex, involving support and/or exploration beyond pure information provision. The major reasons for the call were: pregnancy, birth and postnatal issues (12%), menopause and related issues (12%), depression and related requests (9%), requests for a woman practitioner or women's health clinic (6.5%), menstruation (5%) and contraception (5%). These request frequencies did not differ markedly from those reported for the previous 12 month period (WHV 2001).

In accordance with the common request categories, WHV have developed a number of QIHIRs (pronounced choirs). The content of these resources is reviewed annually, to ensure currency in terms of women's expressed needs and to ensure the accuracy, relevance and currency of the information provided. QIHIRs are available either in print or via the WHV website (www.whv.org.au). In an evaluation project involving both service providers and services users, both the internet and women's health services were commonly cited as the preferred locations for QIHIRs (Vucko et al. 2002).

For the 12-month period to June 2001, there were around 6000 hits to the WHV website. This figure far exceeds that for the telephone information line, although the origin of and reason for each hit are undeterminable, as has been pointed out previously (Wyatt 1997). More specifically, there were around 1600 hits to the QIHIRs page on the website, a figure comparable to that for the telephone information line. Although women did not receive personalised information as they did via telephone, they were able to access QIHIR covering a range of key health topics. The most commonly accessed were for sensitive topics such as abortion, contraception and hysterectomy (WHV 2001).

In contrast to both the telephone information line and the website, WHV's other outlets reached relatively few women. The WHV library attracted 356 visitors in the 12 months to June 2001, most commonly to obtain current health research reports (11%) (WHV 2001). The WHV newsletter, 'HealthSharing Women', has a current subscriber base of 451 (WHV 2001), the majority of whom are based in metropolitan Melbourne (55%). Most subscriptions are from organisations (45%), although a substantial 41% are from individuals (34% salaried and 7% unsalaried).

1.14 – Other women's health services

A range of other regional women's health services operate in Victoria and other states of Australia. Because so numerous, these will not be reviewed comprehensively or in detail. Only selected services for which statistics were available are included.

Women's Health Grampians: In the year 2000-01, 4,034 women contacted the Women's Health Grampians service for health information/referral, or to attend one of 102 group sessions conducted throughout the year. This was a 43% increase on the previous year. The major health issues expressed were: violence against women, mental health, body image, pregnancy/birth, reproductive health, sexuality, and midlife issues (Women Health Grampians, 2001).

Women's Health Queensland Wide (WHQW) Inc: In the year 2000-01, 5,852 women and health workers contacted the WHQW health information line, a 6.9% increase on the previous year (WHQW 2001). The major health concerns were reproductive health (20%), gynaecological health (17%), the middle years (13%), and mental and emotional health (12%). Domestic or sexual violence prompted only 4% of calls. Consistent with other web-based services, the WHQW website showed a substantial increase in the year 2001. A total of 112,575 user sessions were recorded in 2000-2001, up 230% on the previous year. The most commonly visited pages were factsheets on menstruation, hysterectomy, endometriosis, menopause, and teenage pregnancy (WHQW 2001). WHQW also offers

videoconferencing sessions for women living in rural and remote areas. These have focussed on menopausal issues, and have been well-received by rural women (WHQW 2001).

Women's Health Matters (WHM) Information Line: In the year 1999-2000, the Women's Health Matters telephone service received 1,528 calls; there were 211 visits to the Information Centre; 329 visits to the library, and 59 email contacts (WHM 2000).

Lodden Mallee Women's Health Service (LMWHS): The Lodden Mallee Women's Health Service produces a publication 'Whealth' which is distributed free-of-charge to women across the region. A high 37% of readers live on farms or in small country towns. Each publication (3 per year) covers a specific women's issue. In addition, a library service offers over 300 pamphlets on women's health issues. In the year 1999-2000, 611 women accessed the library (LMWHS 2000). The LMWHS has also participated in a number of collaborative research projects with La Trobe University, Bendigo.

1.15 – Summary of service utilisation

Overall, the figures presented for the services reviewed suggest that many women are contacting telephone helplines operating throughout Victoria and other states of Australia. These services appear to be particularly suitable for women experiencing domestic violence and/or relationship separation, enabling the tailoring of information-provision to the needs and circumstances of each individual woman. However, internet-based information provided by several of these services is being increasingly accessed by women, in some cases superseding calls to the telephone helplines. The figures suggest that, while not able to replace the personalised advice and support offered by telephone counsellors, web-based health-information is gaining increasing appeal.

1.2 – FINDINGS OF RESEARCH STUDIES

This section provides an overview of research studies that have explored the common and preferred sources of health information, both in the general population and specifically amongst women. First comparative studies (which compare prevalence of use of various media for acquiring health information) are reviewed. Second, drawing on relevant research studies, each medium is discussed in turn.

1.21 – Comparative studies of sources of health information

Studies comparing various media for health information suggest that passive mass media sources, particularly TV and newspapers, are the most common sources of health information. For example, in the USA population-based study of 499 adults (66% women), conducted by Licciardone et al. (2001), health information was commonly obtained by newspapers and magazines (69%) and TV (56%). Use of the internet for health information (32%) was comparable to that of radio (30%). The authors concluded that "the internet has already surpassed radio as a source of health information, but still lags substantially behind print media and television" (p.31). Being population-based, this study provides a good indication of the USA prevalence rates for each media for health-information seeking.

A study of rural older women conducted by the University of Nebraska (USA) confirmed the high accessibility of information via passive sources (Pullen et al. 2001b). The study of 102 community-based rural women over 65 years demonstrated that newspapers and magazines (94%) and TV (87%) were the most common sources of health information. Information was also commonly obtained via health care providers (58%). Consistent with the other studies, health information was less commonly obtained via family and friends (45%).

Similarly, in a Swedish study of 192 patients admitted to a hospital oncology department over one day, sources of health information were more often passive than active (Carlsson 2000). Passive sources were reported commonly: newspapers (86%), TV and radio (82%), friends (55%), and other patients (46%). Active sources were less common: medical books (37%), telephone helplines (10%), and the internet (6%).

However, some studies show that GPs are used even more often than passive information sources. A random household telephone survey of 1,016 American women compared utilisation of doctors, newspapers and the internet for health information. The study found that doctors were “by far the most sought after source of health information” (Pandey et al. 2002). Being another randomised population survey, this study provides good prevalence rates for use of GPs, the internet and newspapers for health information.

Finally, a UK study compared utilisation of the internet and the UK National Health Service (NHS) telephone helpline for information-seeking prior to attendance at a neurology outpatient clinic (Larner 2002). Because the boundaries of the study were so specific (information-seeking prior to the specified consultation), the findings are not comparable to other studies of more generalised health information seeking outlined above. In this study of new referrals to a neurology outpatients clinic, 198 patients were interviewed. Only 15 (7.6%) had used the internet prior to consultation, and only 4 (2%) had telephoned the NHS service. Overall then, information-seeking from either source was relatively low. However, the findings do suggest that utilisation of the internet exceeded that of the NHS telephone helpline, at least in relation to pre-consultation information seeking.

The prevalence rates for the various media as sources of health information are shown in Table 1.

Table 1. Comparisons in prevalence for various media as sources of health information

Study	Country	Sample size	Sample description	Passive sources				Active sources		
				Newspapers & magazines	TV	Radio	Family and/or friends	Phone helplines	Internet	Health care provider
Licciardone et al. 2001	USA	499	Population-based	69%	56%	30%	—	—	32%	—
Pullen et al. 2001b	USA	102	Rural women >65	94%	87%	42%	45%	—	—	58%
Carlsson 2000	Sweden	192	Consecutive oncology patients	86%	82% ¹		55%	10%	6%	—
Pandey et al. 2002 ²	USA	1,019	Population-based; women only	36% ³	—	—	—	—	25%	78%
Larner 2002	UK	198	Consecutive neurology referrals ⁴	—	—	—	—	2%	7.6%	—

Note. For ease of comparison, prevalence rates have been rounded to nearest full digit figure.

¹82% includes both TV and radio combined.

²Percentages given in the table are approximated from percentages given across different socio-economic classifications in the paper by Pandey et al.

³36% for newspapers only (magazines not included).

⁴ In the study by Larner (2002), patients were asked only about information relevant to their medical condition and accessed prior to the current consultation.

— Not covered by study.

With one exception, these studies of media prevalence for health information acquisition suggest that passive sources – newspapers, magazines and TV – are the most commonly cited sources of health information, both amongst women and amongst the population more generally. Of active sources of health information, health care providers – mostly GPs – are the most common, followed by the internet and, to a lesser extent, telephone helplines.

Unfortunately, none of the studies reviewed included any printed active information sources, such as newsletters, pamphlets or brochures. In order to identify the extent to which the internet is surpassing each of the other active information sources, including printed resources, it would be desirable for future studies to compare utilisation of newsletters, pamphlets/brochures, medical/health books, telephone helplines, GPs and the internet.

Research evidence relating to each of the media will now be reviewed in turn, first those relating to passive information acquisition, namely TV, newspaper, other mass media, and peers and informal networks; and second those relating to active information seeking, namely pamphlets and brochures, newsletters, video resources, touch-screen systems, GPs and other health professionals, and telephone information lines.

1.22 – TV, newspapers and other mass media

TV and other mass media are widely cited as key sources of health information among women. As shown in Table 1, several studies demonstrate that the TV, newspapers and magazines are the most common sources of health information for the populace, including women (Licciardone et al. 2001; Pullen et al. 2001b; Carlsson 2000).

Likewise, mass media is cited as the most common source of information about specific illnesses. A stratified random sample survey of 999 women in Florida, conducted by the University of Miami, USA, found that the media was the most commonly cited source of information about breast cancer. A large proportion (90.2%) of women surveyed identified the media as a source of such information (Metsch et al. 1998). Several earlier studies, reviewed by Astbury and White (1998), similarly highlight the primacy of the media as a source of information for topics such as hormone replacement therapy (HRT; Griffiths 1995, cited in Astbury & White 1998) and menopause (Shoebridge 1997, cited in Astbury & White 1998).

More specifically, there is strong evidence that older cohorts favour these more passive mass media sources. In the USA random household survey conducted by Licciardone et al. (2001), older adults were more likely than their younger counterparts to acquire health information via newspapers, magazines and TV.

However, while TV and mass media are far-reaching, as reflected in these high prevalence rates, there are limitations to the comprehensiveness and personal relevance of information delivered via mass media. This effect, outlined in the Specificity Model presented in the Background section of this review, needs to be taken into account in assessing women's health information preferences. While TV reaches the majority of women, and studies reporting on common sources of health information reflect this wide dissemination, the amount of specific information obtained via mass media – as compared with more active sources – is likely to be low. Mass media and the popular press clearly reach a large proportion of women, but how useful is the information received via these sources?

Only one of the reviewed studies explored the association between media exposure and behaviour change. The study, conducted by researchers at the University of Southern California, USA, surveyed 598 older and elderly women (aged 55-92). Exposure to media-based health information was found to predict both knowledge of breast cancer and, more importantly, screening behaviour. Specifically, media exposure was predictive of having had a recent breast examination by a physician, a mammogram, a pap test, and/or a routine

physical examination (Ruiz et al. 1992). While this finding suggests that media exposure was associated with health-promoting behaviours, the study did not investigate whether women used or sought information from other sources in addition to the media. Further studies are needed to compare the relative usefulness of information received from passive and active sources.

There is also some evidence that the media often delivers misleading and irrelevant information to women about health issues. This poses a challenge for women in determining whether to either accept or reject information obtained from these sources. The issue of quality assurance of health information in the popular press and mass media will be discussed in the section on barriers to information access (Section 3).

1.23 – Informal networks: peers, family and friends

Older women appear to gain a great deal of health information from informal networks, particularly female family members and friends. Studies with older women have focussed particularly on menopause and HRT. For example, in an unpublished Masters thesis reporting on a study undertaken at Curtin University of Technology (Australia), female peers were a primary source of health information for pre-menopausal and menopausal women (Shoebridge 1997, cited in Astbury & White 1998). In an Australian pilot health promotion project about menopause, conducted through the University of Western Sydney NSW, participating women (n=23) indicated that peer support networks were important in their information exchange and should be utilised in meeting older women's informational needs (McVeigh 1996). Participants suggested that peer support groups be developed to optimise the information exchange between peers. Similarly overseas, a British study of 1,225 adult women reported that women's main sources of information about HRT were the media and informal networks (Griffiths 1995, cited in Astbury & White 1998).

Pregnant women also obtain information from family and friends, particularly non-medical information. A small USA study conducted by researchers at Ohio State University found that women's main sources of information about home remedies for induction of labour were family and friends (76%). This type of information was obtained informally much more often than via formal or medical sources, such as books and pamphlets (15%) and health professionals (12%) (Chapman, 2002). This study highlights the role of family and friends in the exchange of non-medical information related to pregnancy and birth.

Peer networks are also an effective information channel in some ethnic communities in Australia. For example, in a study of 199 Vietnamese-born Australian women, conducted by researchers at the University of South Australia, friends and family were the second most important source of information about screening for cervical cancer (Cheek et al. 1999). Consistent with other research findings, the GP was regarded as the most important information source.

There is some evidence that younger women also obtain a large proportion of their health information from informal networks, mostly peers. This is particularly so for sensitive issues, such as sexuality and sexual health (Sorger 1990, cited in Astbury & White 1998).

Indeed, the peer network is regarded as so influential that the use of Peer Leaders or Peer Support has been implemented formally as a method of health promotion in schools, particularly for sensitive issues such as STIs, contraception, and drugs. The model is based on the assumption that sensitive information is more easily shared between people of a similar age. For example, a study involving almost 4000 students, conducted by researchers at the University of Rochester, USA, compared peer-led and teacher-led education programs about Human Immunodeficiency Virus (HIV) and sexuality (Siegel et al. 2001). The study found that students in peer-led programs showed better improvement in knowledge and risky behaviours than did those in teacher-led programs. An Australian study, conducted by

researchers from John Hunter Hospital in Newcastle, NSW, similarly reported improvements in knowledge following a school-based peer-led asthma education program (Gibson et al. 1998). In a review of school-based studies, Mellanby et al. (2000) from University of Exeter, UK, concluded that peer leaders are at least as, or more, effective than adults. However, in a later study Mellanby and colleagues found that while peers were effective in influencing attitudes to sexual behaviour, adult leaders were more effective in imparting factual information and encouraging classroom participation (Mellanby et al. 2001).

Peer educators have also been trained to deliver health information in a range of settings outside school. This includes the delivery of HIV information to uninfected adolescents (Luna & Rotheram-Borus 1999), health information to homeless youth (Connor et al. 1999), and information about HIV, STIs, condom use and condom negotiation to sex workers (Ford et al. 2000). In the latter study, conducted by researchers at the University of Michigan, USA, and implemented with female sex workers in Bali, Indonesia, those working in areas with a peer-educator had better knowledge of HIV, STIs and condom use and lower prevalence of gonorrhoea infection after the program, compared with women in areas without a peer educator. Workplace-based peer-education has also been effective for the delivery of diet-related health information (Larkey et al. 1999).

To a lesser extent, the use of peer leaders has also been effective for the delivery of health information to older women. For example, in a USA program, peer leaders were used to deliver urinary continence information to senior citizens groups (Newman et al. 1996). The program was well-received, with 80% participants reporting better bladder control by the end of the program.

1.24 – The internet

There has been a plethora of research studies, mostly conducted in the last 2-3 years, investigating the internet as a source of health information. Most studies have been conducted overseas, although there is a growing body of good-quality Australian-based research as well (eg. Bessel et al. 2002; Watson et al 2001; McConigley et al. 2001; ACNielsen 2001). Some studies are population-based (Bessell et al. 2002; Wagner & Hibbard 2001; Pennbridge et al. 1999), whereas others focus on specific diagnostic groups such as women with breast cancer (Pereira et al. 2000), patients attending genitorurinary clinics (Ross et al. 2000), and the like. Some surveys focus exclusively on internet users (ACNielsen 2001).

1.241 – Prevalence of internet access and use for health information

Many USA studies have attempted to estimate the prevalence of both internet access and internet use for accessing health information in the population. These USA prevalence rates, based on randomised population samples, provide a useful starting point for estimating and predicting current and future internet usage amongst Australian health information seekers. Only one Australian study, restricted to South Australians, has estimated the Australian population prevalence of internet use for health information seeking (Bessell et al. 2002).

Two USA population-based studies have estimated the prevalence of internet access at around 40%, and its use for accessing health information at around 32%. A USA random household telephone survey of 499 adults (66% women) held during 2000 and conducted by researchers from the University of North Texas found that 32% had used the internet for health information, and a higher 50% "felt comfortable" using it in this way (Licciardone et al. 2001). This contrasts with an earlier random household telephone survey of 1007 adults, conducted by the National Health Foundation in Los Angeles, USA, that found that while 40% had access to the internet, only a minority had used it to obtain health information (Pennbridge et al. 1999).

In terms of actual numbers of internet users, estimates also continue to rise. Researchers from the University of Florida, USA, estimate that in 2000 over 50 million people were seeking health information online (Cline & Haynes 2001). In a discussion paper, Ball and Lillis (2000) estimated that "more than 70 million people in the USA use the internet to research medical conditions for themselves or their families" (p.388). A poll in August 2001 estimated that almost 100 million Americans regularly use the internet for accessing health information (Risk 2001, cited in Wilson 2002). Per day, around six million Americans go online for medical information, more than actually visit a health professional (Fox & Rainie 2002). In terms of predictions for now and the future, Ball and Lillis (2000) estimated that there would be 165 million users by the year 2002. Edworthy (1999), from the University of Calgary, Canada, estimated that there will be over one billion individuals on the internet by the year 2005.

In Australia, the current prevalence of internet usage is slightly higher than the USA, although use of the internet for accessing health information is slightly lower. In 2000, the Australian Bureau of Statistics (ABS) estimated that 50% of Australian adults had accessed the internet in the previous 12 months (ABS 2000). While not comparable, the 2001 ABS Victorian census demonstrated that 38% of adults had used the internet in the preceding week (ABS 2002). A large study of South Australians, co-ordinated by researchers from Monash University in Melbourne, reported a prevalence of 46% internet access. The 12 month prevalence of online health information seeking was 21% (Bessell et al. 2002). The study used data collected in the 2000 South Australian Health Omnibus, a representative sample of 3,027 people aged 15 years and older. Taking into account that internet use in South Australia (SA) is slightly lower than the general Australian population, the authors suggested that the Australian prevalence of online health information seeking is likely to be somewhat higher than 21%.

In Australia, internet access occurs more often from home than from work. In the ABS study of Victorians, 75% of users had accessed the internet from home. Similarly, in the SA survey, 70% of users had accessed the internet from home. Access occurred at work for 35% and 40% in each of these studies respectively (ABS 2002; Bessell et al. 2002). Internet access occurred at both locations for 20% and 46% respectively (ABS 2002; Bessell et al. 2002).

Studies of clinical samples report similar, though somewhat more varied, rates of internet use. A study of 107 breast cancer patients attending follow-up clinics over a 4 month period, conducted by researchers at the University of Alberta, Canada, demonstrated that 43% had used the internet for obtaining cancer information (Pereira et al. 2000). A relatively large cross-sectional survey of 924 outpatients attending a gastroenterology clinic (59% women), conducted by Duke University Medical Centre, USA, reported that 50% had internet access and, of these 51% (25.5% of the full sample) had searched the web for health information in the previous 12 months. Importantly, a much larger 60% said they intended to use the web in this way in the future (O'Connor & Johanson 2000). A study of 82 patients who had undergone coronary artery bypass graft surgery (CABGS) showed that 42.7% were internet users. Amongst users, 51.4% had used the internet for obtaining medical or health-related information, representing around 22% of the full sample (Murero et al. 2001). In a survey of patients attending five genitourinary clinics in London, 41% had internet access. However, only one in ten of these (less than 5% of the full sample) had used the internet to access information about their presenting health problem (Ross et al. 2000). Rates of internet access and use of the internet for health information are shown in Table 2.

Table 2. Prevalence rates for internet access and use of the internet for health information

Study	Country	Sample size	Sample description	Prevalence of internet access	Prevalence of internet for health information
Population-based samples					
Pennbridge et al. 1999	USA	1,007	Random population telephone survey	40%	minority
Licciardone et al. 2001	USA	499	Random population telephone survey	—	32%
Bessell et al. 2002	Australia	3,027	Random statewide interview survey	46%	21%
Clinical samples					
Murero et al. 2001	Netherlands	82	CABGS patients	43%	22%
O'Connor & Johanson 2000	USA	924	Outpatients at a gastroenterology clinic	50%	26%
Pereira et al. 2000	Canada	107	Women with breast cancer attending follow-up	—	43%
Ross et al. 2000	UK	100	Patients at five genitourinary clinics	41%	5%
Carlsson 2000	Sweden	192	Consecutive hospital oncology patients	—	6%

Note. For ease of comparison, prevalence rates have been rounded to nearest full digit figure.

CABGS=coronary artery bypass graft surgery.

— = Not covered by study

1.242 – Comparison of prevalence rates of internet vs other media

But how does the internet compare with other media for health information? Many of the reviewed studies demonstrate that, while internet use is often high, it is less common as a source of health information than more passive methods of information acquisition, most notably the popular mass media, including newspapers, magazines, radio and TV. As shown in Table 1 (presented on page 23), all reviewed studies showed substantially lower use of the internet compared with popular press and TV (Licciardone et al. 2001; Carlsson 2000). Interestingly though, there are trends which suggest that people of higher socio-economic status are increasingly using the internet at almost the same rate as newspapers (Pandey et al. 2002). Importantly, while the study by Carlsson (2000) shows strikingly lower rates of internet usage than the USA studies, it is likely that these Swedish trends have relatively less relevance to Australia.

Amongst internet users, the pattern of media-substitution is even more pronounced. In an Australian survey of 1,600 internet users, 62% of respondents preferred to use the internet more than any other medium whereas only a minority preferred TV (8%), or magazines (8%) (ACNielsen 2001). This pattern of findings suggests that for the majority of internet users, the internet is preferred over more traditional passive media.

However, it might be more accurate to compare internet usage with other active information sources. As shown in Table 1, there is some evidence to suggest that internet usage might be surpassing the use of telephone helplines. The study by Carlsson (2000) estimated prevalence of helpline usage at 10% (as shown in Table 1), whereas higher prevalence rates for the internet have been consistently reported (as shown in Table 2). It is possible that health seekers are choosing to use the internet where they had previously used other active information sources, such as telephone helplines and/or printed educational materials. The study by Lerner (2002) similarly demonstrated higher use of the internet (7.6%) compared with the NHS telephone helpline (2%). However, utilisation of either media was relatively low because the study was restricted to pre-consultation information-seeking. That internet users turn to the internet (62%) far more than health books (12%) provides further evidence that the internet is indeed replacing more traditional methods of active information-seeking (ACNielsen 2001).

1.243 – Reasons for using the internet

There is also evidence that the acquisition of health information is one of the key reasons for using the internet. A Maryland (USA) study of 550 adults over 40 years of age demonstrated that the most common reasons for using the internet are for health information, travel and holiday information, and email (Morrell et al. 2000). The Kaiser Family Foundation (USA) explored use of the web by Generation Xers, concluding that young adults seek health information “more often than they check sports scores, purchase merchandise, or participate in chat rooms” (Rideout 2002; p.26). In contrast though, a study of 1,600 Australian internet users found that a smaller 20% of regular internet users search for information about health and medical conditions (ACNielsen 2001).

In terms of the type of health information sought on the net, most online health information seekers look for information on presenting illnesses and their treatments. In the South Australian representative survey, the health information most commonly sought were the cause or description of a disease or health condition (60%), or the treatment or management of a disease or health condition (45%; Bessell et al. 2002). Similarly, a USA survey of 500 online health information seekers found that the major reason (93%) was to look for information about a particular illness or condition, 64% for information about prescription drugs, and 48% about alternative treatments (Fox & Rainie 2002). In a Canadian study of 107 breast cancer patients, Pereira et al. (2000) similarly found that the health information

most commonly sought on the internet was in relation to cancer and its treatment (91%) and other treatment options (63%).

In addition, information about lifestyle issues is commonly sought. In the USA study, 65% health information seekers looked for information about nutrition, exercise or weight control, and 39% sought information about depression or anxiety (Fox & Rainie 2002). The Australian study did not assess the extent of lifestyle-information seeking (Bessell et al. 2002).

Not surprisingly, online health information seekers are often searching for health information for someone other than themselves. In the study by Fox and Rainie (2002), 50% had searched on behalf of someone else the last time they went online. More specifically, they had searched on behalf of their child (10%), spouse (10%), parent (9%), other relative (10%), friend (8%), a patient or client (2%), or someone else (1%). Not surprisingly, this type of searching was particularly common for those in mid-life. Women were twice as likely as men to be seeking information for a child, whereas there was no gender difference for other proxy-seeking (Fox & Rainie 2000). A larger 81% have gone online at some point because someone they knew was recently diagnosed (Fox & Rainie, 2002).

For some online health seekers, the internet is used as a second opinion in terms of diagnosis and treatment options. In the South Australian study of online users, Bessell et al. (2002) found that 19% of the 643 online health seekers used the information as a second opinion. In the Canadian study, a larger 66% of women who used the internet reported that they commonly followed up information presented by their clinician (Pereira et al. 2000).

However, relatively few women report that they subsequently discuss the internet information with their doctor, pharmacist or other health care provider (Bessell et al. 2002; Pereira et al. 2000). In the Australian study, for example, only 16% of online health seekers discussed the information they obtained with their GP or pharmacist (Bessell et al. 2002). Bessell and colleagues suggested that the reasons consumers chose not to discuss online health information with their health care providers requires further research. Overseas estimates suggest that, of those who seek health information on the internet, over one third (37%) take it to their GP for a final quality check or further discussion (Fox & Rainie 2002).

Reasons for internet use can differ depending on the health-status of the searcher. In a review of literature, Powell and Clarke (2002) note that internet users can be classified as the well, the newly diagnosed and the chronically ill and their caregivers. According to Powell and Clarke (2002), well people search episodically for information relating to short-term medical conditions, pregnancy and prevention; those who are newly diagnosed search intensively and extensively for disease-specific information; whereas the chronically ill and their caregivers search on a more regular basis for information related to new treatments, nutrition advice, and alternative therapies.

Other evidence from a USA study suggests that female users of the internet are motivated to do so because they are health-conscious rather than because they have a health condition. The study compared three models to determine what motivates women to use the internet for health information (Pandey et al. 2002). According to Pandey et al., the Health and Wellness Model proposes that health-conscious women use the internet as yet another mechanism to pursue good health; the Health Needs Model proposes that women use the internet in response to a diagnosis or current illness; and the Search Costs Model proposes that the internet is used in order to reduce information-seeking costs.

In a random household telephone survey of 1,016 USA women, health-conscious women – those who had a healthy diet, exercised regularly, were non-smokers and engaged in regular cancer breast and cervical cancer screening – were more likely to use the internet than were those less health conscious. This supports the Health and Wellness model: the notion that health-conscious women are using the internet as yet another health-information source.

Regarding the Health Needs Model, internet use was not associated with having a current health condition, but showed a mild association with current service use (for maternity-related services only). Regarding the Search Costs Model, internet use was associated with day-to-day life pressures (operationalised as being in the paid workforce, and having interruptions to work-life), but not with geographic distance from healthcare providers. Given that employment is itself associated with internet usage, this association is perhaps misleading.

In a multivariate logistic regression analysis, a 'health-consciousness index' emerged as a significant and independent predictor of internet use, highlighting the Health and Wellness Model as the most useful for understanding women's motivations for using the internet. Younger age and higher socio-economic status also predicted internet use, whereas having a current health condition was not predictive of internet use. Importantly, health conditions amongst other family members were not recorded; thus information-seeking in response to a diagnosis or illness in a family member was not assessed.

1.244 – Socio-demographic profile of internet users

The findings of internet studies are strikingly consistent, with several key trends emerging. First regarding the socio-demographic profile of users, studies show that those who search the internet for health information are younger (Bessell et al. 2002; Morrell et al. 2002; Pandey et al. 2002; Smith-Barbaro et al. 2001; Licciardone et al. 2001; Ross et al. 2000; Carlsson 2000; Pereira et al. 2000) and more well educated (Bessell et al. 2002; Pandey et al. 2002; Fox & Rainie 2002; Murero et al. 2001; Licciardone et al. 2001; Carlsson 2000; Pereira et al. 2000). The socio-economic difference in internet users has been referred to as the "digital divide" (Pandey et al. 2002; Bessell et al. 2002). While some studies show that online health seekers tend to live in metropolitan regions (Licciardone et al. 2001), the only relevant Australian study reported no association between online health seeking and geographic location (Bessell et al. 2002).

Although older age and lower socio-economic status currently pose barriers to internet access and use, these divisions are likely to decline in the future. Given the increasing use of the internet as a health information tool in the young, it is estimated that it will inevitably gain momentum as a key health information system for the future (Licciardone et al. 2001). Already in Australia, use of the internet is currently constant between ages 15-54 (Bessell et al. 2002). Moreover, a recent USA study shows that older internet users (aged 50-64) are more likely than their younger counterparts to look for health information (Fox & Rainie 2002). While some researchers have concluded that the internet is unlikely to become an alternative source of health information for those aged over 75 years (Morrell et al. 2002; Smith-Barbaro et al. 2001), internet usage in the elderly will inevitably increase as the mid-age cohort enters older age. Likewise, it has been suggested that current educational and socio-economic barriers to internet access are likely to decline, and the concomitant digital divide is likely to narrow, as internet service provider and computer package costs decrease (Bessell et al. 2002; Pandey et al. 2002).

Similarly, the gender-divide in computer access is also diminishing. While some early studies suggested women were less likely than men to use the internet, either for health-related or other types of information (Astbury & White 1998), this no longer appears to be the case. Of more than twenty reviewed studies detailing the socio-demographics of internet users, gender emerged as a predictor of use in only three studies (Ross et al. 2000; Trevitt et al. 2001; Bessell et al. 2002), one of which relied on a small sample of only 24 respondents (Trevitt et al. 2001). The Australian study did show that men were more likely than women to have internet access (51% vs. 40% usage) but, at the same time, revealed a trend for women to be more likely than men to use the internet for seeking health information (23% vs. 19%; non-significant difference). Given that women are more likely health information

seekers than men (Fox & Rainie 2002; O'Connor & Johanson 2000; Fox & Rainie 2000), it is possible that women's use of the internet for health information will increase over time. Indeed, women over 50 have been identified as the fastest growing group of internet users (APP News Service, cited in Barnett et al. 2000). Importantly, Wilkins and Navarro (2001) from PATH Organisation, USA, note that those who search the internet for health information represent the same "consumer segments that have always been actively involved in their own health" (p.9).

However, it is perhaps premature to suggest that the digital divide will disappear altogether. Presumably the internet will remain less accessible to certain minority groups (Eysenbach & Jadad 2001). In Australia, this will perhaps include certain facets of the Indigenous community, the unemployed, those living in rural and isolated areas, the elderly, and others. Swanson (1999), from the SA Department of Human Services in Adelaide (Australia), emphasises that there is a risk that people with mental illness and those who are illiterate might be further disadvantaged by information technology. Consistently, Australia's National Health Information Management Advisory Council notes that "new information channels will not obviate the need to communicate in other ways to accommodate the needs of many individuals" (NHIMAC 2001).

1.245 – Advantages and disadvantages of the internet

Compared with other sources, the internet has a range of advantages to consumers in general, and to women as health information seekers, hence its growing appeal. According to researchers from the University of Florida, USA (Cline & Haynes 2001), the internet offers the advantages of interactivity, information-tailoring, and anonymity. Convenience is also a key advantage, as the internet can be used at any time (Metcalf et al. 2001). It also provides a means of getting a second-opinion without the hassle of referral, and potentially a means of communicating with others in similar situations (Metcalf et al. 2001). These advantages have also been noted by the Institute for the Future (2000b) and the Pew Internet Project (Fox & Rainie 2000).

However, these advantages are weighed against a range of disadvantages. These include inequitable access, challenges of orientation, technical language, lack of permanence, and concerns about confidentiality and security (Cline & Haynes 2001; Institute for the Future 2000b). In addition, with the continual increase in information on the web, there are increasing concerns amongst health professionals and others regarding the quality of the information available to consumers, and the difficulties consumers face in successfully determining which information to trust (Institute for the Future 2000b). The issue of quality assurance of health information will be addressed separately in Section 3 of the present review.

1.25 – Pamphlets, brochures and newsletters

Many studies have demonstrated that knowledge improves following exposure to health-related information pamphlets and newsletters. An intervention study conducted by researchers from Indiana University of Pennsylvania, USA, involved the delivery of five home-based newsletters regarding nutrition (with or without follow-up phone call). Women receiving the intervention were compared with a 'no information' control group in terms of knowledge or and interest in nutrition. Both intervention groups demonstrated better knowledge of nutrition than the control group, suggesting that the newsletters had been effective in informing women about nutrition (Taylor-Davis et al. 2000). Likewise, a study of 163 patients attending a genitourinary outpatient clinic (n=73 women) assessed knowledge of chlamydia, its symptoms and consequences. Knowledge was highest amongst those who read health-information pamphlets "often or always" (Devonshire et al. 1999).

In terms of improved knowledge, there is some evidence that pamphlets are as effective as more intensive information provision methods such as touch-screen systems. In a study of 875 women booking into antenatal care at Aberdeen Maternity Hospital, UK, information provision via leaflet and touch-screen were compared. All women were given a leaflet outlining prenatal testing. In addition, intervention women used a touch-screen system carrying the same information. In terms of knowledge, all women demonstrated similar knowledge of the various prenatal testing procedures following the intervention period, suggesting that “touch screen seemed to convey no benefit over well-prepared leaflets in improving understanding of prenatal tests” (Graham et al. 2000; p.155).

Research demonstrates that consumers and patients prefer written materials that are easy-to-read and devoid of technical or medical jargon. A RCT of 610 parents compared comprehensibility of two polio vaccine pamphlets (Davis et al. 1998). One was designed according to easy-to-read principles and tested as being at sixth grade reading level, thus ensuring the comprehensiveness of the information presented. The other was a more technical pamphlet prepared by the Centre for Disease Control. The study found that the ‘easy-to-read’ pamphlet was preferred, regardless of respondents’ reading levels. In addition, parents receiving the ‘easy-to-read’ pamphlet showed better comprehension than did those who received the ‘technical’ pamphlet. In particular, comprehension was highest for information delivered via instructional graphics. The authors concluded that simplicity in readability improved the appeal and usability of the information, and that the key factor in increasing comprehension was the inclusion of instructional graphics (Davis et al. 1998).

However, written information appears to be less effective than other methods when more rigorous outcome measures are used. While pamphlets conveyed the same positive effects as touch screen in terms of knowledge, they did not impact upon women’s anxiety levels (Graham et al. 2000). In contrast, women who had used the touch screen showed a higher uptake of prenatal testing and a decline in anxiety over the course of their pregnancy when compared with women who had received the leaflet only (Graham et al. 2000).

The provision of written information has consistently been shown to promote more effect when provided in the context of personalised advice and support (eg. Thornton et al. 1995; Murphy et al. 1995). For example, in a randomised controlled trial of an evidence-based leaflet to encourage women to make informed choices regarding maternity services, utilisation of the leaflet was found to be severely restricted by a lack of discussion of the leaflet information with women by health professionals (Stapleton et al. 2002; O’Cathain et al. 2002). Other relevant studies are reviewed in later sections of this report (see Section 1.28 – GPs and other health professionals: personalised information).

Of the written information sources described in this section, newsletters stand out as providing more than pamphlets and brochures. There is some evidence to suggest that, as well as increasing women’s knowledge, newsletters promote communication and a sense of belonging, particularly for women living in rural or isolated areas. A survey of 247 subscribers of ‘Network’, the newsletter of the Rural Women’s Network (RWN), demonstrated that around half use the newsletter as a means of communicating or networking with other women and/or women’s groups, and around half share past newsletters with friends. In addition, it was noted that “the sharing of women’s stories and experiences validated their own and other women’s experiences which resulted from feeling a sense of identification with and belonging to a community” (RWN 2000, p.10). Also important in both information exchange and promoting a sense of belonging, the provision of information about up-coming events in the community in ‘Network’ was regarded positively by readers.

1.26 – Videos and video conferencing

Video resources have been shown to be particularly well received and useful for women living in rural or isolated communities. Two Australian intervention studies have demonstrated the benefits of this media.

Networking North Queensland (NNQ) was a two-year project undertaken during 1998-2000 to improve access to health information for rural and remote communities. The project involved the installation of video-conferencing equipment at 21 sites in rural north Queensland. A total of 197 hours of videoconferencing was recorded at 10 of the sites over the 12 month study period. The project also involved the provision of email and internet access in 61 rural and remote communities. The NNQ project was shown to increase rural residents' access to medical, specialist, allied health and primary health services (Watson et al. 2001).

An earlier USA study similarly demonstrated the benefits of video for reaching rural and isolated women. The intervention study, coordinated by the Boston College School of Nursing, was based on the assumption that TV and video would provide the ideal medium for reaching isolated older women with health information and educational programs. The video, which provided information about breast cancer and demonstrated breast self-examination (BSE), was delivered to a volunteer sample of 62 women from Senior Citizens clubs and other community groups. Pre- and post-test interviews demonstrated that women had an improved knowledge of breast cancer, and improved skill in BSE and lump detection following the intervention. The author concluded that videos are especially suitable and effective for information provision for home-bound older women and those living in isolated rural settings (Wood 1996).

1.27 – Touch screen systems

Some GP surgeries and clinics have begun to offer patient information and education via on-site touch-screen systems. However, few studies have explored the effectiveness of this medium. As detailed above, the study by Graham et al. (2000) investigated the effects of the use of touch screen by pregnant women for information about prenatal screening. While touch-screen showed no benefit above a written leaflet in terms of improved knowledge, it was associated with increased prenatal testing and reduced anxiety over the course of pregnancy. This suggests that the touch-screen medium was perhaps more effective than written information in terms of influencing women's decision making and subsequent emotional state.

1.28 – GPs and other health professionals: personalised information

1.281 – General practitioners

There is considerable evidence suggesting that general practitioners are regarded as the most credible and amongst the most preferred source for health information. A USA random telephone survey of 1,007 adults, conducted by the National Health Foundation in California, found that physicians and healthcare providers are more trusted for health information than any other source (Pennbridge et al. 1999). Likewise, in a Glasgow study of 163 patients attending a genitourinary outpatients clinic, doctors were nominated as the preferred source for health information, above information leaflets, women's magazines and TV (Devonshire et al. 1999). Studies with family carers, the majority of whom are mid-life women, similarly demonstrate that GPs are the main and most preferred information source (Schofield et al. 1998). A review of literature, undertaken by researchers from the University of Sheffield, similarly noted that consumers overwhelmingly use the GP as the first point of call for health information (Wilson & Walsh 1996).

There is some evidence that women prefer a female GP, particularly for information or consultation regarding their sexual and reproductive health. A three-year study of 1,360 women, conducted in the UK, explored the types of consultations for which women preferred to see a female health care provider (Brooks & Phillips 1996, cited in Astbury & White 1998). The study found that many women had a preference for a female practitioner, particularly for consultations relating to pap smears (54%), breast examination (48%), vaginal discharge (36%), sexual matters (33%), thrush (29%), and menstrual problems (27%). These figures also highlight that a lot of women do not have a strong preference in terms of practitioner gender. An Australian study of 318 women similarly found that those from non-English speaking backgrounds (NESB) more commonly preferred a female practitioner: 78% of Vietnamese women, 68% of Turkish women, and 64% of Filipino women preferred a female practitioner (Small et al. 1997, cited in Astbury & White 1998). Importantly, it is likely that Indigenous women do not share this preference for female healthcare practitioners (Small et al. 1977, cited in Astbury & White 1998).

Personalised physician information has been shown to be more effective than written information alone. For example, in the study by Taylor-Davis et al. (2000), intervention women all received the same information newsletters. However, half the women received a follow-up phone call in addition to the newsletter, enabling assessment of personalising of the information. As hypothesised, women who received the follow-up phone call subsequent to the newsletters showed better knowledge than those who received the newsletters alone (Taylor-Davis et al. 2000). Two evaluations of the Carer Support Kit available to Australian family carers have similarly suggested that the information is best received in the context of personalised support and advice (CAA 1999; Murphy et al. 1995). It has been noted that interpersonal information channels are effective because they provide immediate feedback and support, which enhances consumer confidence in the advice received (Wilson & Walsh 1996).

More importantly, several studies have demonstrated that GP advice motivates women to use risk screening and other health care services. A study of 102 rural women, conducted by researchers from the University of Nebraska (USA), found that health provider recommendation is a key predictor of the use of preventive health services (Pullen et al. 2001a). Similarly, a stratified random sample survey of 999 women found that GPs were influential in motivating women to engage in screening behaviour (Metsch et al. 1998). Women who named their doctor as an important source of health information were almost twice as likely as other women to have had a recent mammogram.

In addition to personalised information, some GP surgeries offer a library of books and other resources. An Australian study investigated the use of a general practice library over a 15 month period (Charlton 1997). Of 164 questionnaire respondents, there were 229 borrowings, most by women (88%). For 47% of borrowers, the doctors surgery was the main source of health information. Most reported increased knowledge (88%), reduced anxiety (48%) and positive behaviour change (79%) as a result of the health information they had borrowed (Charlton 1997). A British literature review cites a similar study in which 92% of consumers indicated that they would use a health library located within the local hospital (Wilson & Walsh 1996).

However, there is some evidence that women want more information from GPs and other healthcare providers than they are currently receiving. Using data from a 1998 survey of women's health, researchers from the Centre for Health Policy Research, USA, found that women receive limited physician information about health-related behaviours (Wyn & Solis 2001). A random doorknock survey of 214 Australian women, conducted by researchers from the Hunter Centre for Health Advancement in Newcastle, reported that women's suggestions included the provision of better health information from doctors and other health care professionals (Brown & Doran 1996). Moreover, in a study of 23 NSW women participating in

a pilot health promotion program about menopause, many women felt that their concerns were often trivialised by GPs, and many were frustrated by a lack of accurate, up-to-date information (McVeigh 1996).

The recent uptake by GPs of software programs, such as Medical Director, offers a new alternative in the mechanisms available for the delivery of health information to women through GPs. While the present review has not identified any research that has specifically evaluated this method, it is apparent that there is a need to ascertain whether the use of such software programs has any impact on the provision of health information. This issue should also be considered in the concurrent literature review related to health care providers.

1.282 – Other health professionals

Information given by health professionals other than GPs is also well received and effective. In a RCT of 1,691 pregnant women booking antenatal care, coordinated by researchers at Leeds University, UK, women received either 'usual care', an individual information session, or a group information session. Five midwives and one doctor were trained to conduct the individual and group sessions. Usual care involved the provision of routine information by the midwife or doctor making the booking. Compared with women who received usual care, women in both intervention groups demonstrated better knowledge, reported more satisfaction, and reported reduced anxiety later in pregnancy (Thornton et al. 1995). The intervention also promoted more considered uptake of prenatal tests, as outlined in the 'Background and rationale for the present review' of the present review. Importantly though, women in the intervention groups received more information than those in the usual care control group. Hence, it is unclear whether the positive outcomes are attributable to the personalisation of the information or simply to the fact that the information was more detailed.

1.29 – Telephone information lines

After reviewing a number of research studies, Astbury and White (1998) concluded that telephone information lines were one of the most popular sources of health information for women. Telephone information lines enable trust to be established and information to be tailored to the individual needs of the caller, hence part of their appeal, particularly for sensitive women's issues (vanBalen et al. 2001). The anonymity is also appealing: a UK study demonstrated that caller anonymity is a particularly positive feature of telephone services (Sims & Golightly 1998). In addition, the telephone poses a relatively inexpensive and easy method of information acquisition, particularly with the provision of freecall 1800 lines. Moreover, telephone helplines have been shown to be extremely cost-effective at a fiscal level, effectively replacing a GP appointment for around 60% of callers (Hughes et al. 2002). That callers are often mailed written material reinforces the personalised information obtained over the phone.

The NHS telephone helpline established in the UK in 1998 has been studied in detail and provides a good model of telephone information dissemination. The service, which was set up to provide fast information and advice on all health issues, has received over 3000 calls since its launch and currently covers over two thirds of England's population (Mayor 2000). On the whole the service appears to provide a fast, efficient and cost-effective service to UK women (Hughes et al. 2002; Mayor 2000; Sims & Golightly 1998).

Telephone helplines appear to be particularly effective for women in crisis situations, such as those living with domestic violence. As detailed in Section 1, for several of the helplines currently operating in Victoria, domestic violence is the major reason for contact (WIRE 2000; Women's Health Grampians 2001). This highlights the importance of helplines in crisis situations.

Calls to telephone information lines appear to increase in direct response to mass media advertising and reports. For example, the peak times for calls to the cancer-related telephone advice line were reported to follow TV or newspaper coverage of cancer (Brodie 2001). Likewise, calls to national Quit Lines increase significantly during anti-smoking media campaigns, both in Australia (Quit 1999) and the UK (Owen 2000). One study also suggests that calls to information helplines increases in response to written information materials. The Healthwise Communities Project (HCP) distributed health information to all residents in Boise, Idaho. Researchers from Stanford University (USA) conducted a random household survey, both before and after the intervention, to assess the impacts on the use of medical reference books, telephone advice lines, and computers. There was a significant increase in the use of both books and telephone advice lines following the intervention (Wagner & Hibberd 2001).

However, telephone helplines appear somewhat limited when their utilisation is compared with other media. For example, in the study by Carlsson (2000), health information was acquired via telephone helplines by only 10% of patients, compared with much higher rates for passive sources such as TV and newspapers (see Table 1). Larner (2002) similarly reported extremely low utilisation of the NHS telephone helpline (2%) amongst 198 neurology outpatients prior to consultation, with active internet use slightly higher at 7.6%.

Indeed, there is evidence that women are turning to the internet instead of telephone helplines. As detailed in Section 1, several women's health services currently operating in Australia show decreasing use of telephone helplines together with increasing website activity (WHV 2001; WIRE 2000; 2001). In addition, the prevalence rates reported in several comparative studies reviewed earlier suggest at least some degree of internet substitution. On the contrary though, Brodie (2001) noted that calls to a cancer information line, averaging 1000 per week, did not decrease following the launch of a website connected to the service.

1.3 – SUMMARY

This section has provided an overview of research and other reports of women's current and preferred channels for accessing health information. Comparative studies show that the mass media and popular press, specifically TV, newspapers and magazines, are the most commonly cited sources of health information for women and for the population generally. However, information obtained via active seeking – most commonly from GPs and other health professionals – is seen as more credible and is often more useful in terms of assisting women in health-related decisions. The internet is also being used increasingly for obtaining health information, apparently more so than some other active sources, including telephone helplines and written resources. Nonetheless, telephone helplines remain an effective and necessary information source for women in crisis. Likewise, newsletters remain appropriate for isolated groups, especially women living in remote and rural areas, and for those with a chronic health condition.

2 – CRITICAL TIMES AT WHICH WOMEN ACCESS HEALTH INFORMATION

Information needs differ depending on the timing of the information and, in the case of both chronic or acute illness, the stage of the disease progression or treatment process. This section outlines the critical times at which women need or want to access health information, and the specific events which tend to prompt women to actively seek health information. With the plethora of internet-related research, much of what is known about the timing of health information relates to active information-seeking on the web.

2.1 – BEFORE CONSULTATION WITH A HEALTH PROFESSIONAL

There is some evidence that adults, including women, access information before attending a GP or outpatient appointment. A USA study of 500 online health information seekers found that 65% accessed information before visiting a doctor. In the UK study of neurology outpatients though, only 10% had accessed information about their medical condition prior to consultation (Larner 2002). This lower incidence is presumably a result of the strict specifications used in the study, as patients were asked only about information related to their current medical condition.

Consistently, GPs report that many patients present with internet-based information. In a study of 900 Australian GPs, ACNielsen (2001) found that a high 89% reported that patients had presented to them with health information they had accessed from the internet. Overseas rates are somewhat lower. A Norwegian study of 1,276 doctors reported a rate of 75% (Hjortdahl et al. 1999, cited in Gerber & Eiser 2001), while a Scottish study of 160 GPs found a lower rate of 58% who had been presented with internet information by patients (Wilson 1999).

The presentation of internet information within a consultation can have implications for the GP. In a UK study involving 375 web-using GPs, Potts and Wyatt (2002) found that 64% reported longer consultations and 44% reported more unnecessary investigations. In the Scottish study, of those GPs approached by patients with internet information, 77% reported longer consultations and 85% reported higher patient expectations (Wilson 1999). A relatively high 65% of GPs indicated that the information obtained by patients from the internet was new to them (Wilson 1999).

2.2 – BEFORE UNDERGOING TESTS, TREATMENTS OR SURGERY

Women also indicate that they want to be informed before undergoing tests, treatments and surgery, to assist them in their decision process. Researchers at the University of Cambridge, UK, conducted a qualitative study of 23 women at high risk for ovarian cancer who had undergone prophylactic bilateral oophorectomy to manage their inherited risk of breast cancer. While generally satisfied with the surgery, many women indicated that they would have liked to receive more information about the physical and emotional after effects of the surgery before their surgery (Hallowell 2000). Likewise, several studies have demonstrated that women want to be informed about all possible side effects of medications (Ziegler et al. 2001) and of prenatal tests (Oliver et al. 1996).

2.3 – FOLLOWING CONSULTATION WITH A HEALTH PROFESSIONAL

At the same time, there is also evidence that women seek information following a diagnosis or GP appointment. As indicated earlier, this information is often used as a means of obtaining a second opinion (Bessell et al. 2002; Pereira et al. 2000). For example, breast cancer patients commonly seek information in relation to their illness and its treatment, and

other treatment options, and seek to verify information presented by their GP (Pereira et al. 2000).

2.4 – AS A SUBSTITUTE FOR A CONSULTATION WITH A HEALTH PROFESSIONAL

There is also some evidence that women use health information to substitute for consultation with health professionals. As noted earlier in this review, a random USA household survey of 1,812 parents (mostly mothers) demonstrated that the provision of good quality health information decreased paediatric consultations with doctors in the following year (Wagner & Greenlick 2001).

It is likely that the internet is also used for self-diagnosis, parental diagnosis of childhood illness, and/or treatment of acute and chronic conditions. Some researchers have suggested that the driving force behind the burgeoning of online health information is the lack of, and consumers' dissatisfaction with, information obtained from health professionals (Eysenbach & Jadad 2001). A consumer perspective on this issue goes further to propose that there is currently a move away from GPs. Tyson (2000) suggests that as consumers' "desire for more involvement in and control over the management of their health" is increasing, they "will rely less on physicians and shop for alternatives more" (p.1). Only one of the reviewed studies assessed physician substitution by internet information: Fox and Rainie (2002) found that a relatively small 18% of online health information seekers used web information to diagnose or treat a medical condition on their own, without consulting their doctor. Perhaps this remains an area for future research.

2.5 – AT THE TIME OF DIAGNOSIS

A great deal of information is given to patients at the time of a diagnosis, particularly in regard to chronic or life-threatening conditions (Rees & Bath 2000). Again there is some evidence to suggest that personalised information is preferred. In a comprehensive literature review of literature published between 1988-98, Rees and Bath (2000) concluded that women with breast cancer and their family members preferred verbal information from health professionals at the time of diagnosis.

However, information provided at the time of diagnosis of an illness – the time at which much disease-specific information is provided – is not well absorbed, remembered, understood or utilised. In their study of 105 women with breast cancer, Luker et al. (1996) noted that attention and recall are severely limited at the time of diagnosis, and that information delivered at this time is rarely absorbed.

Different personal styles might further inhibit information uptake for some people. In a Swedish study, Elf and Wikblad (2001) explored different styles of information seeking. They determined that some people are "blunters" who avoid information, whereas others are "monitors" who actively seek information. Of 30 cancer patients undergoing chemotherapy, blunters were more dissatisfied with the information they had received. The authors concluded that they had perhaps received the information too early in the disease process and were therefore more inclined to avoid it. Other researchers have similarly noted that some breast cancer patients actively seek information while others actively *avoid* information, hence the need to tailor the amount and timing of information to each individual woman (Rees & Bath 2001).

The Barwon-Southwest BSEP Project is currently undertaking a trial aimed to disseminate appropriate and timely information to women with breast cancer. Based on research that women feel "bombarded with information" while others "were given nothing", the project aims to provide information on an individual and continual basis (BSEP News 2002). The Barwon-Southwest BSEP project provides an example of information provision tailored to the needs of each specific woman.

2.6 – OVER THE COURSE OF TREATMENT

Once diagnosed with a chronic illness or disability, there is evidence that information needs are maintained over time. This is particularly true for women undergoing long-term treatments. A Canadian study of 33 women with breast cancer undergoing radiation therapy demonstrated that high information needs were expressed in the first, third and last week of the therapy, as well as a month after the conclusion of treatment (Harrison et al. 1999). While the actual information needed might change over time, this finding suggests that high information needs are likely to be maintained over the course of treatment for life-threatening illnesses such as cancer. Similarly, a study of 105 women with breast cancer found that 66% of women still had unmet health information needs at the time of follow-up, approximately 21 months after diagnosis (Luker et al. 1996).

2.7 – DURING STRESS OR CRISIS

Many people actively seek information when stressed or in a crisis. However, evidence suggests that information cannot be easily or effectively utilised at these times. In an Australian study examining uptake and utilisation of the Carer Support Kit available through the Carers' Association of Australia (CAA), carers who were currently stressed or experiencing health problems were less likely than others to use the kit (Murphy et al. 1995). This was despite their having gone to the effort of telephoning the CAA to request the kit. Indeed, the authors concluded that having telephone contact with a CAA worker represented part of the motivation for applying for the kit, and possibly even addressed some of the presenting issues, hence reducing the need for the kit information. A more recent evaluation of the Carer Support Kit, conducted by the CAA (CAA 1999), reported a similar finding. The authors concluded that "carers often seek information when in crisis, [but] responding with a pack of information at this time may not be the most useful or cost-efficient response" (CAA 1999, p.10).

2.8 – ACTIVE INFORMATION SEEKING IN RESPONSE TO PASSIVE INFORMATION EXPOSURE

Some information seeking occurs in response to passive information acquisition. Most often this applies to calls to telephone helplines in response to viewing or reading a TV or newspaper report or advertisement. As noted earlier, calls to a cancer information and advice line peaked following newspaper or TV coverage of cancer (Brodie 2001). Likewise, calls to smoking Quit Lines peak during media campaigns (Owen 2000; Quit 1999). Indeed, such campaigns are developed on the premise that viewers will be prompted to telephone the information line to obtain more detailed and personally-relevant information (Quit 1999).

2.9 – SUMMARY

In summary, it appears that women seek information both before consultation or before a procedure to assist with decision-making, and after consultation to verify the information obtained from health professionals. For women with a current diagnosis or a chronic medical condition requiring ongoing treatment, high information needs appear to be maintained over time. In addition, information gleaned through passive sources, such as a newspaper or TV report or advertisements, might prompt women to actively seek further information on the topic from other sources. Importantly, there is evidence to suggest that current crises or stress can preclude effective utilisation of health information, and that information delivered at the time of diagnosis is not easily absorbed or understood.

3 – BARRIERS TO WOMEN IN THEIR ACCESS TO HEALTH INFORMATION

This section addresses barriers currently facing women in their access to health information. Based on the literature reviewed, the major barriers include quality assurance, confidentiality, and readability/comprehensibility of the information obtained. A model for the dissemination of good-quality women's health information, based on the USA experience, is briefly outlined. Specific barriers facing specific groups of women will be addressed separately in Section 4.

3.1 – QUALITY ASSURANCE

With the current information explosion, particularly in regard to the World Wide Web and the internet, the issue of quality assurance (QA) of health information has gained increased importance. Issues of poor quality and the need for evaluation of quality also applies to the mass media and the popular press. The issue of QA will be addressed separately for each of these two media.

3.11 – The internet

While the internet is commonly regarded as a positive tool, enabling women to become more self-sufficient in terms of health care for themselves and their families (eg. Eysenbach & Jadad 2001), healthcare professionals and researchers have become increasingly concerned about the quality of health information currently available on the internet (eg. Rhodes 2000; Timmons 2001; Best & Bedi 2001; Institute for the Future 2000b). In all the studies reviewed, only one provided evidence that the quality of health information on the internet has improved in the last few years (Pandolfini & Bonati 2002). In contrast, the reasons for concern are many.

First, in searching for health information relating to a specific topic, online consumers access many sites which are not relevant. For example, a study conducted by Baylor College of Medicine, USA, involved a search for "rheumatoid arthritis" information. Of 531 sites accessed, only 51% actually contained information relevant to rheumatoid arthritis (Suarez-Almazor et al. 2001). In a similar study, conducted by the University of Louisville, USA, a search for "laparoscopy" information accessed 14,030 hits. However, most of these were duplicates, a page within a site, or dead links (Allen et al. 2002).

Second, online searchers access a great deal of information that is inaccurate. A UK study, conducted by the Birmingham Women's Health Care National Health Service Trust, evaluated the quality of internet information about menorrhagia (Latthe et al. 2000). As a measure of quality, the study assessed the extent to which websites met their stated objectives. Using the key words "heavy periods" and "patient information", the study located nine web pages, none of which satisfied their stated objectives. Two web pages did not display the source of the information, and none described the editorial review process used (Latthe et al. 2000). Similarly, in the laparoscopy study described above, many of the 46 pages containing educational material were found to contain "controversial or misleading statements" (Allen et al. 2002). Specifically, 70% of pages were rated as inaccurate by at least one of the three reviewers, and 37% were rated as inaccurate by all three reviewers (Allen et al. 2002). In a review paper undertaken by researchers from the University of Florida, USA, Cline and Haynes (2001) found that much of the information on internet sites is inaccurate.

More specifically, information on websites is often outdated. In the study by Latthe et al. (2000), only five of the nine menorrhagia web pages stated the currency of the information, adding to the difficulty in determining quality assurance. In a larger study conducted at the University of Maryland, USA, 265 sites containing information about urinary incontinence were evaluated by two external content reviewers. Only 15 sites met the inclusion criteria.

Many sites were found to contain out-dated information. In addition, about 40% of sites did not show when they were posted, precluding determination of the currency of the information (Diering & Palmer 2001). Likewise, in another study undertaken by Latthe and colleagues, in which 121 website on five common health topics were evaluated, only 59 sites (49%) showed currency of the information (Kunst et al. 2002).

Third, some internet sites promote health-care products in which the developers of the site have a commercial interest, thereby acting as an advertising mechanism for the company. For example, in the study designed to evaluate rheumatoid arthritis sites, 51% of the sites accessed were posted by profit-organisations. These sites were significantly more likely than others to be promoting alternative therapies in which the profit-based companies had a financial interest. Specifically, 71% of profit-based sites promoted products or alternative therapies, compared with 44% therapy-promotion in sites posted by non-profit organisations, universities or individuals (Suarez-Almazor et al. 2001). Similarly, of the 104 unique and relevant sites identified in the laparoscopy study described above, 28 (27%) had medical products for sale (Allen et al. 2002).

Given the plethora of information on the web, together with the issues discussed above, online searchers are faced with the task of determining which sites are relevant and useful, and which are not. As noted by many of the researchers involved in the studies reviewed, the fact that websites often fail to date and source the information supplied, and rarely give details of QA procedures, it is extremely difficult for women to evaluate the quality of health information they obtain from the internet. On the basis of their study findings, for example, Latthe et al. concluded that it is difficult for women "to determine which web page is credible and useable and which should be ignored" (2000; p.39).

This is exacerbated by the fact that consumers are perhaps ill equipped to appraise and judge the credibility of information they access on the internet. In a study of 21 internet users, conducted through the University of Heidelberg in Germany, participants were observed while accessing internet answers to a series of health questions and were later interviewed (Eysenbach & Kohler 2002). Although participants said that they looked at the source of information in assessing its credibility, "no participants checked any "About Us" sections of the website, disclaimers, or disclosure statements" (p.573). Indeed, most users explored only the first few links on any website. Very few participants later remembered which websites they accessed the information from or who had developed the sites, further highlighting difficulties in evaluating conflicting information from various sources at the conclusion of a search or download. In a USA study of 500 online health information seekers, Fox and Rainie (2002) similarly found that only a quarter of respondents are vigilant in verifying the source and currency of information, with half the respondents doing so "sometimes", "hardly ever" or "never" (p.4).

Despite these difficulties, evidence suggests that consumers are confident in the quality of the information they obtain, which further underscores concerns about use of the internet for health information. In the USA study of 924 gastroenterology patients (59% women), 86% of those who had accessed health information from the internet were either "somewhat certain" or "very certain" that the information they got was of good quality. Only 14% of internet users reported that they were "uncertain" of the information they had obtained (O'Connor & Johanson 2000). Likewise, 72% of those studied by Fox and Rainie (2002) felt that all or most of the health information online could be believed. In an earlier study, almost all found the information useful and 70% indicated that it had influenced their treatment-related decision making (Fox & Rainie 2000). In contrast, in the Canadian study of 107 breast cancer patients and their families, 53% of internet users were unsure about the trustworthiness of the medical information they obtained on the internet (Pereira et al. 2000). In a UK qualitative study of perceptions of a consumer website, conducted by the University of Ontario, trustworthiness emerged as a key issue and concern for patients (Quintana et al. 2001).

In addition, QA concerns rarely stop consumers from actually accessing health information over the web. Several studies have shown that people who do not use the web for accessing health information, rarely state that concerns about reliability have inhibited their use of the internet (Pereira et al. 2000). Most often, non-use of the internet for accessing health information is attributed to not having computer and/or internet access. In the study by Pereira et al. (2000), reasons for non use were commonly having no internet access (53%) or being unfamiliar with the internet (33%), with a relatively small 13% stating distrust of the information as their reason for non-use.

As a result of their concerns about the health information on the internet, researchers and health professionals have endeavoured to set specific criteria for its evaluation (eg. Wilson 2002; Best & Bedi 2001; Brown 2001; Trevitt et al. 2001). Criteria tend to focus both on (a) the authority and credibility of the source, and (b) the accuracy, objectivity, reliability, relevance and currency of the information (Brown 2001; Shepperd et al. 1999).

Using the set criteria, QA can occur to filter information as it is downloaded from the internet. Several filtering mechanisms for QA are currently operating. For example, both American and English researchers have discussed the role of “gateway sites” or “kiosks”, which operate a selective process to screen information that does not meet specified criteria (Wilson 2002; Jones et al. 2001; Shepperd et al. 1999). In their 5-year forecast, the Institute for the Future have similarly noted that sites will increasingly be developed to filter content for internet users (Institute for the Future 2000b). One example of a gateway to evaluated quality resources in health and medicine is OMNI (www.biome.ac.uk) (Wilson 2002). However, while filtering mechanisms make the internet more accessible and user-friendly, they are relatively expensive both to establish and to maintain (Wilson 2002; Jones et al. 2001).

Alternatively, QA criteria can be used to rate information on websites. In this scenario, websites display a logo or symbol to indicate a commitment by the provider of adherence to a specific code of conduct (Wilson 2002). Accreditation can be either self-applied (on formal application and acknowledgement by the label provider) or external (applied by a third party). Health on the Net Foundation (www.hon.ch) and Hi-Ethics (www.hiethics.com) are two self-applied quality labels currently operating for checking and labelling health information websites (Wilson 2002). Two third-party quality and accreditation labels currently being piloted are MEDCERTAIN in Europe (www.medcertain.org) and URAC in the USA (www.urac.org). Third party accreditation is considered the most advanced approach, ensuring consistent and authoritative assessment of the quality and credibility of web-based information (Wilson 2002; Trevitt et al. 2001). Some researchers, such as Timmons (2001) from the School of Nursing at Nottingham University, UK, also recommend that health professionals need to guide patients and carers in using the internet, and in evaluating the information they find.

A third option is that users check a site and its contents using an evaluation tool (Wilson 2002). Example of these include DISCERN (www.discern.org.uk), NETSCORING (www.chu-rouen.fr) and QUICK (www.quick.org.uk) (Wilson 2002). These user guidance systems enable users to check if a site and its contents comply with certain standards of quality (Wilson 2002). While these systems are relatively cheap, the onus of use falls entirely on the consumer, hence concerns that they will not be widely utilised (Wilson 2002).

Some websites are specifically designed by teams of health professionals, which is another means of optimising the quality of health information on the internet (Hern et al. 1998). An example is NETWELLNESS (www.netwellness.org), designed by a team of nurses, physicians, pharmacists and dieticians. However, while specific well-designed sites are useful, the problem for consumers in evaluating internet information more generally still stands.

In Australia, the National Health Information Management Advisory Council (NHIMAC) has been established to oversee the development, coordination and implementation of national health information standards. The NHIMAC has prepared a national action plan for the health sector – Health Online: A Health Information Action Plan for Australia. The first edition of Health Online, released in 1999, provided the basis for a national strategic approach to health information delivery (NHIMAC 2001). The most recent edition explores the issue of quality assurance of electronic health information, specifically in regard to both web-based information sites and online patient records (NHIMAC 2001).

The NHIMAC has developed a website for ensuring the QA of health information accessed by consumers from the internet (www.healthinsite.gov.au). 'Health/insite' provides "an easy-to-navigate central entry point that links only to quality-assessed health web pages provided by information partners" with the Commonwealth Department of Health and Aged Care (NHIMAC 2001, p.70). To date, 46 organisations currently publishing quality web-based consumer health information have become partners by linking their sites to 'Health/insite'. 'Health/insite' enables users to search for health information through a number of paths including life events, conditions/diseases, lifestyle issues, and expert views about specific topics (NHIMAC 2001). The site currently provides access to six health topic areas: cancer, diabetes, cardiovascular health, child health, food and nutrition, and kidney and urinary tract diseases. The quality and reliability of the information accessed through 'Health/insite' is guaranteed (NHIMAC 2001).

3.12 – Mass media and popular press

There are a number of reasons why QA is important in regard to information delivered by the media and popular press. First, research has demonstrated that topics addressed in the popular press do not coincide with either women's major health concerns or the key conditions affecting women's morbidity and mortality. A study conducted by researchers at the University of Michigan, USA, examined 12 issues of two popular women's magazines ('Good Housekeeping' and 'Woman's Day') and 63 issues of two high profile, refereed medical journals ('New England Journal of Medicine' and the 'Journal of the American Medical Association'). The study also tallied the most common health questions of women presenting to the University of Michigan Women's Health Resource Centre. The study found that less than a third of articles in the magazines dealt with women's health issues, and those that did were most often diet-related. These articles tended to emphasise weight loss rather than health-promotion. Most importantly, the magazines did not cover the health issues either addressed in medical journals or presented by women themselves.

The main women's health topics addressed in medical journal articles (representing about a third of all articles) were pregnancy, HRT, breast and ovarian cancer, and birth defects. Strikingly similar, women's presenting problems related to pregnancy, fertility, reproductive health, and cancer. However, none of these issues were well represented in the women's magazines examined (Moyer et al. 2001). A number of earlier studies have similarly highlighted the discrepancies between women's real health concerns and the health issues covered in the popular press (Shoebridge 1997, cited in Astbury & White 1998).

Second, the specific health information provided in popular women's magazines is often either inaccurate or inadequate. An American study reviewed seven popular women's magazines to find 59 articles about breast cancer (Marino & Gerlach 1999). These were evaluated by experts in terms of adequacy and accuracy. The authors reported that, in general, the articles commonly contained either inaccuracies or inadequacies. Specifically, the risk factors for breast cancer were rarely covered or discussed adequately, the popular 'lifetime risk' statistic was rarely explained adequately, and the average age of diagnosis of the women featured was commonly much younger than the median age of 65 for breast cancer diagnosis in the USA (Marino & Gerlach 1999). Another study by Gerlach similarly

demonstrated that colon cancer, claimed to be the third leading cause of cancer mortality in USA women, was under-represented in articles published in seven popular women's magazines published from 1987-1995 (Gerlach et al. 1997).

A similar USA study found misinformation about oral cancer in the popular press (Canto et al. 1998). The study reviewed 50 articles on oral cancer covered in 18 newspapers and 32 popular magazines. Articles were commonly found to be inadequate in terms of risk factors, only a small 32% mentioning cigarettes for example. Over 50% of the articles did not mention the warning signs of oral cancer, and few suggested clinical oral cancer examinations by a health professional (14%) or the use of self-examination (8%) (Canto et al. 1998).

Advertising for women's health products shown in women's magazines is similarly misleading. An Australian study, conducted by researchers at Griffith University, Queensland, examined advertisements for menstrual products in 48 popular women's magazines (Raftos et al. 1998). The authors concluded that "the findings revealed that advertisements provided confusing, conflicted and paradoxical messages" for women (p.174). For example, the study found that, while commonly depicting menstruation as normal, advertisements encouraged women to keep it hidden and secret. The study demonstrated that advertisements in popular women's magazines can send confusing messages to women, particularly adolescent women, about their femininity and self-identity.

3.2 – CONFIDENTIALITY

Confidentiality is particularly relevant in regard to sensitive issues such as sexual health, reproductive health, and substance use. A USA study of 2,224 adolescent students in Massachusetts was conducted by researchers at the Harvard Medical School in Boston (Thrall et al. 2000). Of the sample, 1,715 (77%) had a regular health care provider. The study found that getting a confidentiality assurance was important in promoting both discussion with and examination by the health care provider. Specifically, adolescents who were guaranteed confidentiality by the health care provider were more likely to have discussions about sexually transmitted diseases (STDs), pregnancy prevention, facts about sex, and/or substance abuse. They were also more likely to have had a pelvic examination by the health care provider. This study highlights concerns about confidentiality as a key barrier precluding information-seeking and emphasises that information relating to sensitive or personal issues needs to be delivered in a confidential way.

Lack of anonymity is particularly salient for young women, most notably those living in country towns. A qualitative study of Australian women of all ages noted that the issue of confidentiality is highlighted for younger women who are on their parents' Medicare card (Barwon-South Western Regional Women's Health Committee 1997, cited in Astbury & White 1998). A study of young Victorian adolescents found that many were reluctant to consult either a GP or pharmacist, or to go to a welfare centre, for fear that their parents would find out. This was particularly so for rural adolescents (Sorger 1990, cited in Astbury & White 1998). A more recent focus group study of young women, conducted by the Loddon Mallee Women's Health Service, similarly found that lack of anonymity in small towns often prevents young women from seeking health information, particularly relating to sensitive or personal issues (LMWHS 2000).

A study of female sex workers in New Zealand also highlights the way in which confidentiality concerns might preclude women from accessing appropriate and good quality health information and health care. The study of 303 sex workers, conducted by the Christchurch School of Medicine, found that female sex workers tend to rely on informal networks for advice and support (Plumridge & Abel 2000). While 83% had a GP, only 62% of those who had used their GP for a health check had disclosed that they were sex workers. Overall, only half had disclosed to any health professional that they worked in the sex industry (Plumridge

& Abel 2000). Presumably this lack of confiding with their GP inhibited women's access to needed information and/or health care services. This study highlights the need for all women to be given access to health information in a confidential manner, and to be assured that health care consultations occur in a confidential environment.

3.3 – READABILITY AND COMPREHENSION OF HEALTH INFORMATION

Readability and comprehension of health information is also a barrier, both for women and men. The issue of readability is relevant to both the internet and written resources. With literacy lowest amongst some of the highest risk groups – those of lower socio-economic status, who have worse health status and increased risk for preventable and treatable health problems – inadequate health literacy can preclude access to health information for those who need it most (Eysenbach & Jadad 2001).

It has been suggested that most of the information on the internet is pitched significantly higher than the average reading level of the American public (Eysenbach & Jadad 2001). In the study of 82 CABGS patients, conducted for the International Institute of Infonomics in the Netherlands (Murero et al. 2001), of those who had used the internet for accessing medical information (18 patients), only three had found the readability level of the information acceptable. All had difficulties with comprehension of at least some of the information obtained, and recommended that sites be developed by their physicians to ensure appropriateness of the information included.

As noted earlier, research demonstrates that consumers and patients prefer health education materials that are easy-to-read and devoid of technical or medical jargon. The RCT of 610 parents (detailed in Section 1.25 – Pamphlets, brochures and newsletters) demonstrated that patients receiving the “easy-to-read” pamphlets showed better comprehension than those receiving the “technical” pamphlet (Davis et al. 1998). The “easy” pamphlet was preferred regardless of respondents' reading levels. The authors concluded that simplicity in readability and the inclusion of instructional graphics improves the appeal and usability of written information (Davis et al. 1998).

A recent evaluation of the Carer Support Kit, conducted by the CAA (CAA 1999), similarly found that readability is a barrier to the utilisation of written information. In an evaluation involving over 600 carers, the kit was found to be under-utilised because it relied on a high level of literacy and entailed too much written information (CAA, 1999).

On the contrary though, some health education materials are too simple for specific sub-groups of patients. It has been noted that readability tests fail to take account of patients' experience and knowledge. Specifically, “during the course of an illness patients rapidly become familiar with quite complex terminology” (Shepperd et al. 1999; p.765).

Thus, finding the correct balance in terms of pitch – easy to read but not patronising – is important. In a review of guidelines for producing quality health information, Vucko et al. (2002) list the guidelines used for development of WHV's QIHIRs. The parameters state that the information needs to be both “easy to understand” and, at the same time, to cover “a depth and breadth of issues that are appropriate to the consumer's request” (Vucko et al. 2002, p.12).

3.4 – BARRIERS FOR SPECIFIC GROUPS OF WOMEN

Specific groups of women face specific barriers in accessing and utilising health information. These are addressed separately in Section 4 of this review.

3.5 – A MODEL OF QUALITY HEALTH INFORMATION FOR WOMEN – THE USA EXPERIENCE

The USA Department of Health and Human Services has been involved in the establishment of the National Centre of Excellence in Women's Health. The goal of the centre is the use of information technology to improve the care of women. Telemedicine, the internet and Resource Centres employing internet educational modalities are used to disseminate good quality health information to women in the community. In addition, facilities for online distance education are made available for clinicians. According to researchers from the University of California, the Centre of Excellence provides a model for quality health information delivery that can be adopted by other centres worldwide (Crandall et al. 2001).

3.6 – SUMMARY

The major barriers for women in accessing health information concern issues of quality, confidentiality, and comprehension. These barriers apply differentially to the various information sources, with QA being most concerning in regard to internet-based health information. QA by internet users is inhibited by the enormous quantity of information, and difficulties in verifying its source, currency and accuracy. Many filtering mechanisms and accreditation systems have been developed to optimise the quality of internet-based health information.

4 – INFORMATION ACCESS FOR SPECIFIC GROUPS OF WOMEN

This section reviews literature relevant to information needs and preferences of specific groups of women. These groups are identified as representing high-needs segments of the population, in part informed by the health issues identified by Astbury and White (1998), but also determined by the availability of research reports.

4.1 – YOUNG WOMEN

Confidentiality appears to be a particularly important issue in regard to the dissemination of health information for younger women. For this age group, information relating to sexual and reproductive health is particularly relevant, hence the salience of confidentiality. As detailed in Section 3.2 – Confidentiality, a USA study of 2,224 adolescent students demonstrated that getting a confidentiality assurance was important in promoting both discussion with and examination by the health care provider (Thrall et al. 2000). This study emphasised that adolescents are reluctant to seek health information, particularly that relating to sensitive or personal issues, due to concerns about confidentiality. As a consequence of this lack of disclosure and/or information-seeking by young women, GPs and other health professionals are limited in their provision of relevant information to young women.

Confidentiality concerns are particularly problematic for young people living in small towns. The Lodden Mallee Women's Health Service conducted focus groups into the health needs of young women in small communities. Participating young women indicated a desire for more information on relationships, body image and eating disorders. Again they expressed concerns that lack of anonymity in small towns often prevents them from accessing information, especially for personal or sensitive issues (LMWHS 2000).

Given concerns about confidentiality, it is perhaps not surprising that evidence highlights the mass media as the commonly preferred channel for health information for young women. The least personalised of all channels, the media delivers information without the recipient having either to request it or to disclose their reasons for being interested in it. A study of 128 young women, conducted by the Royal Women's Hospital Absolutely Women's Health service, investigated young women's preferences regarding channels for delivering health information to young women (RWH, 2002). For each question, women were asked to rank-order a set of pre-defined response options. The study found that young women preferred that health information be delivered either through "real stories" from other women, or through the media. Not surprisingly, a combined method involving the use of celebrities as role models for imparting health information via the media was also commonly suggested. Women were also asked to suggest the best way to attract young rural women to health promotion activities. Respondents commonly suggested mass media, such as the TV, radio and magazines (around 80%). Information delivered in schools was mentioned by about 20% of women (RWH 2002).

Likewise, the internet offers a means of accessing information anonymously and confidentially. A report of a USA study refers to young women as belonging to the "Cyber Generation", and emphasises that computer technology is "an integral part of their social and academic lives" (Girl Scout Research Institute 2002). In a study undertaken by the Girl Scouts of the USA, 1,246 teenage girls aged 13-18 were involved in focus group interviews, journal-keeping, a written survey and/or an online survey. The report emphasised that teenagers see the internet "as a way to get information that they might be embarrassed to ask about in person" (2002, p.18), highlighting the issue of confidentiality and the importance to young women of anonymity in health-information seeking. The study also highlights the importance of the internet for many teenage women, and the potential for this to increase.

However, as many respondents in the study were recruited via the internet itself, the findings can not be generalised to all teenagers.

But to what extent do young girls use the internet to access health information? The research findings regarding reasons for internet use in the young are somewhat conflicting. The USA study of girl scouts reported that girls spent most of their online time socialising, with very few respondents using the internet for seeking health information (Girl Scout Research Institute 2002). Similarly, in the RWH study of young women's health information channel preferences, the internet was mentioned by very few women (RWH 2002). In contrast, a study of 412 school students, conducted by researchers at Mount Sinai School of Medicine in New York, USA, found that half (49%) had used the internet to get health information (Borzekowski & Rickert 2001). Across the sample of young women and men, the main three areas for health-information seeking were STIs; diet, fitness and exercise; and sexual behaviours. In addition, the girls sought information on birth control, physical and sexual abuse, and dating violence. Most regarded the information as trustworthy, useful and relevant (Borzekowski & Rickert 2001). This study again highlights the importance of the internet for young women in accessing information about sensitive health topics.

4.2 – OLDER WOMEN

Older women have particular health information needs and utilise specific health information dissemination sources. For example, the NSW study by McVeigh (1996) highlighted that older women are often frustrated by a lack of accurate, up-to-date information about menopause and HRT. Information access is particularly problematic for older women with lower educational backgrounds. A USA study of menopausal women demonstrated that those with lower education were less likely to have access to menopause information (Domm et al. 2000). Likewise, older women currently have less access to computers and therefore internet-based information than their younger counterparts (Bessell et al. 2002; Morrell et al. 2002; Pandey et al. 2002; Smith-Barbaro et al 2001; Licciardone et al. 2001; Ross et al. 2000; Carlsson 2000; Pereira et al. 2000). However, as noted earlier, older internet users are more likely than the young to search for health information (Fox & Rainie 2002).

Older women are particularly dependent on their GP for information and support. While GPs see around 80% of the general population in a year, a higher 90% of elderly people consult with their GP each year. In addition, older people are more likely to have multiple visits to their GP in any one year (ABS, 1995). This highlights the importance of GPs in the provision of health information to older and elderly women.

Older women also utilise informal networks, particularly in regard to information about menopause and HRT, most often relying on female family members and friends. For example, several studies have demonstrated that female peers are amongst the main source of such information, both in Australia (McVeigh 1996; Shoebridge 1997, cited in Astbury & White 1998) and overseas (Griffiths 1995, cited in Astbury & White 1998). Another key source of information about menopause is the media (Griffiths 1995, cited in Astbury & White 1998). Each of the studies of older women have been outlined in detail in earlier sections of this review.

4.3 – INDIGENOUS WOMEN

There has been relatively little research on the informational needs and preferences facing Aboriginal and Torres Strait Islander women. As has been previously noted, with around half of Victorian Kooris living in rural areas, "Koori women may be doubly-disadvantaged when it comes to accessing health information" (Astbury & White, 1998; p.71). Similarly Mokak (1998) notes that many Indigenous people carry multiple layers of disadvantage, often also being financially disadvantaged and living in isolated rural areas. At least in part, the lower

service use by Indigenous people is due to difficulties in accessing health-related information. For example, Indigenous carers have little knowledge of the range of service available or of their eligibility for accessing them (Mokak 1998).

A consultation with over 400 Indigenous people from across NSW was conducted by the NSW Ageing and Disability Department in 1996 (Mokak 1998). Indigenous communities carry higher levels of disability than other Australian groups, and a different profile in terms of aging, with 40 considered the cut-off for "frail elderly". There is also some evidence that Indigenous people show lower service use patterns than other Australians (Mokak 1998).

In terms of format for printed educational materials evidence suggests the use of pictorial representation and consistency in design is desirable. Studies reviewed by Astbury and White (1998) suggest that Indigenous women respond better to pictorial rather than written information, hence their preference for videos, computer programs, video games, and community arts projects. Mokak recommended that all information be presented in an easily identifiable format, such as an aboriginal design or in the colors of the Aboriginal flag (Mokak 1998).

4.4 – WOMEN FROM DIVERSE LINGUISTIC AND CULTURAL BACKGROUNDS

The issue of access to health information is particularly relevant for women from diverse linguistic and cultural backgrounds. Using data from the Longitudinal Study of Immigrants in Australia (LSIA), the Key Centre for Women's Health in Melbourne explored access to health information amongst immigrant women in Australia (Kelaher et al. 1999). The study involved 5,178 immigrants who entered Australia on a migrant visa between September 1993 and August 1995. Somewhat counter intuitively, women who had received health information were older and less likely to have a chronic health problem. In contrast though, women who had received health information from a non-Government Organisation (NGO) were younger and more likely bilingual. Younger women were also more likely to have used services, as were English-speaking women.

There is some evidence that women from diverse linguistic and cultural backgrounds are less likely to receive appropriate health information. For example, in the study of Victorian family carers, those from non-English speaking backgrounds were less likely than Anglo-Celtic carers to have received information about services (Schofield et al. 1998). Likewise, older ethnic women complain of a lack of up-to-date and accurate information about menopause and HRT (McVeigh 1996).

Lack of culturally-appropriate health information can preclude access to necessary health checks and screening procedures. For example, in a study of Greek and Italian women, undertaken by the Centre for Culture, Ethnicity and Health (CEH) in Victoria, many women reported that lack of culturally-specific information precluded breast examination by a health professional (Brushin et al. 1997, cited in Astbury & White 1998). Furthermore, even those who know about services often don't know how to access them or whether they are eligible (Schofield et al. 1998). These factors might be exacerbated by the fact that those from diverse cultural backgrounds are more reliant on their GP as the sole information source (Schofield et al. 1998).

There is also some evidence that, even in the context of culturally-specific written information, non-English speaking women do not find written information particularly useful in terms of service acquisition. For example, a recent evaluation of community-language versions of the Carer Support Kit found that women receiving translated kits showed extremely low service use after receiving the kit, much lower than that demonstrated by women who received an English-language kit (CAA 1999). Most NESB carers instead depended on ethnic-specific service providers for information. The evaluation concluded that

carers from other cultural and linguistic backgrounds “expressed a strong preference for receiving information from a trusted source or in person” (CAA 1999, p.13).

The move toward internet-based health information might be particularly advantageous for Australia’s ethnic and non-English-speaking communities. According to the SA Department of Human Services Adelaide, the internet offers a relatively easy source of health information in a range of languages, which is particularly relevant for women who do not have English as a first language (Swanson 1999). Likewise for service providers, the internet offers a relatively cheap mode of information delivery in a range of community languages (Swanson 1999).

4.5 – WOMEN AS CARERS

The Victorian Carers’ Program (VCP) was a large-scale, population-based longitudinal research and health-promotion program investigating the experiences and needs of around 1000 family carers (Schofield et al. 1998). The study, conducted from 1992-1997, found that the majority of family carers are women (78%). Most are mid-life women caring for aging parents. The remainder includes wives caring for husbands and mothers caring for children with disabilities. A carer was found in over 5% of Victorian households, although the prevalence of care giving amongst mid-life women has been estimated to be substantially higher.

The VCP involved in-depth exploration of the information preferences and needs of family carers. The common and the most preferred source of information about the care-recipient’s condition was the GP, medical specialists and allied health professionals (Schofield et al. 1998). All other sources, both active sources such as an organisation, a support group, government agencies and printed material, and passive sources such as the media, and friends and family, were used and preferred by only a minority of carers (Schofield et al. 1998). Regarding information about services and supports to assist carers, GPs, allied health professionals and government agencies were both the main and preferred source of support information for carers. Again, passive information sources, such as the media, and friends and family, were the main or preferred source by only a minority of carers. Overall these findings suggest that carers rely most on information provided in a personalised way, either from medical or other health professionals. Relatively few appear to rely on or prefer written information, just as few rely on passive sources – such as media, or friends and family – to satisfy their information needs.

Given their prominence and accessibility to carers, GPs have gained a great deal of attention in recent policy recommendations. The Carers’ Support Needs Project undertaken by the Social Policy Research Centre (SPRC) for the NSW Ageing and Disability Department (Thomson et al. 1997), consulted with 158 key stakeholders to identify appropriate strategies for assisting dementia carers in accessing services. Of ten strategies suggested, the targeting of GPs was identified as the most important intervention point for carers, and in most need of urgent attention. The Carers’ NSW Association study of service use and non-use also identified GPs as an important service link for carers (Payne & Ehrlich 1998).

4.6 – WOMEN LIVING IN RURAL AND REMOTE AREAS

Rural and isolated women face particular barriers in their access to good quality information. Transportation problems and lack of access to services are common difficulties faced by women living in rural and remote areas. A qualitative study of rural Western Australian women (Bishop et al. 1993, cited in Astbury & White 1998) found that lack of accurate and up-to-date health information and difficulties with access were a great concern for rural women. Sole parents in rural communities were identified as being particularly disenfranchised.

Electronic media, newsletters and support groups have all been used to enhance information access for women in living in rural and remote areas. Electronic media have included videoconferencing, teleconferencing, the internet and email. Each of these methods appears to have particular merits in reaching rural women.

Videoconferencing involves health experts in the delivery of health information to groups of women in an interactive way. As detailed earlier, NNQ was a two-year project undertaken during 1998-2000 to improve access to health information for rural and remote communities. The project involved the installation of video-conferencing equipment at 21 sites in rural north Queensland. A total of 197 hours of videoconferencing was recorded at 10 of the sites over the 12 month study period. The project also involved the provision of email and internet access in 61 rural and remote communities. The NNQ project was shown to increase rural residents' access to medical, specialist, allied health and primary health services (Watson et al. 2001).

Since the NNQ project was first initiated in Northern Queensland, Women's Health Queensland Wide has continued to provide video-conferencing to consumers and health professionals in rural Queensland (WHQW 2001). Menopause information sessions have now been video conferenced to women in Central and Southern Queensland. Topics covered include menopause and HRT, diet in the middle years, alternatives to HRT, and breast health. While figures suggest that more than 300 women have attended the videoconferences, the actual figure is thought to be considerably higher (WHQW 2001). In evaluating the sessions, 96% of women found videoconferencing to be a suitable method for health education and indicated that they would attend another session in the future. The key features of the sessions which appealed to women were their interactive nature and the convenience of having access to health experts "without having to travel hundreds of kilometres" (WHQW 2001, p10).

In their Health Online report, the NHIMAC also discuss the specific barriers to information access faced by rural and remote Australians. According to the report, "the main concerns relate to the inequalities between metropolitan and regional Australia in the availability of services, their cost and quality" (NHIMAC 2001, p.47). Access to both telephone and the internet has traditionally cost more in rural areas. The Commonwealth Government has supported the delivery to all Australians of untimed local telephone calls and untimed local call access to the internet, which involves upgrading of remote telecommunications infrastructure. In addition, a rural health website (www.ruralhealth.gov.au) was launched in October 2000, with a commitment to the provision of current and accurate information on rural health issues, policies and services for consumers, service providers, researchers, policy makers and health professionals (NHIMAC 2001). The government is also currently considering the cost-effectiveness of satellite communications for areas of outback Australia. The report also highlights the important role of videoconferencing in remote service delivery (NHIMAC 2001).

Several initiatives for increasing information access for rural people have focussed on carers. In 1995, the South Australian Carers Association used a community development approach to provide support to rural carers (Carers' SA, 1995). The project, which spanned a 12-month period, involved initial community awareness raising, followed by the establishment of a Carer Support Network and a number of Carer Support Groups. Participating carers reported an increased knowledge of and linkage with services, and a greater ease in discussing issues with their GP (Carers' SA, 1995).

Telephone conferencing has also been proposed as a method of information-exchange and support for rural carers. In the Carers' NSW Association study, each group of six carers was linked up by phone at a specified time once a week for 6-8 weeks (Carers' NSW 1997). Carers reported reduced isolation, self-validation, the ability to express negative feelings

such as frustration and guilt, and a sense of relief in expressing long-withheld emotions. The telephone conferencing approach appears to have particular merits for rural carers. It eliminates difficulties associated with attending support groups or counselling sessions, such as transport and respite needs. Limitations of the approach included difficulties getting used to the medium (in terms of interruptions, opportunities to speak up etc.), time limitations, the need for good verbal skills, and occasional difficulties with lines and link-up by Telstra.

The internet has also been trialled as a means of information for those living in rural areas. A joint action research project undertaken by the SA Carers' Association and Department of Social Security in 1996 involved installing computers into the homes of 10 carers in the northern suburbs of Adelaide. Participating carers expressed high satisfaction with the project, with increased access to disability-specific and carer information, both in Australia and overseas. Email contact also provided support between participants, and with other interstate and international carers. Indeed, carers found that mailing lists became a valuable source of online support (Carers' SA 1996).

There is also evidence that newsletters are particularly relevant and effective for rural women, both in terms of increasing knowledge and, perhaps more importantly, in promoting communication and encouraging a sense of belonging. As outlined earlier, a survey of 247 subscribers of 'Network', the newsletter of the RWN, demonstrated that just under half use the newsletter as a means of communicating or networking with other women and/or women's groups, many indicating that they share past newsletters with friends. They noted that the newsletter encouraged a sense of belonging, particularly through the sharing of women's stories and experiences (RWN 2000, p.10).

4.7 – LESBIAN WOMEN

Three key Australian studies of lesbian women were reviewed. A study by Katrina Newnham, undertaken for a Masters of Health Sciences, involved focus groups with 13 lesbian women, six GPs and four key informants (Newnham 2001). It had the primary aim of identifying the characteristics of 'lesbian-friendly' general practice, and involved an extensive literature review relevant to the aims of the present review. A report of the Lesbian Health Information Project (LHIP), undertaken by the Royal Women's Hospital (RWH) 'Well Women's Service', involved consultation with 120 lesbian women, 80 RWH staff and 25 external health professionals. It had the primary aim of determining the feasibility and acceptability of developing a Lesbian Information Service within the existing infrastructure of the RWH. Again both the results and the constituent literature review are relevant to the aims of the present review. Finally, a study by researchers for the Australian Research Centre in Sex, Health and Society, La Trobe University, involved 206 same-sex attracted young people (SSAY) recruited via the internet (Hillier et al. 2001). The study investigated reasons for using the internet. Again the literature reviewed in the report is relevant to the present review.

Lesbian women face specific health issues which put them in need for specific health information. First, lesbian women have an assumed lower risk for certain illnesses, including gynecological cancers, STIs and HIV. This assumption exists both within the medical profession and within the lesbian community, and brings with it a lower rate of presentation for health checks and screening (Newnham 2001; RWH 2000). However, contrary to common belief, lesbian women are in fact at increased risk for some cancers and STIs (Newnham 2001; Hillier et al. 2001). Higher rates of nulliparity and lower use of the contraceptive pill contribute to this increased risk, with childbirth, lactation and contraception use being protective factors for several cancers (Newnham 2001; RWH 2000). In addition, some research studies have demonstrated that lesbian women are more heterosexually active than their heterosexual peers, hence their increased risk for some STIs (Hillier et al. 2001). Lower rates of presentation and screening further exacerbates the risk (Newnham

2001), as do higher rates of long-term use of substances including tobacco and alcohol (RWH 2000). In addition, some studies have demonstrated that lesbian women show higher rates of depression and suicide than heterosexual women, partly due to issues related to coming out (Newnham 2001; Hillier et al. 2001).

At the same time, there are a number of factors which decrease lesbian women's access to relevant health information. First, lesbian women are often reluctant to disclose their sexual orientation, partly due to fear of discrimination by health professionals (RWH 2000; Newnham 2001). In addition, the common assumption by health professionals that women are heterosexual often underlies the consultation, directs questions about sexual history, further decreasing the likelihood that lesbian women will be given appropriate health information (Newnham 2001; RWH 2000). Indeed, there is some evidence that an assumption of heterosexuality can lead to inappropriate diagnoses and/or treatments (Newnham 2001). That GPs receive limited education about the health issues relevant to lesbians further exacerbates this lack of information dissemination (Newnham 2001). Indeed, health professionals consulted in the LHIP project themselves indicated poor knowledge and awareness of the health issues for lesbian women (RWH 2000).

There is some evidence that lesbian women prefer a female GP both for health checks and for health information. In the study by Newnham (2001), lesbian women identified the characteristics of lesbian-friendly health care. Many – though not all – preferred a female practitioner. Female GPs were thought to be more sensitive to female patients and less threatened by a disclosure of lesbianism. Newnham cited other research which similarly demonstrated a preference amongst lesbians for a female health practitioner, particularly for gynecological and mental health. In Newnham's study, women also wanted non-judgmental communication, plain language, and an appreciation of the issues lesbian women face. Moreover, women wanted someone who demonstrated respect towards *all* women, regardless of a disclosure of homosexuality (Newnham 2001).

In terms of current health information channels, it appears that lesbian women rely on different channels than their heterosexual counterparts. According to findings from the LHIP project, lesbian women rely predominantly on informal networks and lesbian newspapers and magazines for health information. The consultation found that while they do seek information from GPs, a source commonly preferred by heterosexual women, lesbian women "have varying experience and response" (RWH 2000, p.46).

In terms of the types of information lesbian women want, the LHIP project identified a number of key areas. First, information regarding sexual health: woman to woman sexual transmission of infections, and safe sex. Second, information regarding cancer screening: pap tests and breast checks. Third, information regarding fertility and reproductive health: self-insemination, safe insemination, and assisted insemination (RWH 2000).

The development of lesbian-specific health information services has been proposed as a good way of meeting the needs of lesbian women in Victoria. The LHIP project determined that a lesbian health information service could be accommodated within the existing services of the RWH. The new service is to include a telephone information line and a Centre of Excellence for lesbian women, as well as involving the dissemination of printed resources (RWH 2000).

As with all women's groups, lesbian women will increasingly turn to the internet to meet their health information needs. However, there has been relatively little research in this area. A study of 206 same-sex attracted young people looked at use of the internet for sexual health and other information (Hillier et al. 2001). The sample, which included only 25% women, had an average age of 18. About half the sample had used the internet to access information about sexuality and safe sex, and about two thirds regarded the internet as important or very important for accessing sexual health information. Many SSAY women had also used the

internet for help with depression and suicide. However, that the sample was recruited via the internet limits the ability to generalise the results. The authors also noted that gay women and lower SES groups were underrepresented in the sample (Hillier et al. 2001).

4.8 – WOMEN LIVING IN DOMESTIC VIOLENCE SITUATIONS

Domestic violence has long-term mental and physical health consequences for women (Astbury et al. 2000; Roberts et al. 1998), and has been shown to increase the likelihood of depression, anxiety, substance abuse and pregnancy complications (Richardson & Feder, 1996). Based on a UK review of literature, it has been estimated that domestic violence affects more than 25% of women (Richardson & Feder 1996). In a study of 406 women in ambulatory clinics, conducted by researchers at the University of Miami School of Medicine, USA, 40% had experienced abuse and 7% were currently in an abusive relationship (Caralis & Musialowski 1997).

Many studies have shown that women want to be asked about domestic violence, and expect this of their GP (Hegarty et al. 2000; Richardson & Feder 1996). Likewise, women want information and advice about options, including available community and legal services, and they believe that this should come from their GP (Caralis & Musialowski 1997; Richardson & Feder, 1996). At the same time though, women experiencing domestic violence feel concomitant shame and isolation, which represent barriers to disclosure (Astbury et al. 2000).

However, most researchers agree that barriers to disclosure – which thereby preclude access to appropriate health information and other services for women in domestic violence situations – lie predominantly with GPs (Mazza et al. 2000). For example, in the Miami study, only 12% of women had been asked about abuse by their GP, even though 68% indicated that they would be comfortable disclosing the information. Furthermore, of those who had disclosed, 20% indicated that the GP did not take action to inform or assist them (Caralis & Musialowski 1997). According to Richardson and Feder (1996), domestic violence remains largely undetected due to GPs concerns about lack of time, lack of knowledge, and feelings of powerlessness to provide a solution. In addition, women's perceptions that GPs are hostile and/or lack empathy regarding domestic violence further reduce women's likelihood of disclosure (Hegarty et al. 2000; Richardson & Feder, 1996).

Many researchers have recommended that GPs incorporate risk assessment and screening for domestic violence into their routine consultations with all women (Mazza et al. 2000; Thompson et al. 1998; Richardson & Feder, 1996). Importantly, the introduction of domestic violence assessment protocols has been shown to increase both information dissemination and referral of women to appropriate services (Shepard et al. 1999).

In addition, it has been recommended that GPs and other service providers need to be educated about domestic violence issues, in order to improve their attitudes and optimise their skills (Saathoff & Stoffel, 1999; Roberts et al. 1997). A focus group study of 65 women, conducted by researchers from the Hunter Centre for Health Advancement in Newcastle, NSW, identified areas for improvement in the delivery of services for women living with domestic violence (Bates et al. 2001). Improvement of the service environment and education of service providers were amongst the key areas identified. In addition, services for Indigenous women were highlighted as a key area for improvement.

Telephone helplines also represent an effective information channel for women in domestic violence situations. A review of annual reports of health information services offered in Australia, and outlined earlier in this report, reveals that many callers to telephone information services are seeking information and assistance with domestic violence (WIRE 2000; Women's Health Grampians, 2001). As discussed, telephone helplines offer relatively easy and inexpensive access to personalised information in an anonymous setting (Sims &

Golightly, 1998; vanBalén et al. 2001), hence their appeal to women in domestic violence situations.

4.9 – SUMMARY

This section has reviewed research regarding access for specific groups of women seen to have specific information needs. For young women, the issue of confidentiality in information gathering is particularly salient, hence the effectiveness of peer-education programs, particularly for sensitive health topics. For older women too, peer networks appear to be influential, with research focussing on menopause and HRT issues. GPs are also important for this group. Indigenous women and those from diverse linguistic and cultural backgrounds appear to have lower usage of health information, either written or via GPs, hence their relatively low utilisation of screening and treatment services. Given language and cultural barriers facing both groups of women, written informational materials are often seen as inappropriate. While the internet is a relatively good channel for non-English speaking women, providing easy access to information in a range of languages, this is not the case for Indigenous women. Women in caring roles also have difficulty accessing appropriate information, both disability-specific and service-specific, with GPs apparently the most preferred source. Videoconferencing and newsletters appear to be particularly relevant information sources for women living in rural and remote areas, with the internet increasingly becoming an effective channel. Lesbian women face specific barriers in terms of health-provider assumptions and prejudices, which often preclude access to appropriate health information. Lesbian women apparently rely most often on informal networks and lesbian newspapers and magazines for health information. Likewise, women in domestic violence situations face many GP-based barriers which inhibit disclosure and thereby reduce access to needed information and other assistance. Telephone helplines offer relatively easy and inexpensive access to personalised information in an anonymous setting, and are therefore an effective channel for providing information and support to women living with domestic violence.

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LIST OF ABBREVIATIONS

ABS	Australian Bureau of Statistics
BSE	breast self-examination
CAA	Carers' Association of Australia
CABGS	coronary artery bypass graft surgery
GP(s)	general practitioner(s)
HIV	Human Immunodeficiency Virus
HRT	Hormone replacement therapy
LHIP	Lesbian Health Information Project
LSIA	Longitudinal Study of Immigrants in Australia
LMWHS	Lodden Mallee Women's Health Service
NESB	non-English speaking background
NGO	non-Government Organisation
NHIMAC	National Health Information Management Advisory Council
NHS	National Health Service
NNQ	Networking North Queensland
QA	quality assurance
QIHIRs (pronounced choirs)	Quality Information Health Issues Resources
RCT	randomised controlled trial
RWN	Rural Women's Network
SA	South Australia
SPRC	Social Policy Research Centre
SSAY	same-sex attracted young people
STIs	sexually transmitted infections
TV	television
UK	United Kingdom
USA	United States of America
VCP	Victorian Carers' Program
WHV	Women's Health Victoria
WHQW	Women's Health Queensland Wide
WHM	Women's Health Matters
WHIC	Women's Health Information Centre
WIRE	Women's Information Referral Exchange
WWH	Working Women's Health
www	world wide web