It goes with the Territory!

ACT Women's views about Health and Wellbeing Information

Angela Carnovale and Elizabeth Carr

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About Women's Centre for Health Matters Inc.

The Women's Centre for Health Matters Inc. (WCHM) is a community based organisation which works in the ACT and surrounding region to improve women's health and wellbeing. WCHM believes that the environment and life circumstances which each woman experiences affects her health outcomes. WCHM focuses on areas of possible disadvantage and uses research, community development and health promotion to provide information and skills that empower women to enhance their own health and wellbeing. WCHM undertakes research and advocacy to influence systems' change with the aim to improve women's health and wellbeing outcomes. WCHM is funded by ACT Health. The findings and recommendations of this report are those of WCHM and not necessarily those of ACT Health.

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EXECUTIVE SUMMARY

Women are the primary seekers of health and wellbeing information in the ACT, not only for themselves, but also for their children and other family members, yet they face significant challenges. When women have access to appropriate health and wellbeing information they are able to make informed choices about their own and their family's health and access services and support relevant to their needs.

In the ACT, we are facing a chronic shortage of GPs, clinic closures, redefinition of the roles of pharmacists and nurse practitioners and federal reform of primary and community based healthcare systems. This changing external environment and the increasing complexity of health information means that women face significant challenges in identifying credible and trustworthy information, and this in turn impacts on their ability to maintain good health and wellbeing.

Since women are the main family decision makers for health issues and the main family carers, their access to appropriate health and wellbeing information is crucial. They need to be able to make informed choices about their own and their family's health, and access relevant services and support.[1] Unfortunately, there is scant research identifying ACT women's needs and preferences in relation to health and wellbeing information; the ways in which they appraise information; the barriers that restrict them from accessing information; and the gaps in their information landscape.

It is for these reasons this report, *It goes with the Territory,* was commissioned by the Women's Centre for Health Matters (WCHM). This report explores the views and preferences of ACT women in accessing health and wellbeing information and how this information is transformed into knowledge. Women's views and personal stories were sought through a variety of media — a survey (674 responses), seven focus groups and a follow-up survey. This primary data was then supplemented by an extensive literature review.

The findings of this report are consistent with previous research undertaken by WCHM and demonstrate that women's access to health and wellbeing information can be affected by social and economic circumstances; the social determinants of health. ACT women want information to be *available, affordable, accessible* and *appropriate.* These 'four As' form the basis of WCHM's definition of gender sensitive health service delivery and are integral to maintaining good health and wellbeing.

The report findings demonstrate that barriers to accessing health services and information — including for preventive health — are part of the social determinants of women's lives that can lead to health inequalities. These barriers include:

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[1] Murphy. M., Murphy, B. & Kanost, D. (2003), *Access to Women's Health Information: A Literature Review of Women as Information Seekers*, Women's Health Victoria, Melbourne, 8.

- high cost of health care for some women;
- lack of awareness of existing services;
- shortages of general practitioners, specialist medical services, and a spectrum of health services;
- lack of female doctors, especially for reproductive and sexual health;
- lack of culturally appropriate and gender sensitive services and information; and,
- health and wellbeing services which may not deal holistically with the physical, social and emotional wellbeing and cultural needs of women, especially disadvantaged groups.

In an environment where governments are increasingly required to provide economic responses to the provision of health and social services, accessible health and wellbeing information would strengthen women's self-management and play a part in reducing women's reliance on the health system. Women with knowledge of available options are better equipped to use the ACT health care system effectively; especially in understanding what issues can be dealt with at home, how best to deal with issues and when to contact a health care provider. Good quality health and wellbeing information can successfully substitute consultations with health professionals, which can increase a woman's autonomy and save her money.[2]

This report makes a number of recommendations. These were developed in consultation with the women and organisations that participated in the research, the WCHM Board of Directors and WCHM staff.

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[2] *Ibid.*, 9.

RECOMMENDATIONS

- WCHM to work with ACT Health to identify how to actively promote other alternatives to GPs, and to explain the tiered levels of intervention that are available within the ACT (in particular Walk-in Centres, pharmacists, nurses, practice nurses, nurse practitioners, CALM services, HealthDirect, and the hospital emergency departments) to increase the awareness of and trust by ACT women, with a particular focus on information for each about:
    - their scope of practice;
    - confirmation of their qualifications and skills; and
    - when to use them or access them.

- WCHM to work with ACT Health in relation to the GP Taskforce recommendation on the development of a GP Register, and to ensure the incorporation of the feedback from ACT women.

- WCHM to work with ACT Health to consider the issues raised by women about the ACT Health website and white pages entries, and the need for better navigation about the range and scope of available services for women in the ACT.

- WCHM to advocate with ACT Government about the need to continue to explore, pilot and evaluate new community based primary care that is supplementary to both GP practices and emergency departments in hospitals, and which meets women's needs, including tiered approaches which also use technologies such as health information lines and internet sites.

- WCHM to develop its website (working in partnership with other key stakeholders and women) to provide assistance to ACT women as health consumers in using the internet and in navigating and assessing the information that is accessed through the internet, particularly through:
    - the provision of tools to support ACT women to understand how to assess and identify trusted sites — by enabling women to access trusted information they will be able to make more rational and informed health decisions without needing to access GPs every time to check information;
    - the use of navigation tools to assist them to find their way around the health system and to access services in and outside the health system that lead to better health outcomes;
    - the development and trialling of a central approach to health and wellbeing information in the ACT for women with a focus on the current gaps identified (Having a baby in Canberra, sexual health and menopause for older women, and young women and eating disorders).

INTRODUCTION

Women are generally the ones who look for health and wellbeing information, not only for themselves but also for their partners, children, parents, extended family members, friends and other members of their communities. More than this, women are the main family decision makers for health issues and the main family carers. When women have access to appropriate health and wellbeing information they are able to make informed choices about their own and their family's health and access the relevant services and support.[3] Furthermore, good quality health information can successfully substitute for consultation with health professionals thereby increasing women's autonomy and bringing them fiscal benefit.[4]

Despite this, women continue to report that they receive inadequate health information. The research identifying ACT women's needs and preferences, the ways in which they appraise information, and the barriers that restrict them from accessing the information they need and the gaps in their information landscape is scant. And yet the task remains imperative; understanding the means through which women access health and wellbeing information and the ways in which this information is transformed to knowledge ensures that these means can continually be improved.

In a previous survey of 180 women aged 15 years and over conducted by the Women's Centre for Health Matters Inc. (WCHM) in March 2008 on health and wellbeing issues for women in the ACT, the most consulted professional on physical health, mental health, and general health and wellbeing were general practitioners (GPs).[5] The survey also found that women in the ACT were confronted by a number of barriers to acting on their health and wellbeing issues. These included: affordability of treatment; long waiting lists for appointments; difficulties with transport; not having enough time to take action; not knowing where to get help; and not seeing the issue as a health priority.[6] A significant observation from the survey is that women's perceptions of their interactions with health practitioners would improve if the practitioners improved their communication skills, increased their use of accredited interpreters, provided greater access to relevant health information, improved scheduling and waiting times and improved access to bulk billing.[7]

Understanding that appropriate, relevant and timely information is a precursor to the good health and wellbeing of women and their families, WCHM investigated the current health and wellbeing information needs of women living or working in the ACT and Queanbeyan. WCHM set out to develop a better understanding of the ways in which (different groups of) ACT women access

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[3] Murphy. M., Murphy, B. & Kanost, D. (2003), *Access to Women's Health Information: A Literature Review of Women as Information Seekers*, Women's Health Victoria, Melbourne, 8.

[4] *Ibid.*, 9.

[5] Women's Centre for Health Matters, 2008, *Health and Wellbeing Issues for Women in the Australian Capital Territory*, WCHM, Canberra, 4.

[6] *Ibid.,* 5.

[7] *Ibid.,* 5.

information about their health and wellbeing, the ways in which they prefer to access this information and the barriers they face, as well as to identify the gaps in health and wellbeing information in the ACT. This report is a presentation and exploration of what WCHM discovered.

The current study involved a survey conducted by WCHM in August and September of 2009, complemented by seven focus groups with specific populations of women. The information sources explored in the survey were: general practitioners (GPs); pharmacists; allied health professionals (Dieticians, Occupational Therapists, Physiotherapists, Podiatrists, Speech Pathologists etc); alternative therapists (Massage Therapists, Chiropractors, Acupuncturists, Naturopaths, Homeopaths etc); hospitals and emergency departments; psychologists, social workers and counsellors; ACT health services; internet; telephone helplines; senior members of cultural groups; beauticians and hairdressers; mass media; paper based publications; schools; and family members and friends. The groups with which WCHM conducted focus groups were: women under twenty-five years (young women); women over fifty-five years (older women); Aboriginal women; mental health carers; women from culturally and linguistically diverse (CALD) backgrounds; women with disabilities; and women living with mental health issues. WCHM acknowledges that the list of information sources and specific groups of women is not exhaustive.

The research was in part inspired by a study conducted in 2002–03 by Women's Health Victoria (WHV) on the health information seeking trends of Victorian women, for which there was no equivalent in the ACT. Similar to the WHV study, WCHM conducted a literature review and survey in order to identify the sources that women use and prefer to use for health information; their level of satisfaction with these sources; the barriers to accessing necessary health information; and their unmet needs. However, while WHV conducted telephone interviews, WCHM conducted self-implemented surveys in paper and electronic format, followed by specific focus groups to explore the needs of different groups of women. Furthermore, unlike WHV, WCHM did not seek the information needs and opinions of service providers and instead investigated wellbeing information needs and the role of health literacy in understanding health information.

WCHM developed a concept of good quality health and wellbeing information throughout the study through the literature used for review and the research participants. Good quality health and wellbeing information when discussed in this report is defined as that information which increases an individual's knowledge about health, wellness, illness and disease; assists an individual in making choices about their lifestyle and decisions about their health; and reduces anxiety about health issues.[8] A discussion was had in each of the focus groups about this definition, with each of the participants adding to but not taking away from these three components. The most common additions were that good quality health information:

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[8] Murphy. M., Murphy, B. & Kanost, D. (2003), *Access to Women's Health Information: A Literature Review of Women as Information Seekers*, Women's Health Victoria, Melbourne, 8.

- is comprehensive and comprehensible to a wide audience;
- is written in clear, non-medical language;
- is not patronising; and,
- does not undermine women as their own guide in matters of health and wellbeing.

It was also seen as imperative that information and information sources are gender and culturally sensitive, which is discussed throughout the report.

This report is broken into three sections. Section one is a presentation of the survey findings following the four sections of the survey: sources of health and wellbeing information; barriers to obtaining health and wellbeing information; barriers to accessing general practitioners; and demographic characteristics of the survey respondents.

Section two is a presentation of the focus group findings. It covers each of the information sources and an overview of each of the population groups with which WCHM conducted focus groups. In depth discussions of each of the population groups will be available separately as companion reports in the coming months.

Section three is a discussion of the major themes identified from the research findings.

The report begins with a review of the literature on how and where women seek health and wellbeing information. The literature review was undertaken to place the study in the context of similar national and international research as well as to examine the growing body of academic research on how adults, particularly women, access and use health information, giving special attention to sources used and the barriers faced by specific groups of women.

METHODOLOGY

The research design involved three phases — a survey, a literature review and focus groups.

SURVEY

A mixture of online and hard copy data collection methods were used for the survey. Respondents qualifying for the survey were women living or working in the ACT or Queanbeyan. A total of 674 valid surveys were collected.

Hard copy surveys were distributed through key organisations to groups who were unlikely or unable to access the survey online. Surveys were delivered to the organisations along with pre-paid, self-addressed express envelopes so that they could be returned to WCHM at no cost. Organisations that received hard copy surveys were the Women's Information and Referral Centre, Citizens Advice Bureau, Women's Health Service, BreastScreen, Winnunga Aboriginal Health Service, and a selection of six GP clinics throughout Canberra.

The online survey was available via a link on the WCHM website and was distributed throughout email networks and personal contacts. A link to the survey was also available on the websites of the ACT Office for Women, Health Care Consumers Association, YWCA of Canberra and the Women's Information and Referral Centre.

Percentages presented from this survey are based on the total number of valid responses made to the particular question reported on. In most cases, results reflect respondents who expressed a view and for whom the questions were applicable. 'Not applicable/don't know' answers have been included in the valid percent where this aids in the interpretation of results.

LITERATURE REVIEW

Several boundaries governed the scope of the literature review. Firstly, all articles are from peer-reviewed journals to ensure high standards of research. Secondly, almost all literature was published since 2002. This was to avoid duplicating analysis of literature already discussed in literature reviews from the Key Centre for Women's Health in Society (covering 1986–1998) and Women's Health Victoria (covering 1998–2003).[9,10] However, some articles prior to 2002 have been mentioned if they have remained relevant to the issues and trends discussed, and were not explored in the other literature reviews. Another reason for mostly using recent articles was to take into account the rapid changes in women's health and wellbeing information seeking behaviours. Studies chosen were not confined to only those with women as their participants or focus of study, however, to be included in the review studies had to mention women's access to

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[9] Murphy. M., Murphy, B. & Kanost, D. (2003), *Access to Women's Health Information: A Literature Review of Women as Information Seekers*, Women's Health Victoria, Melbourne, 8.

[10] Astbury, J, and D. White. (1998) "Addressing women's health information needs: the adequacy of current and emerging health information systems. A literature review". Melbourne: Key Centre for Women's Health in Society.

health information or a trend or barrier that was specific to women. The review focused on local and national research but international studies have also been reviewed.

This literature review was undertaken by searching for relevant peer reviewed articles in the academic databases Medline/Pubmed,[11] CINAL[12] and OVID.[13] All searches were restricted to post 2002 and to articles written in English. A few additional searches were done by following the references of important articles if they met the defining criteria.

Major search terms used were 'women' with 'access to health information', 'health seeking information' and 'health literacy'. Hundreds of articles were found. After a cursory review, 56 articles were selected for closer study on the basis of their relevance to the research objectives. Reports from the Australian Bureau of Statistics were used to find prevalence rates and statistics for specific questions such as internet usage.

FOCUS GROUPS

The survey data was complemented by seven focus groups held with six different populations, which WCHM considered might be vulnerable to having their needs unmet. The focus group discussions were conducted to ensure an understanding of the needs of different groups of women. The groups of women with which WCHM conducted the focus groups were: young women (under 25); older women (over 55); Aboriginal Women; mental health carers; women from culturally and linguistically diverse (CALD) backgrounds; women with disabilities; and women living with mental health issues.

Participants for the focus groups were recruited through individuals, peak community sector networks or community organisations working with the specific groups of women. A flyer explaining the study was tailored to each of the particular groups and sent out through existing networks.

The focus groups were held from October 2009 until February 2010 at locations that were suitable to the participants. Each discussion lasted between 1.5 to 2.0 hours and was recorded, with the consent of the participants, on a voice recorder. The recordings were then transcribed and accompanied by notes taken at the focus group by a second WCHM staff member.

The focus group discussions followed a pattern similar to the survey. At the beginning of every discussion participants were asked to provide their own definition of good quality health and wellbeing information and were then invited to comment on WCHM's working definition. Some broad questions about where participants look for information on particular health and wellbeing information were asked, which led into discussions about specific information sources as they were raised by the participants.

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[11] http://www.ncbi.nlm.nih.gov/pubmed/

[12] http://www.ebscohost.com/cinahl/

[13] http://www.ovid.com/site/index.jsp

Two focus groups were held with young women, with five participants in one and four in the other. One focus group was held with older women, which had nine participants. One with Aboriginal women with ten participants. One with mental health carers with five participants. One with CALD women with eleven participants. And one with women living with mental health issues with seven participants.

WCHM undertook to conduct a focus group with women with disabilities but was unsuccessful in recruiting sufficient participants. Instead we developed a follow-up survey for women with disabilities that asked similar questions to those that would have framed a focus group discussion. WCHM received four responses to this follow-up survey.

WCHM also tried to conduct focus groups with general carers and women who are pregnant or who have recently had a baby in Canberra but were unable to arrange participants.

LITERATURE REVIEW

OBJECTIVES

The objectives of the literature review include:

- To place the WCHM survey and focus group findings within the context of national and international evidence based literature.
- To explore the tertiary research on particular health and wellbeing information sources such as GPs, pharmacists, allied health professionals, alternative therapists, women's health centres, the internet, telephone helplines, paper based publications, mass media and family and friends.
- To examine the growing body of tertiary research on how women access and use health information, with special attention to the sources used and barriers experienced by specific groups of women.
- To investigate the tertiary research on the information needs of specific groups of women such as young women, older women, Aboriginal and Torres Strait Islander women, women from culturally and linguistically diverse backgrounds, women with disabilities, and women with mental health issues.
- To investigate the role of health literacy in the effectiveness of health and wellbeing information.

FINDINGS

- Women are active seekers of health information for themselves and their families.
- Women seek health and wellbeing information from a variety of sources.
- GPs are the preferred source of health information for Australian women.
- The internet is increasingly being used as a convenient and inexpensive health information source, particularly by young women.
- While the internet is awash with health literature, most women's awareness of its limitations and ability to source credible sites remains imperfect.
- There remain groups of women with specific difficulties in accessing information to meet their needs.
- There are many barriers undermining the value of health information such as unspecific overgeneralised information, illiteracy and women's time poverty.
- The need to improve women's health literacy is important given the consequences of not effectively applying health information.

INTRODUCTION

Women are the largest group of health and wellbeing information seekers, obtaining information not only for themselves but also for their partners, children, parents, extended family members, friends and other members of their communities.[14,15,16] Yet many women are unconvinced that the health and wellbeing information they obtain is adequate to meet their needs.[17] Furthermore, women are often given less information than men for the same health issues, such as heart conditions.[18]

Australian women access health and wellbeing information using a variety of sources for a multitude of reasons during their lifespan.[19,20] They actively seek it (consulting a health website, telephone helpline or health professional) and passively absorb it (from mass media or everyday discussions and interactions).[21] While some individuals actively seek health information and care, others will live with pain, stress or ill health without seeking adequate information or services.[22] Not seeking out specific information to meet one's needs, relying on passively absorbed information or being a passive patient (less involved or interested in one's health decisions) results in less positive outcomes that can drastically affect a woman's present and future health and wellbeing.[23,24]

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[14] Wathen, C & Harris, R. (2006) "An examination of the health information seeking experiences of women in rural Ontario, Canada". *Information Research.* 11(4). Pp.1–11.

[15] Pandey, S., Hart, J. & Tiwary, S. (2003). "Women's health and the internet: understanding emerging trends and implications". *Social Science & Medicine*. 56(1). Pp.179–191.

[16] Marcell, A., Howard, T., Plowden, K. & Watson, C. (2009). "Exploring Women's Perceptions About Their Role in Supporting Partners' and Sons' Reproductive Health Care". *American Journal of Men's Health*. 5(11). Pp.1–9.

[17] Murphy, M. & Murphy, B. (2003). *Access to Women's Health Information: A Survey of Victorian Women as Information Seekers*. Women's Health Victoria; Melbourne. 28.

[18] Rushford, N., Murphy, B., Worcester, M., Goble, A., Higgins, R., LeGrande, M., Rada, J. & Elliot, P. (2007). "Recall of information received in hospital by female cardiac patients". *European Journal of Cardiovascular Prevention & Rehabilitation*. 14(3). Pp.463–469.

[19] Murphy, M., Murphy, B. & Kanost, D. (2003). *Access to Women's Health Information: A Literature Review of Women as Information Seekers*. Women's Health Victoria; Melbourne. 5-7 & 33-6.

[20] Wyn, R. & Solis, B. (2001). "Women's Health Issues Across the Lifespan". *Women's Health Issues*. 11(3). Pp.148–159.

[21] Murphy, M. & Murphy, B. (2003). *Access to Women's Health Information: A Survey of Victorian Women as Information Seekers*. Women's Health Victoria; Melbourne. 28.

[22] Mortimer, M. Ahlberg, G. & the MUSIC-Norrtalje Study Group. (2003). "To seek or not to seek? Care-seeking behaviour among people with low-back pain". *Scandinavian Journal of Public Health*. 31. Pp.194–203.

[23] Brown, R., Butow, P., Henman, M., Dunn, S., Boyle, F. & Tattersall, M. (2002). "Responding to the active and passive patient: flexibility is the key". *Health Expectations*. 5. Pp.236–245.

[24] Murphy, M. (2003). *Access to Women's Health Information: Research Summary*. Women's Health Victoria; Melbourne. 7.

Recent years have seen a shift towards individuals being better informed about, and taking more responsibility for, their health and wellbeing.[25] The global trend to be more informed and active in one's health and lifestyle choices is especially true for women.[2627] However, while women want to be active participants in health decision making,[28] they need access to good quality, trustworthy, appropriate and timely health information.[29,30] Those who participate in health decisions have better health outcomes and while many women report they want more involvement in this process,[31] there is a common belief that GPs are the main decision makers and do not take their clients' opinions seriously.[32] Giving women more and better quality health information increases the likelihood of effective communication with health care providers and in turn optimises shared decision making.[33]

INFORMATION SOURCES

General Practitioners

In 2002, Women's Health Victoria surveyed a community sample of 500 Victorian women about their health information seeking trends and preferences.[34] General practitioners were women's main source for seeking health information; with 95.8 percent having previously sought health information from their GPs.[35] GPs were also the preferred source for women of all age groups, although the strength of this trend correlated with increasing age.[36] As well as being an often used and preferred source, women also consider GPs to be the most trusted source of health information.[37]

Despite the trend for GPs to provide the majority of health information, many women continue to seek more comprehensive information from other sources.[38] Warner and Procaccino surveyed

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25 Smith, S., Dixon, A., Trevena, L., Nutbeam, D. & McCaffery, K. (2009). "Exploring patient involvement in healthcare decision making across different education and functional health literacy groups". *Social Science & Medicine*. 69. Pp.1805–1812.

26 Kummervold, P., Chronaki, C., Lausen, B., Prokosch, H., Rasmussen, J., Santana, S., Staniszewski, A. & Wangberg, S. 2008. "eHealth Trends in Europe 2005-2007: A Population-Based Survey". *Journal of Medical Internet Research*. 10(4). Pp.e42.

27 Rahmqvist, M. & Bara, A. (2007). "Patients retrieving additional information via the Internet: A trend analysis in a Swedish population, 2000-2005". *Scandinavian Journal of Public Health*. Vol 35(5). Pp.533–539.

28 Warner, D. & Procaccino, J. (2007) "Women Seeking Health Information: Distinguishing the Web User". *Journal of Health Communication*. 12(8). Pp. 787–814.

29 Smith, S., Dixon, A., Trevena, L., Nutbeam, D. & McCaffery, K. (2009). "Exploring patient involvement in healthcare decision making across different education and functional health literacy groups". *Social Science & Medicine*. 69. Pp.1805–1812.

30 Belle Brown, J., Carroll, J., Boon, H. & Marmoreo, J. (2002). "Women's decision-making about their health care: views over the life cycle". *Patient Education and Counselling*. 48. Pp.225–231.

31 Nutbeam, D. (2009). "Building health literacy in Australia". *Medical Journal of Australia*. 191(10). Pp.525–526.

32 Stewart, D., Abbey, S., Shnek, Z., Irvine, J. & Grace, S. (2004). "Gender Differences in Health Information Needs and Decisional Preferences in Patients Recovering From an Acute Ischemic Coronary Event". *Psychosomatic Medicine*. 66. Pp.42–48.

33 Warner, D. & Procaccino, J. (2007) "Women Seeking Health Information: Distinguishing the Web User". *Journal of Health Communication*. 12(8). Pp. 787–814.

34 Murphy, M. & Murphy, B. (2003). *Access to Women's Health Information: A Survey of Victorian Women as Information Seekers*. Women's Health Victoria; Melbourne. 12.

35 *Ibid.*

36 *Ibid.*

37 Pennbridge, J., Moya, R. & Rodrigues, L. (1999). "Questionnaire survey of California consumers' use and rating sources of health care information including the Internet". *Western Journal of Medicine*. 171(5-6). Pp.302–305.

38 Cowan, C. & Hoskins, R. (2007). "Information preferences of women receiving chemotherapy for breast cancer". *European Journal of Cancer Care*. 16(6). Pp.543–550.

300 women from community and public venues and women's organisations to identify why and where women look for health information and how they use that information.[39] The authors reported two reasons why women were not satisfied with GP information provision. Firstly, women felt rushed during their consultation and unable to ask additional questions. And secondly, women felt the information was not clear or thorough enough to satisfy their health information needs or develop understanding.[40]

Information about general wellbeing and health behaviours was also considered to be missing from the GP and client interaction. This is a noteworthy omission when it comes to clients who suffer from chronic preventable illness but engage in detrimental or risky behaviours (smoking, overeating, lack of exercise) making them more susceptible to degrading health.[41] Barriers identified by women who seek health and wellbeing information from GPs include lack of time with the practitioner; the lack of depth and breadth of information provided; and a lack of information provided on specific issues such as sexual health.[42,43]

There are also significant barriers that affect general practitioners' ability to provide women with health and wellbeing information. These include insufficient time with patients; lack of remuneration for providing preventative health information; and the inappropriateness of preventative information for the acutely ill.[44,45]

Women's Health Victoria found that women who use a GP as their primary source of health information would rely primarily on other sources if they could find good quality and reliable information.[46] This suggests that the burden on GPs could be reduced if women knew of other sources where they could access timely, relevant and trustworthy health and wellbeing information.

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[39] Warner, D. & Procaccino, J. (2004). "Toward Wellness: Women Seeking Health Information". *Journal of the American Society for Information Science and Technology*. 55(8). Pp.709–730.

[40] *Ibid.*

[41] Wyn, R. & Solis, B. (2001). "Women's Health Issues Across the Lifespan". *Women's Health Issues*. 11(3). Pp.148–159.

[42] Murphy, M. & Murphy, B. (2003). *Access to Women's Health Information: A Survey of Victorian Women as Information Seekers*. Women's Health Victoria; Melbourne. 24.

[43] Murphy, M., Murphy, B. & Kanost, D. (2003). *Access to Women's Health Information: A Literature Review of Women as Information Seekers*. Women's Health Victoria; Melbourne. 26-27.

[44] Waters, E., Haby, M., Wake, M. & Salmon, L. (2000). "Public health and preventive healthcare in children: current practices of Victorian GPs and barriers to participation". *Medical Journal of Australia*. 173(2). Pp.68–71.

[45] Murphy, M., Murphy, B. & Kanost, D. (2003). *Access to Women's Health Information: A Literature Review of Women as Information Seekers*. Women's Health Victoria; Melbourne. 6-7.

[46] Murphy, M. & Murphy, B. (2003). *Access to Women's Health Information: A Survey of Victorian Women as Information Seekers*. Women's Health Victoria; Melbourne. 24.

Pharmacists and Allied Health Professionals

Pharmacists and allied health professionals are also useful sources of health information.[47] Women's Health Victoria found that while pharmacists were regarded as providing high quality health information second to GPs, they were the sixth most preferred information source.[48] This indicates that although pharmacists are acknowledged as a useful source of health information, they are perhaps under utilised compared to other sources.

Allied health professionals are able to provide patients with more time for health information discussions during consultations and involve patients more fully in their health care decisions.[49,50]

Women's Health Centres

Drawing on data from a study of nearly 400 clients of women's health and generalist community health centres, Dorothy Broome explored the need for centres where health care and information is provided by women for women. Broome argued that Women's Health Centres are a vital service because they provide or assist women to find general and specific health information, support women in discerning and comprehending health information, and provide adequate time to listen to women's complex health and wellbeing issues.[51]

> *If I go to the GP I feel I have to have an identifiable physical problem whereas I would go to a women's health centre if I wanted to discuss more general troubling issues and wanted help in understanding beyond a purely physical symptom*[52]

Women report that they feel rushed during consultations with GPs and are not provided adequate information and explanations.[53,54] Women's Health Centres generally provide women with longer consultations or at least provide opportunities for informed discussions on health and wellbeing with other women. By providing a space for discussion, these centres promote social networking, peer learning and teaching and provide links to additional information sources if required.[55,56] The demand for women's health centres may increase in the future as they give the personal contact, trust and time women need to discuss sensitive health issues.[57]

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[47] Wathen, C. & Harris, R. (2007). "'I Try to Take Care of It Myself.' How Rural Women Search for Health Information." *Qualitative Health Research*. 17(5). Pp. 639–651.

[48] Murphy, M. & Murphy, B. (2003). *Access to Women's Health Information: A Survey of Victorian Women as Information Seekers*. Women's Health Victoria; Melbourne. 18.

[49] Broom, D. (1999). "By Women, for Women: The Continuing Appeal of Women's Health Centres". *Women & Health*. 28(1). Pp.5–22.

[50] Wathen, C. & Harris, R. (2007). "'I Try to Take Care of It Myself.' How Rural Women Search for Health Information." *Qualitative Health Research*. 17(5). Pp. 639–651.

[51] Broom, D. (1999). "By Women, for Women: The Continuing Appeal of Women's Health Centres". *Women & Health*. 28(1). Pp.5–22.

[52] *Ibid.,* 14.

[53] *Ibid.,* 13.

[54] Murphy, M. & Murphy, B. (2003). *Access to Women's Health Information: A Survey of Victorian Women as Information Seekers*. Women's Health Victoria; Melbourne. 24.

[55] Broom, D. (1999). "By Women, for Women: The Continuing Appeal of Women's Health Centres". *Women & Health*. 28(1). Pp.5–22.

The Internet

Internet usage is increasing dramatically across Australia and the globe.[58] It is now common in many work and living spaces and is impacting upon society in a similar way to the telephone in the late nineteenth and early twentieth centuries.[59] The internet is also increasingly being used as a source of health and wellbeing information, with young women consistently the most active in this regard.[60,61] Kummervold et al. surveyed a community sample of 14 956 individuals across seven countries, to investigate the trends of European health related internet use over an 18 month period. Of their sample, 46.8 percent perceived the internet as an important source of health information, while the importance of other sources of health information stayed level or decreased.[62]

Women's Health Victoria found that while information from the internet can be unreliable or untrustworthy, it was the second most preferred source of health and wellbeing information for Victorian women.[63] At the time of their survey (2002–03), the Australian Bureau of Statistics (ABS) found that only 37 percent of Australian households had access to the internet.[64] In 2008, this figure had increased to 72 percent.[65] Of the 28 percent of Australians without internet access at home, 47 percent had no interest or use for it and another 25 percent accessed it in other locations such as work, tertiary institutions or family members' and friends' houses.[66] The ACT has the highest proportion — 74 percent — of households in Australia with a broadband internet connection.[67] Together these figures suggest that a large number of Australian women, particularly in the ACT, have convenient access to the internet as a potential source of health and wellbeing information.

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56 Murphy, M., Murphy, B. & Kanost, D. (2003). *Access to Women's Health Information: A Literature Review of Women as Information Seekers.* Women's Health Victoria; Melbourne. 15-16.

57 Mason, M. (2008). "Listening to women's problems". *Nursing Standard.* 22(46). Pp.24–25.

[58] Kummervold, P., Chronaki, C., Lausen, B., Prokosch, H., Rasmussen, J., Santana, S., Staniszewski, A. & Wangberg, S. 2008. "eHealth Trends in Europe 2005-2007: A Population-Based Survey". *Journal of Medical Internet Research.* 10(4). Pp.e42.

[59] Pandey, S., Hart, J. & Tiwary, S. (2003). "Women's health and the internet: understanding emerging trends and implications". *Social Science & Medicine.* 56(1). Pp.179–191.

[60] Kummervold, P., Chronaki, C., Lausen, B., Prokosch, H., Rasmussen, J., Santana, S., Staniszewski, A. & Wangberg, S. 2008. "eHealth Trends in Europe 2005-2007: A Population-Based Survey". *Journal of Medical Internet Research.* 10(4). Pp.e42.

[61] Rahmqvist, M. & Bara, A. (2007). "Patients retrieving additional information via the Internet: A trend analysis in a Swedish population, 2000-2005". *Scandinavian Journal of Public Health.* Vol 35(5). Pp.533–539.

[62] Kummervold, P., Chronaki, C., Lausen, B., Prokosch, H., Rasmussen, J., Santana, S., Staniszewski, A. & Wangberg, S. 2008. "eHealth Trends in Europe 2005-2007: A Population-Based Survey". *Journal of Medical Internet Research.* 10(4). Pp.e42.

[63] Murphy, M. & Murphy, B. (2003). *Access to Women's Health Information: A Survey of Victorian Women as Information Seekers.* Women's Health Victoria; Melbourne. 15 & 25.

[64] Australian Bureau of Statistics. (2000). *Use of the Internet by Householders.* ABS Cat. No. 8147.0. Australian Bureau of Statistic; Canberra.

[65] Australian Bureau of Statistics. (2009). *Household Use of Information Technology, Australia 2008-9.* ABS Cat. No. 8146.0. Australian Bureau of Statistics; Canberra.

[66] Australian Bureau of Statistics. (2009). *Australian Social Trends: Internet Access at Home in Australia 2008-9.* ABS Cat. No. 4102.0. Australian Bureau of Statistics; Canberra.

[67] Australian Bureau of Statistics. (2009). *Household Use of Information Technology, Australia 2008-9.* ABS Cat. No. 8146.0. Australian Bureau of Statistics; Canberra.

Young women remain the most active users of the internet for health and wellbeing information,[68,69,70] although there is an increasing tendency for older women to do so too.[71] Within the population of older women, those who are more socially connected and of higher socio-economic status, have better access to information via the internet than those less socially connected, less educated and of lower socio-economic status. [72, 73] Dey et al. conducted a cross-sectional study of women attending a breast screening service in NSW to understand perceptions and behaviours towards accessing health information from the internet. They found that 62 percent of the BreastScreen clients had used the internet specifically to find health information, with 70 percent reporting that they would use it if diagnosed with breast cancer.[74]

In addition to clinical health information and information to answer specific health queries, [75,76] women often use the internet to find personal stories from those with similar health issues and to connect with others in similar circumstances.[77] There is a trend for women with higher educational levels to seek out more factual health information; while women with poorer health and lower income and educational levels seek online support groups and social networking.[78] In the United States, women are increasingly seeking online support networks to help fulfil their "need to be heard and respected when they looked for information about their health or on behalf of others". [79] This could partially result from women being unable to find adequate time to discuss health and wellbeing information during consultations with health professionals.[80]

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[68] Kummervold, P., Chronaki, C., Lausen, B., Prokosch, H., Rasmussen, J., Santana, S., Staniszewski, A. & Wangberg, S. 2008. "eHealth Trends in Europe 2005-2007: A Population-Based Survey". *Journal of Medical Internet Research*. 10(4). Pp.e42.

[69] Rahmqvist, M. & Bara, A. (2007). "Patients retrieving additional information via the Internet: A trend analysis in a Swedish population, 2000-2005". *Scandinavian Journal of Public Health*. Vol 35(5). Pp.533–539.

[70] Atkinson, N. Saperstein, S. & Pleis, J. (2009). "Using the Internet for Health-Related Activities: Findings From a National Probability Sample". *Journal of Medical Internet Research*. 11(1). Pp.e4.

[71] Kummervold, P., Chronaki, C., Lausen, B., Prokosch, H., Rasmussen, J., Santana, S., Staniszewski, A. & Wangberg, S. 2008. "eHealth Trends in Europe 2005-2007: A Population-Based Survey". *Journal of Medical Internet Research*. 10(4). Pp.e42.

[72] Wilson, C., Flight, I., Hart, E., Turnbull, D., Cole, S. & Young, G. (2008). "Internet access for delivery of health information to South Australians older than 50". *Australian and New Zealand Journal of Public Health*. 32(2). Pp.174–176.

[73] Rahmqvist, M. & Bara, A. (2007). "Patients retrieving additional information via the Internet: A trend analysis in a Swedish population, 2000-2005". *Scandinavian Journal of Public Health*. Vol 35(5). Pp.533–539.

[74] Dey, A., Reid, B., Godding, R. & Campbell, A. (2008). "Perceptions and behaviour of access of the Internet: a study of women attending a breast screening service in Sydney, Australia". *International Journal of Medical Informatics*. 77. Pp.24–32.

[75] Kummervold, P., Chronaki, C., Lausen, B., Prokosch, H., Rasmussen, J., Santana, S., Staniszewski, A. & Wangberg, S. 2008. "eHealth Trends in Europe 2005-2007: A Population-Based Survey". *Journal of Medical Internet Research*. 10(4). Pp.e42.

[76] Rahmqvist, M. & Bara, A. (2007). "Patients retrieving additional information via the Internet: A trend analysis in a Swedish population, 2000-2005". *Scandinavian Journal of Public Health*. Vol 35(5). Pp.533–539.

[77] Sillence, E., Briggs, P., Harris, P. & Fishwick, L. (2007). "How do patients evaluate and make use of online health information?" *Social Science & Medicine*. 64(9). Pp.1853–1862.

[78] Atkinson, N. Saperstein, S. & Pleis, J. (2009). "Using the Internet for Health-Related Activities: Findings From a National Probability Sample". *Journal of Medical Internet Research*. 11(1). Pp.e4.

[79] Wathen, C. & Harris, R. (2007). "'I Try to Take Care of It Myself.' How Rural Women Search for Health Information." *Qualitative Health Research*. 17(5). Pp. 639–651.

[80] *Ibid.*

Use of the internet for health and wellbeing information can be a problem if individuals do not have the experience or knowledge to identify reliable and credible information.[81,82] Many women access health information through common search engines and can be unaware that some sites promote particular political or religious views or sell products or services.[83]

One recommendation in the literature was to have health specific websites endorsed by government or other authoritative organisations such as Breast Cancer Australia.[84,85] The Australian Medical Association or Government health bodies could create a brand or seal to make endorsed websites easily identifiable. However, in order for endorsed health information websites to provide quality health information, they must be intensively monitored and managed, which would require resources to ensure information is kept up to date with current health research and protected from outside interference.[86] In the US, internet moderators are employed to ensure the quality of information, while in other countries — including Victoria — intensive monitoring and promotion of reputable websites is already underway through some government health information portals.[87]

Telephone Helplines

In Australia, telephone helplines are a minor source of health information compared to other sources.[88] Some helplines are well utilised, such as QUITline, which receives over 130 000 calls a year for information and counselling to reduce tobacco consumption.[89] General telephone helplines are useful sources of health and wellbeing information for individuals who need advice after hours, women from culturally and linguistically diverse backgrounds and women with young children.[90]

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[81] Kontos, E., Bennett, G. & Viswanath, K. (2007). “Barriers and Facilitators to Home Computer and Internet Use Among Urban Novice Computer Users of Low Socioeconomic Position”. *Journal of Medical Internet Research*. 9(4). Pp.e31.

[82] Warner, D. & Procaccino, J. (2007) “Women Seeking Health Information: Distinguishing the Web User”. *Journal of Health Communication*. 12(8). Pp. 787–814.

[83] *Ibid.*

[84] Dey, A., Reid, B., Godding, R. & Campbell, A. (2008). “Perceptions and behaviour of access of the Internet: a study of women attending a breast screening service in Sydney, Australia”. *International Journal of Medical Informatics*. 77. Pp.24–32.

[85] Cowan, C. & Hoskins, R. (2007). “Information preferences of women receiving chemotherapy for breast cancer”. *European Journal of Cancer Care*. 16(6). Pp.543–550.

[86] Alfred, A., Esterman, A., Farmer, E., Pilotto, L. & Weston, K. (2006). “Women’s decision making at menopause: A focus group study”. *Australian Family Physician*. 35(4). Pp.270–272.

[87] Wathen, C & Harris, R. (2006) “An examination of the health information seeking experiences of women in rural Ontario, Canada”. *Information Research*. 11(4). Pp.1–11.

[88] Murphy, M. & Murphy, B. (2003). *Access to Women’s Health Information: A Survey of Victorian Women as Information Seekers*. Women’s Health Victoria; Melbourne. 26.

[89] Miller, C., Wakefield, M. & Roberts, L. (2003). “Uptake and effectiveness of the Australian telephone Quitline service in the context of a mass media campaign”. *British Medical Journal: Tobacco Control*. 12(2). Pp.53–58.

[90] St George, I. & Cullen, M. (2001). “The Healthline pilot: call centre triage in New Zealand”. *New Zealand Medical Journal*. 114(1140). Pp.429–430.

Paper Based Publications

Paper based publications that provide health and wellbeing information to women include newspapers, books, pamphlets and magazines.

> *The media are an important source of health information for many women and probably influence their perceptions of susceptibility and appropriate health-protective behaviours.*[91]

This is particularly true for conditions affecting women such as breast cancer, where good quality and timely health information could help to reduce Australia's morbidity and mortality rates. However, current paper based publications in Australia, such as women's magazines and newspapers are not conveying accurate, evidence-based information to promote healthy behaviours and adequate screening but are instead misinforming women or leading them astray.[92] Women's Health Victoria found that although paper based publications were used at a similar rate to the internet, women preferred more personalised sources where they could engage with another person.[93,94]

Family Members and Friends

Women often use informal networks of friends as health and wellbeing information sources. Women's Health Victoria found that young women in particular prefer informal networks for their health and wellbeing information, despite recognising that information from this source can be unreliable or outdated.[95] This may be because young women value obtaining information from easily accessible, informal and personal sources that they have a trusting relationship with, seeking advice from health professionals as a last resort.[96,97] This trend may also be because young women are concerned with confidentiality and are wary of information sources that will not respect this, even if the sources they use are of lesser quality.[98]

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[91] Jones, S. (2004). "Coverage of Breast Cancer in the Australian Print Media – Does Advertising and Editorial Coverage Reflect Correct Social Marketing Messages?" *Journal of Health Communication*. 9(4). Pp.309–325.

[92] *Ibid.*

[93] Murphy, M. & Murphy, B. (2003). *Access to Women's Health Information: A Survey of Victorian Women as Information Seekers*. Women's Health Victoria; Melbourne. 26.

[94] *Ibid.*

[95] Murphy, M. & Murphy, B. (2003). *Access to Women's Health Information: A Survey of Victorian Women as Information Seekers*. Women's Health Victoria; Melbourne. 13,15, 17 & 24

[96] Belle Brown, J., Carroll, J., Boon, H. & Marmoreo, J. (2002). "Women's decision-making about their health care: views over the life cycle". *Patient Education and Counselling*. 48. Pp.225–231.

[97] Wathen, C. & Harris, R. (2007). "'I Try to Take Care of It Myself.' How Rural Women Search for Health Information." *Qualitative Health Research*. 17(5). Pp. 639–651.

[98] Murphy, M. & Murphy, B. (2003). *Access to Women's Health Information: A Survey of Victorian Women as Information Seekers*. Women's Health Victoria; Melbourne. 18.

Smith et al. in an Australian study of 73 individuals with varying education and health literacy found that women with lower educational levels and lower health literacy would often seek assistance from their family members and friends to sort through health information and make health decisions.[99]

Women from culturally and linguistically diverse backgrounds often have access to supportive networks within their community where they can share information and support.[100] Working with women in their communities to identify their collective health literacy needs, validate their personal experiences and provide a medium to engage in peer learning has proven highly successful for CALD women.[101]

Ingredients of Useful Health and Wellbeing Information

Women benefit most by receiving information from a range of sources, particularly during acute or stressful events.[102,103] Providing women access to multiple sources allows them greater autonomy and control over the health and wellbeing information they engage with.

> *I don't think I can point out just one [source]. I think it's a combination of things…I kind of take the advice that I get from all of those and see what suits… in the end I'm the one that has to make the choices to what is best for my family.*[104]

Providing multiple sources of information is especially valuable during consultations, diagnoses, and at the onset of new life stages.[105] Information sources are also beneficial when they help to develop women's decision making skills and provide practical applications of health and wellbeing information.[106]

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[99] Smith, S., Dixon, A., Trevena, L., Nutbeam, D. & McCaffery, K. (2009). "Exploring patient involvement in healthcare decision making across different education and functional health literacy groups". *Social Science & Medicine*. 69. Pp.1805–1812.

[100] Murphy, M., Murphy, B. & Kanost, D. (2003). *Access to Women's Health Information: A Literature Review of Women as Information Seekers*. Women's Health Victoria; Melbourne. 21.

[101] Williams-Brown, S., Baldwin, D. & Bakos, A. (2002). "Storytelling as a method to teach African American women breast health information". *Journal of Cancer Education*. 17(4). Pp.227–230.

[102] Rushford, N., Murphy, B., Worcester, M., Goble, A., Higgins, R., LeGrande, M., Rada, J. & Elliot, P. (2007). "Recall of information received in hospital by female cardiac patients". *European Journal of Cardiovascular Prevention & Rehabilitation*. 14(3). Pp.463–469.

[103] Murphy, M., Murphy, B. & Kanost, D. (2003). *Access to Women's Health Information: A Literature Review of Women as Information Seekers*. Women's Health Victoria; Melbourne. 6.

[104] Wathen, C & Harris, R. (2006) "An examination of the health information seeking experiences of women in rural Ontario, Canada". *Information Research.* 11(4). Pp.1–11.

[105] Murphy, M., Murphy, B. & Kanost, D. (2003). *Access to Women's Health Information: A Literature Review of Women as Information Seekers*. Women's Health Victoria; Melbourne. 6.

[106] Renkert, S. & Nutbeam, D. (2001). "Opportunities to improve maternal health literacy through antenatal education: an exploratory study". *Health Promotion International*. 16(4). Pp.381–388.

Health and wellbeing information is beneficial when it is delivered in a personal manner and can be applied to women's lives. Online support groups are an increasingly popular means for women to obtain information and emotional support and to reduce isolation during illness.[107] Personal stories of others from a similar demographic, or who are going through a similar health or illness trajectory, are a useful way to present health and wellbeing information. Listening to personal stories has been shown to help women be more proactive in asking questions of their health providers.[108]

BARRIERS TO OBTAINING HEALTH AND WELLBEING INFORMATION

There are many barriers that prevent women from accessing health and wellbeing information, three of which have been selected from the literature for examination. The first is not being able to access personally relevant or specific information on particular issues. The second is poor quality information or information that lacks credibility. And the third is time poverty, which is a barrier for both information providers and women seeking information.

Another barrier identified in the literature — but not considered in great depth here — is the sheer volume of information, often inconsistent or conflicting, that causes confusion.[109, 110] Some women report that they are "just overwhelmed," and "It's tough…because there's just too many options."[111] A large volume of conflicting information can create more questions than answers, creating confusion as to where women should source their health and wellbeing information.

Personally Relevant and Specific Health and Wellbeing Information

Despite the numerous sources discussed above and the multitude of health and wellbeing information available, women continue to report being unable to access information on specific health issues and needs.[112] There are few academic studies that examine what types of health and wellbeing information women seek and what they feel is missing.[113] However, these basic questions are important for all health information providers who wish to ensure they are effectively meeting women's needs.

Literature that deals with these questions argue that women want four things. Firstly, they want factual and comprehensive information on illness as well as general information on health and wellbeing. Secondly, personalised information relevant to their circumstances. Thirdly, the

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[107] Hardyman, R., Hardy, P., Brodie, J. & Stephens, R. (2005). "It's good to talk: comparison of a telephone help line and website for cancer information". *Patient Education and Counselling*. 57. Pp.315–320.

[108] Sillence, E., Briggs, P., Harris, P. & Fishwick, L. (2007). "How do patients evaluate and make use of online health information?" *Social Science & Medicine*. 64(9). Pp.1853–1862.

[109] Nicholson, W., Gardner, B., Grason, H. & Powe, N. (2005). "The Association Between Women's Health Information Use and Health Care Visits". *Women's Health issues*. 15(6). Pp.240–248.

[110] Belle Brown, J., Carroll, J., Boon, H. & Marmoreo, J. (2002). "Women's decision-making about their health care: views over the life cycle". *Patient Education and Counselling*. 48. Pp.225–231.

[111] Wathen, C. & Harris, R. (2007). "'I Try to Take Care of It Myself.' How Rural Women Search for Health Information." *Qualitative Health Research*. 17(5). Pp. 639–651.

[112] Murphy, M. (2003). *Access to Women's Health Information: Research Summary*. Women's Health Victoria; Melbourne. 6.

[113] Warner, D. & Procaccino, J. (2007) "Women Seeking Health Information: Distinguishing the Web User". *Journal of Health Communication*. 12(8). Pp. 787–814.

opportunity to discuss health and wellbeing issues with people of experience or knowledge to assist them in decision making. And finally, women want information about accessing health professionals and experts in specific fields.[114]

Health information is ineffective if it is not relevant to women's needs or if they are unaware of why it may be important to them personally. "Personally relevant health information is an important factor that can change individuals' perceptions of their health needs."[115] When women are more aware of their health and wellbeing needs and risks, efforts to promote preventative health care, such as screening, are more effective. Effective health promotion and illness prevention are important tools in reducing the burden of preventable illness for women and society as a whole.[116] Good quality health promotion and illness prevention information should highlight the short and long term benefits, be personally relevant and practical.[117]

Credibility and Quality Assurance of Health and Wellbeing Information

Women need access to good quality and credible health and wellbeing information. In 2003, Women's Health Victoria found that Victorian women most commonly sought health information from the internet, popular press, family members and friends despite recognising that information from these sources can lack credibility or quality.[118] The women identified lack of time and difficulty in accessing more reputable sources as reasons for this.[119] This discussion will focus on the internet as a health and wellbeing information source.

Women's Health Victoria highlighted reasons why many women obtain poor quality health information.[120] Firstly, many women search for health information through general search engines which return links to the most used sites, not necessarily the most relevant, accurate or up-to-date sites.[121,122] For example, a survey of the quality of websites providing health information on laparoscopy from popular search engines showed that out of 14,030 sites only 46 contained specific educational material. When critically analysed, as many as 32 of these contained misleading or controversial health information.[123] The second concern is that many of the sites women access are commercial, and sell 'medical' products that have not undergone

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114 Wathen, C. & Harris, R. (2007). "'I Try to Take Care of It Myself.' How Rural Women Search for Health Information." *Qualitative Health Research*. 17(5). Pp. 639–651.

115 Parslow, R., Jorm, A., Christensen, H. & Rodgers. B. (2004). "Use of medical services after participation in a community-based epidemiological health survey". *Social Psychiatry & Psychiatric Epidemiology*. 39(4). Pp. 311–317.

116 *Ibid.*

117 Sullivan, K., White, K., Young, R., Scott, C. & Mulgrew, K. (2008). "Developing a stroke intervention program: What do people at risk of stroke want?" *Patient Education & Counselling*. 70(1). Pp.126–134.

118 Murphy, M. & Murphy, B. (2003). *Access to Women's Health Information: A Survey of Victorian Women as Information Seekers*. Women's Health Victoria; Melbourne. 17-18.

119 *Ibid.*

120 Murphy, M., Murphy, B. & Kanost, D. (2003). *Access to Women's Health Information: A Literature Review of Women as Information Seekers*. Women's Health Victoria; Melbourne. 37.

121 *Ibid.*

122 Warner, D. & Procaccino, J. (2007) "Women Seeking Health Information: Distinguishing the Web User". *Journal of Health Communication*. 12(8). Pp. 787–814.

123 Allen, J., Finch, R., Coleman, M., Nathanson, L., O'Rouke, N. & Fielding, G. (2002). "The poor quality of information about laparoscopy on the World Wide Web as indexed by popular search engines". *Surgical Endoscopy*. 16. Pp.170–172.

double blind randomised controlled trials,[124] relying instead on fraudulent claims and consumer testimonials.[125] This can cause frustration to women who are looking for information to assist them in health decision making, such as in regard to Hormone Replacement Therapy and alternative therapies.[126]

It is especially concerning that many women use the internet to self-diagnose and treat,[127] particularly when many of them do not know how to check the credibility of a website[128] and are unaware of medically endorsed, quality assured websites.[129] In Australia there are numerous medically endorsed websites such as the Jean Hailes Foundation website, Health*insite,* The Better Health Channel, the ABC Health and Wellbeing information portal and Informed Health Online. There are also a number of good quality and credible international websites such as MayoClinic, the British Medical Journal, OncoLink (for sound breast cancer information) and MEDLINEplus.[130] However, such sites may be underutilised because "most women are unaware of existing reliable websites".[131] A related problem for many — especially older — women is their inexperience navigating the world wide web, further complicating effective use of this medium.[132]

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124 Murphy, M., Murphy, B. & Kanost, D. (2003). *Access to Women's Health Information: A Literature Review of Women as Information Seekers*. Women's Health Victoria; Melbourne. 38.

125 Warner, D. & Procaccino, J. (2007) "Women Seeking Health Information: Distinguishing the Web User". *Journal of Health Communication*. 12(8). Pp. 787–814.

126 Alfred, A., Esterman, A., Farmer, E., Pilotto, L. & Weston, K. (2006). "Women's decision making at menopause: A focus group study". *Australian Family Physician*. 35(4). Pp.270–272.

127 Harris, R. & Wathen, N. (2007) "'If My Mother Was Alive I'd Probably Have Called Her.' Women's Search for Health Information in Rural Canada". *Reference and User Services Quarterly*. 47(1). Pp.67–79.

128 Murphy, M., Murphy, B. & Kanost, D. (2003). *Access to Women's Health Information: A Literature Review of Women as Information Seekers*. Women's Health Victoria; Melbourne. 37-8.

129 Warner, D. & Procaccino, J. (2007) "Women Seeking Health Information: Distinguishing the Web User". *Journal of Health Communication*. 12(8). Pp. 787–814.

130 Fry, R. (2001). *Elixer of e-Health.* Available at: http://www.abc.net.au/health/consumerguides/stories/2001/08/09/1837359.htm

131 Alfred, A., Esterman, A., Farmer, E., Pilotto, L. & Weston, K. (2006). "Women's decision making at menopause: A focus group study". *Australian Family Physician*. 35(4). Pp.270–272.

132 Dey, A., Reid, B., Godding, R. & Campbell, A. (2008). "Perceptions and behaviour of access of the Internet: a study of women attending a breast screening service in Sydney, Australia". *International Journal of Medical Informatics*. 77. Pp.24–32.

Time Poverty and Time Constraints

Health professionals are more likely to provide health and wellbeing information to patients who request it, however, many women feel rushed during a consultation and unable to request the information they need.[133] Some women report limiting their consultation time to prevent "taking up too much of their doctor's time when other patients were waiting to be seen".[134]

Time constraints often mean that health information is delivered as a one-way factual transfer from health professionals to clients. This is less effective than a two-way dialogue where women actively develop their own decision making skills for looking after their own and their family's health.[135] Just providing factual information is a short-term bandage for improving women's health — unless it can be applied practically it is easily forgotten. Helping women to develop their health literacy by increasing consultation time to ensure they can access, understand, and use quality health information, is a much sounder long-term approach.[136]

There is an emerging field of literature on women's lack of time and how it impacts upon their health and wellbeing and health literacy. What is known is that many women lack sufficient time to make their health and wellbeing a priority, and lack the choice to organise their time differently. Insufficient time due to work and caring responsibilities is the most common reason provided by women for not seeking information to maintain or improve their health and wellbeing.[137] Also, competing pressures and high stress often means that women are unable to recall information once it has been given.[138] Verbal information supported by paper based information may be one way to ensure that women can revisit and recall health and wellbeing information.

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[133] Broom, D. (1999). "By Women, for Women: The Continuing Appeal of Women's Health Centres". *Women & Health*. 28(1). Pp.5–22.

[134] Wathen, C. & Harris, R. (2007). "'I Try to Take Care of It Myself.' How Rural Women Search for Health Information." *Qualitative Health Research*. 17(5). Pp. 639–651.

[135] Renkert, S. & Nutbeam, D. (2001). "Opportunities to improve maternal health literacy through antenatal education: an exploratory study". *Health Promotion International*. 16(4). Pp.381–388.

[136] Adams, R., Stocks, N., Wilson, D. & Hill, C. (2009). "Health literacy: A new concept for general practice?" *Australian Family Physician*. 38(3). Pp.144–147.

[137] Kontos, E., Bennett, G. & Viswanath, K. (2007). "Barriers and Facilitators to Home Computer and Internet Use Among Urban Novice Computer Users of Low Socioeconomic Position". *Journal of Medical Internet Research*. 9(4). Pp.e31.

[138] Rushford, N., Murphy, B., Worcester, M., Goble, A., Higgins, R., LeGrande, M., Rada, J. & Elliot, P. (2007). "Recall of information received in hospital by female cardiac patients". *European Journal of Cardiovascular Prevention & Rehabilitation*. 14(3). Pp.463–469.

SEEKING TRENDS AND BARRIERS FOR SPECIFIC GROUPS OF WOMEN

It is well acknowledged that specific groups of women have differing health and health information needs.[139] This brief overview examines the health information seeking trends and barriers of specific groups of women. These include: young women; older women; Aboriginal and Torres Strait Islander women; carers; women from culturally and linguistically diverse backgrounds; women with disabilities; pregnant women and new mothers; women who are experiencing or have experienced incarceration; women seeking information on alternative therapies; and marginalised groups of women with poor access to services or low English literacy.

Young Women

The need for confidentiality determines where young women seek health and wellbeing information.[140] They are particularly wary of health professionals, and are reluctant to seek information about sensitive issues such as sexual health and reproductive health, bullying, mental health issues and drug and alcohol use.[141,142] Concern for confidentiality means they are less likely to utilise reputable sources such as GPs, relying instead on friends, the internet and mass media.[143] A reluctance to see GPs may contribute to young women being the leading seekers of health information from the internet.[144]

Older Women

Women's Health Victoria found that older women reported significant problems and concerns around accessing health information, especially on specific issues such as menopause.[145] Accessing information was especially difficult for older women who did not have dependent children or who were unwell, living alone, or less educated.[146] Older women are generally more dependent on their primary health care provider, less autonomous, and less assertive than younger women. As a result they may consult their GP more frequently to meet their health and

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[139] Murphy, M., Murphy, B. & Kanost, D. (2003). *Access to Women's Health Information: A Literature Review of Women as Information Seekers*. Women's Health Victoria; Melbourne. 44.

[140] *Ibid.*

[141] Carlisle, J., Shickle, D., Cork, M. & McDonagh, A. (2006). "Concerns over confidentiality may deter adolescents from consulting their doctors. A qualitative exploration". *Journal of Medical Ethics*. 32. Pp.133–137.

[142] Murphy, M., Murphy, B. & Kanost, D. (2003). *Access to Women's Health Information: A Literature Review of Women as Information Seekers*. Women's Health Victoria; Melbourne. 41.

[143] Murphy, M. (2003). *Access to Women's Health Information: Research Summary*. Women's Health Victoria; Melbourne. 7.

[144] Kummervold, P., Chronaki, C., Lausen, B., Prokosch, H., Rasmussen, J., Santana, S., Staniszewski, A. & Wangberg, S. 2008. "eHealth Trends in Europe 2005-2007: A Population-Based Survey". *Journal of Medical Internet Research*. 10(4). Pp.e42.

[145] Murphy, M., Murphy, B. & Kanost, D. (2003). *Access to Women's Health Information: A Literature Review of Women as Information Seekers*. Women's Health Victoria; Melbourne. 5-7 & 33-6. 45.

[146] *Ibid.*

wellbeing information needs.[147,148] They also seek information from family members and friends when they cannot obtain it from other sources.[149,150]

Aboriginal and Torres Strait Islander Women

Aboriginal and Torres Strait Islander women generally have poorer health outcomes, lower socio-economic status and education levels, lower utilisation of healthcare services, greater morbidity of preventable illness, and poorer access to health information.[151,152] A study conducted by Davies et al. investigated how to communicate messages about risk factors for chronic illness and climacteric (menopausal) symptoms to Aboriginal women. They collaborated with Indigenous elders and artists to develop appropriate health information materials that were culturally sensitive and available in Aboriginal languages.[153] The success of the study suggests that Aboriginal and Torres Strait Islander women would benefit from improved health literacy and access to comprehensible, verbal and visual health and wellbeing information.[154]

Carers

Women's Health Victoria highlighted two major barriers for female carers to access appropriate quality health information. Firstly, many carers who seek information on behalf of individuals with poor health or disability prefer to access health information through one-on-one discussions with a GP or support service. This limits the sources of health information available to personalised mediums. Therefore, given the time pressures on GPs and women alike, carers may not be getting health information they require to meet their and their family's health care needs.[155]

Women from Culturally and Linguistically Diverse Backgrounds

Women from culturally and linguistically diverse (CALD) backgrounds require specific services to help them access good quality health and wellbeing information.

The health information available to CALD women is not always culturally appropriate or it is discriminatory.[156] Women's Health Victoria found that women who had English as a second language were dissatisfied with their access to quality health information. This was partly

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[147] *Ibid.*, 45.

[148] Murphy, M. & Murphy, B. (2003). *Access to Women's Health Information: A Survey of Victorian Women as Information Seekers.* Women's Health Victoria; Melbourne. 15 & 29.

[149] Wathen, C. & Harris, R. (2007). "'I Try to Take Care of It Myself.' How Rural Women Search for Health Information." *Qualitative Health Research.* 17(5). Pp. 639–651.

[150] Murphy, M., Murphy, B. & Kanost, D. (2003). *Access to Women's Health Information: A Literature Review of Women as Information Seekers.* Women's Health Victoria; Melbourne. 45.

[151] *Ibid.*, 45-6.

[152] Murphy, M. (2003). *Access to Women's Health Information: Research Summary.* Women's Health Victoria; Melbourne. 7-9.

[153] Davis, S., Knight, S., White, V., Claridge, C., Davis, B. & Bell, R. (2003). "Climacteric symptoms among Indigenous Australian women and a model for the use of culturally relevant art in health promotion". *Menopause.* 10(4). Pp.345–351.

[154]Murphy, M., Murphy, B. & Kanost, D. (2003). *Access to Women's Health Information: A Literature Review of Women as Information Seekers.* Women's Health Victoria; Melbourne. 46.

[155] *Ibid.*, 47.

[156] *Ibid.*

because of cultural inappropriateness and partly due to the prejudices of health professionals.[157] Discrimination and cultural insensitivity are major barriers for CALD women, and comes mostly from health professionals. Six immigrant Muslim women participating in a Canadian qualitative study reported experiencing discrimination when accessing maternity services. Not only did the women report lack of culturally and linguistically appropriate material they also encountered prejudice and stereotyping.[158]

CALD women prefer information that is tailored to their culture and personal circumstances from a trusted person rather than through a translated information pack. If they receive information that discusses health concerns of similar women and how they make use of health services, they are more likely to realise their own health risks. Then they can respond by making positive health choices, such as participating in breast cancer screening.[159] This narrative based information is a positive way to engage CALD women with health information, connect them to service providers, enhance peer learning and validate personal experiences.[160] The internet is also a source where women can find culturally appropriate health and wellbeing information and support.[161]

Women with Disabilities

Although women with a disability have greater health and wellbeing information needs, they face greater disadvantage and more barriers in attempting to have their needs met.[162] For example, women with visual impairment expressed frustration “that most educational materials about health issues that concern them were written materials, rendering them useless.”[163] Women with disabilities also identified negative stereotyping from health professionals and short consultation times as a major barrier that made them feel depersonalised and burdensome — especially when doctors were unable to provide facilities or advice to meet their needs. The internet is a useful source from which women with disabilities can access health and wellbeing information[164] even though the information is not personalised and is not always trustworthy.[165]

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[157] Murphy, M. & Murphy, B. (2003). *Access to Women’s Health Information: A Survey of Victorian Women as Information Seekers*. Women’s Health Victoria; Melbourne. 28.

[158] Reitmanova, S. & Gustafson, D. (2008). “‘They Can’t Understand It’: Maternity Health and Care Needs of Immigrant Muslim Women in St. John’s, Newfoundland”. *Maternal and Child Health Journal*. 12(1). Pp.101–111.

[159] Simonian, K., Brown, S., Sanders, D., Kidd, C., Murillo, V., Garcia, R. & Marks, S. (2004). “Breast health information: Messages that appeal to young women and older women of colour”. *Journal of Cancer Education*. 19(4). Pp.232–236.

[160] Williams-Brown, S., Baldwin, D. & Bakos, A. (2002). “Storytelling as a method to teach African American women breast health information”. *Journal of Cancer Education*. 17(4). Pp.227–230.

[161] Murphy, M., Murphy, B. & Kanost, D. (2003). *Access to Women’s Health Information: A Literature Review of Women as Information Seekers*. Women’s Health Victoria; Melbourne. 47.

[162] McColl, M., Forster, D., Shortt, S., Hunter, D., Dorland, J., Godwin, M. & Rosser, W. (2008). “Physician Experience Providing Primary Care to People with Disabilities”. *Healthcare Policy*. 4(1). Pp.e129.

[163] Smeltzer, S., Sharts-Hopko, N., Ott, B., Zimmerman, V. & Duffin, J. (2007). “Perspectives of Women with Disabilities on Reaching Those Who Are Hard to Reach”. *Journal of Neuroscience Nursing*. 39(3). Pp.167.

[164] Murphy, M., Murphy, B. & Kanost, D. (2003). *Access to Women’s Health Information: A Literature Review of Women as Information Seekers*. Women’s Health Victoria; Melbourne. 49.

[165] Murphy, M. (2003). *Access to Women’s Health Information: Research Summary*. Women’s Health Victoria; Melbourne. 8-9.

Pregnant Women and New Mothers

Pregnant women and new mothers generally report good access to health and wellbeing information from a variety of sources. These women often use maternal, family and children's health services to a greater degree and through having children have many opportunities to hone their skills of accessing and applying health literature to meet their needs.[166]

Women Who have Experienced or are Experiencing Incarceration

Women who are experiencing or have experienced incarceration have specific needs that are often unmet by mainstream health and wellbeing information sources. The Jailbreak Health Project — a New South Wales Government initiative — delivers relevant and accurate information on HIV, hepatitis and sexual health via a weekly thirty-minute radio program, to those who have been or are incarcerated,.[167] The authors of a study analysing the initiative found that its success arose from meeting an otherwise unmet need — for incarcerated women to be engaged in discussions about relevant health and wellbeing issues.[168]

Women Seeking Information on Alternative Therapies

Some women believe that general practitioners inhibit their ability to access non-medicalised and non-westernised health and wellbeing information. Many women report feeling dismissed when their GP is reluctant to consider or provide information on alternate health care therapies.[169] These women believe the medicalisation of health and wellbeing is a barrier to managing their health and wellbeing in the way that they would like to.[170] Seeking advice from alterative therapy sources is especially prominent for issues such as menopause as many women do not wish to go down a disease/treatment path, but would rather information that regards menopause as a natural life stage.[171]

Marginalised Groups of Women with Low English Literacy and Poor Access to Services

Average levels of English literacy and comprehension skills are vital for women accessing and utilising health and wellbeing information in Australia. If women are unable to read and comprehend textual information, they are limited in the number of information sources they can use. As a result they are excluded from the positive affects of having their needs met by a range of good quality information.[172] Women's Health Victoria found that Aboriginal and Torres Strait

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[166] Murphy, M. & Murphy, B. (2003). *Access to Women's Health Information: A Survey of Victorian Women as Information Seekers*. Women's Health Victoria; Melbourne. 28.

[167] Minc, A., Butler, T. & Gahan, G. (2007). "Jailbreak Health Project - incorporating a unique radio programme for prisoners". *International Journal of Drug Policy*. 18(5). Pp.444–446.

[168] *Ibid.*

[169] Wathen, C & Harris, R. (2006). "An examination of the health information seeking experiences of women in rural Ontario, Canada". *Information Research*. 11(4). Pp.1–11.

[170] *Ibid.*

[171] Alfred, A., Esterman, A., Farmer, E., Pilotto, L. & Weston, K. (2006). "Women's decision making at menopause: A focus group study". *Australian Family Physician*. 35(4). Pp.270–272.

[172] Murphy, M., Murphy, B. & Kanost, D. (2003). *Access to Women's Health Information: A Literature Review of Women as Information Seekers*. Women's Health Victoria; Melbourne. 42.

Islander women and women from culturally and linguistically diverse backgrounds often could not find health and wellbeing information that was linguistically or culturally accessible.[173]

Marginalised women, especially those experiencing poverty, have significantly reduced access to sources of health and wellbeing information.[174] Lack of access to information is coupled with poorer health outcomes, lower education levels, lower socio-economic status and lower service utilisation for marginalised women compared to other Australian women.[175]

HEALTH LITERACY

There are many sources providing a plethora of health and wellbeing information to women, ranging in quality, credibility, complexity and purpose. For women to benefit from the information they need to be able to understand it, assess its credibility, and apply it to their own or their family members' lives. It is with good health literacy that this can be achieved.

Health literacy is defined as:

> *Health literacy is the ability to make sound health decisions in the context of everyday life — at home, in the community, at school, in the workplace, in the health care system, in the marketplace and in the political arena. It enables people to increase their control over their health, their ability to seek out health information, to navigate complex systems, take responsibility and participate effectively in all aspects of life.*[176]

Health literacy affects all aspects of health knowledge and health care. It assists individuals to engage with and understand health and wellbeing information, to navigate health systems, to access care, and to understand their own health risks and needs.[177,178]

The Department of Health and Ageing recently reported that 60 percent of Australians lack the basic health literacy skills required to obtain, understand and use health information.[179] In terms of improving the national level of health literacy Australia trails behind other western countries.[180] Yet, Australia carries a huge burden of chronic and preventable illness, and a lot more preventative work could be done if Australian's health literacy was improved.[181]

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[173] Murphy, M. & Murphy, B. (2003). *Access to Women's Health Information: A Survey of Victorian Women as Information Seekers.* Women's Health Victoria; Melbourne. 19.

[174] *Ibid.*

[175] Murphy, M. (2003). *Access to Women's Health Information: Research Summary.* Women's Health Victoria; Melbourne. 8.

[176] Kickbusch, I. (2008). *Healthy Societies: Addressing 21st Century Health Challenges.* Adelaide Thinkers in Residence; Adelaide. 46.

[177] Torres, R. & Marks, R. (2009). "Relationships Among Health Literacy, Knowledge About Hormone Therapy, Self Efficacy and Decision Making Among Postmenopausal Health." *Journal of Health Communication.* 14(1). Pp.43–55.

[178] von Wagner, C., Knight, K., Steptoe, A. & Wardle, J. (2007). "Functional heath literacy and health promoting behaviour in a national sample of British adults". *Journal of Epidemiology and Community Health.* 61(12). Pp.1086–1090.

[179] Nutbeam, D. (2009). "Building health literacy in Australia". *Medical Journal of Australia.* 191(10). Pp.525–526.

[180] Adams, R., Stocks, N., Wilson, D. & Hill, C. (2009). "Health literacy: A new concept for general practice?" *Australian Family Physician.* 38(3). Pp.144–147..

[181] Oldroyd, J., Proudfoot, J., Infante, F., Davies, G., Bubner, T., Holton, C., Beibly, J. & Harris, F. (2003). "Providing healthcare for people with chronic illness: the views of Australian GPs". *Medical Journal of Australia.* 179. Pp.30–33.

There is evidence of “a strong association between health literacy and self-efficacy” with respect to improving health and wellbeing outcomes for women. Adequate health literacy to know what one can do to improve health and wellbeing; and good self-efficacy to have the knowledge and belief in oneself to make any needed changes.[182] However, improved health literacy does not mean providing women with more information, as information alone will not assist women in managing their health and wellbeing or promote lasting behaviour changes.[183]

Practical applications of health literacy include being able to read medical documents, such as consent forms or medication instructions;[184] knowing when and how to be screened for disease;[185] knowing when bodily functions are symptomatic of ill health; and knowing how and where to seek necessary health care.[186, 187]

A sufficient degree of health literacy assists individuals to communicate with health professionals in a more balanced and informed manner, reducing the risk of negative interactions.[188] Individuals with low health literacy can be overwhelmed by health professionals’ language,[189] may not feel respected for what information or understanding they do have, and can feel patronised.[190] Good health literacy ensures that women can engage in productive conversations with their health care providers. This helps the GP/client relationship to be one of trust and mutual respect, allows for the negotiation of health care decisions, and equalises the sharing of power and responsibility for maximising women’s health and wellbeing.[191] Improved health literacy has also been shown to improve patient satisfaction.[192]

Low health literacy reduces an individual’s understanding of their health, compliance with health plans, and results in poorer psychological and physical health and wellbeing outcomes and

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[182] Torres, R. & Marks, R. (2009). “Relationships Among Health Literacy, Knowledge About Hormone Therapy, Self Efficacy and Decision Making Among Postmenopausal Health.” *Journal of Health Communication*. 14(1). Pp.43–55.

[183] Renkert, S. & Nutbeam, D. (2001). “Opportunities to improve maternal health literacy through antenatal education: an exploratory study”. *Health Promotion International*. 16(4). Pp.381–388.

[184] Hardyman, R., Hardy, P., Brodie, J. & Stephens, R. (2005). “It’s good to talk: comparison of a telephone help line and website for cancer information”. *Patient Education and Counselling*. 57. Pp.315–320.

[185] Torres, R. & Marks, R. (2009). “Relationships Among Health Literacy, Knowledge About Hormone Therapy, Self Efficacy and Decision Making Among Postmenopausal Health.” *Journal of Health Communication*. 14(1). Pp.43–55.

[186] Adams, R., Stocks, N., Wilson, D. & Hill, C. (2009). “Health literacy: A new concept for general practice?” *Australian Family Physician*. 38(3). Pp.144–147.

[187] Renkert, S. & Nutbeam, D. (2001). “Opportunities to improve maternal health literacy through antenatal education: an exploratory study”. *Health Promotion International*. 16(4). Pp.381–388.

[188] Torres, R. & Marks, R. (2009). “Relationships Among Health Literacy, Knowledge About Hormone Therapy, Self Efficacy and Decision Making Among Postmenopausal Health.” *Journal of Health Communication*. 14(1). Pp.43–55.

[189] Adams, R., Stocks, N., Wilson, D. & Hill, C. (2009). “Health literacy: A new concept for general practice?” *Australian Family Physician*. 38(3). Pp.144–147.

[190] Wathen, C. & Harris, R. (2007). “‘I Try to Take Care of It Myself.’ How Rural Women Search for Health Information.” *Qualitative Health Research*. 17(5). Pp. 639–651.

[191] Smith, S., Dixon, A., Trevena, L., Nutbeam, D. & McCaffery, K. (2009). “Exploring patient involvement in healthcare decision making across different education and functional health literacy groups”. *Social Science & Medicine*. 69. Pp.1805–1812.

[192] Adams, R., Stocks, N., Wilson, D. & Hill, C. (2009). “Health literacy: A new concept for general practice?” *Australian Family Physician*. 38(3). Pp.144–147.

higher morbidity and mortality.[193,194,195] Low health literacy has ramifications for an individual's future health and use of health care services. It has been associated with a poor understanding of one's own health; reduced use of preventative health strategies; reduced use of primary health services; reduced likelihood of taking medications as prescribed; poor self-care; and a reduced ability to interact and engage with health care providers.[196]

Poor health literacy increases with age, low educational level and low income.[197] Men generally have poorer health literacy than women, however, regardless of gender, education, ethnicity, age and income, better health literacy still significantly increases a person's self-rated level of health, and the chance of engaging in health promoting behaviours.[198] This is an important point for effective health promotion as it clearly shows poor health literacy is part of a complex tapestry of disadvantage.[199]

Good health literacy is often not a priority for busy Australian women. The limitations of improving health literacy are similar to those of providing health and wellbeing information — it relies upon women having the time and the inclination to take them up. It is encouraging to see the Australian government taking action to place health literacy as "a core element" of the new National Curriculum for schools.[200] It is hoped that this will not simply focus on facts but teach students to critically analyse health information and apply it (or not) to their lives.

Health literacy could also be promoted through GP and hospital libraries.[201, 202] Such libraries could serve as portals for individuals to access information in a variety of formats from a variety of sources. Small Australian pilot trials of such libraries showed women were the greatest users, with 98 percent of borrowers finding they had increased their knowledge, decreased anxiety or changed their behaviours in a positive way. The GPs that participated in the trials felt positively towards having the information libraries as they were useful reinforcers of messages, increased patient understanding and assisted in saving consultation time "explaining complex conditions".[203] Practice nurses could assist in developing health literacy, by taking time to

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[193] Torres, R. & Marks, R. (2009). "Relationships Among Health Literacy, Knowledge About Hormone Therapy, Self Efficacy and Decision Making Among Postmenopausal Health." *Journal of Health Communication*. 14(1). Pp.43–55.

[194] Tokuda, Y., Doba, N., Butler, J. & Paasche-Orlow, M. (2009). "Health literacy and physical and psychological wellbeing in Japanese adults". *Patient Education and Counselling*. 75. Pp.411–417.

[195] *Ibid.*

[196] *Ibid.*

[197] von Wagner, C., Knight, K., Steptoe, A. & Wardle, J. (2007). "Functional heath literacy and health promoting behaviour in a national sample of British adults". *Journal of Epidemiology and Community Health*. 61(12). Pp.1086–1090.

[198] *Ibid.*

[199] *Ibid.*

[200] National Health and Hospitals Reform Commission. (2009). *A Healthier Future for All Australians Final Report*. Commonwealth of Australia; Canberra.

[201] Charlton, I. (1997). "Usefulness of a patient library in a suburban general practice", *Medical Journal of Australia*. 167. Pp. 579-581.

[202] Harris, R. & Wathen, N. (2007) "'If My Mother Was Alive I'd Probably Have Called Her.' Women's Search for Health Information in Rural Canada". *Reference and User Services Quarterly*. 47(1). Pp.67–79.

[203] Charlton, I. (1997). "Usefulness of a patient library in a suburban general practice". *Medical Journal of Australia*. 167. Pp.579–581.

assess women's needs and identifying relevant information with the women.[204,205] Such interactive health information programs may begin to help fill the need women have voiced in sorting the multitude of information.

CONCLUSION

Significant research discussed in this literature review highlights the barriers that women experience in accessing health and wellbeing information, and the importance of addressing these. While brief, it is hoped this literature review will stimulate discussion about how this could be done in the Australian context. Women's health literacy and access to health and wellbeing information is vital for reducing the burden of preventable and chronic illness on the health care system and optimising women's health and wellbeing.

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204 Nutbeam, D. (2000). "Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century". *Health Promotion International*. 15(3). Pp.259–267.

205 Nutbeam, D. (2009). "Building health literacy in Australia". *Medical Journal of Australia*. 191(10). Pp.525–526.

SURVEY FINDINGS

1.1 DEMOGRAPHIC CHARACTERISTICS OF THE SURVEY RESPONDENTS

There were 674 complete survey responses. This sample represents .5% of the female population over 15 years in the ACT.[206]

Age: Twenty-two percent (n=144) of survey respondents were 15-29 years; 23% (n=145) were 30–39 years; 21% (n=135) were 40–49 years; 20% (n=128) were 50–59 years; and 14% (n=89) were 60 years or older. The age distribution of women in the ACT is 22.9% 15–29 years; 15.4% 30–39 years; 15.2% 40–49 years; 13.2% 50–59 years; and 14.9% 60 years or older.[207]

Educational Attainment: Seventeen percent (n=109) of respondents had completed a high school qualification; 81% (n=522) had completed some post high school study (Certificate I–IV, Diploma, Advanced Diploma, Bachelor’s Degree, Postgraduate Degree, Diploma or Certificate).

Household Composition: Twenty-one percent (n=137) of respondents were single (including separated or widowed) with no dependent children; 31% (n=197) were partnered with no dependent children; 8% (n=53) were single (including separated or widowed) with dependent children; 33% (n=209) were partnered with dependent children; and 7% (n=46) listed their household composition as other.

Household Income: Sixteen percent (n=96) of respondents reported a total household income of $41,599 or less; 34% (n=199) reported a total household income between $41,600 and $88,399; and 50% (n=292) reported a total household income of $88,400 or more.

Location: Eighteen percent (n=118) of respondents were living in Canberra’s Inner North; 7% (n=45) were living in Canberra’s Inner South; 17% (n=117) were living in Belconnen; 11% (n=74) were living in Gungahlin or Hall; 15% (n=98) were living in Weston Creek or Woden; 22% (n=146) were living in Tuggeranong; and 7% (n=42) were living in Queanbeyan, Jerrabomberra or Other NSW.

Work Status: Fifty-six percent (n=362) of respondents were working full-time; 23% (n=150) were working part-time or casual; 11% (n=71) were not working (studying full-time, not currently in paid employment, or full-time mother or carer); and 9% (n=60) were retired.

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[206] Australian Bureau of Statistics, (2006), *Census of Population and Housing: Age by Sex - Australian Capital Territory*, ABS Cat. No. 2068.0, Australian Bureau of Statistics; Canberra.

[207] *Ibid.*

Aboriginal or Torres Strait Islander: Of the survey respondents, 6% (n=39) identified as Aboriginal or Torres Strait Islander. There are 1256 Aboriginal or Torres Strait Islander women in the ACT who make up a total of 0.9% of the female population 15 years and older.[208]

Caring Responsibilities: Of the survey respondents, 11% (n=76) said that they have caring responsibilities for someone other than a dependent child. There are 15,648 women in the ACT who provide unpaid assistance to a person who is not their dependent child who make up 11.7% of the female population 15 years and older.[209]

Culturally and Linguistically Diverse: Of the survey respondents, 15% (n=102) reported that they are from culturally or linguistically diverse backgrounds. There are 41,553 women in the ACT who were born overseas who make up 31% of the female population 15 years and older.[210]

Women with Disabilities: Of the survey respondents, 30% (n=199) reported that they have a disability or a long-term or chronic health condition. There are 5,373 women in the ACT who require assistance due to a disability or a long-term or chronic health condition, making up make up 4.0% of the female population 15 years and older.[211]

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[208] Australian Bureau of Statistics, (2006), *Census of Population and Housing: Indigenous Status by Age by Sex - Australian Capital Territory*, ABS Cat. No. 2068.0, Australian Bureau of Statistics; Canberra.

[209] Australian Bureau of Statistics, (2006), *Census of Population and Housing: Unpaid Assistance to a Person with a Disability by Age by Sex - Australian Capital Territory*, ABS Cat. No. 2068.0, Australian Bureau of Statistics, Canberra.

[210] Australian Bureau of Statistics, (2006), *Census of Population and Housing: Country of Birth of Person by Age by Sex - Australian Capital Territory*, ABS Cat. No. 2068.0, Australian Bureau of Statistics, Canberra.

[211] Australian Bureau of Statistics, (2006), *Census of Population and Housing: Core Activity Need for Assistance by Age by Sex - Australian Capital Territory*, ABS Cat. No. 2068.0, Australian Bureau of Statistics, Canberra.

1.2 SOURCES OF HEALTH AND WELLBEING INFORMATION

Unless otherwise specified, the survey findings were consistent across the different demographic groups. Survey findings for Aboriginal and Torres Strait Islander women, carers, older women, CALD women, women with disabilities and young women will be detailed in the companion reports.

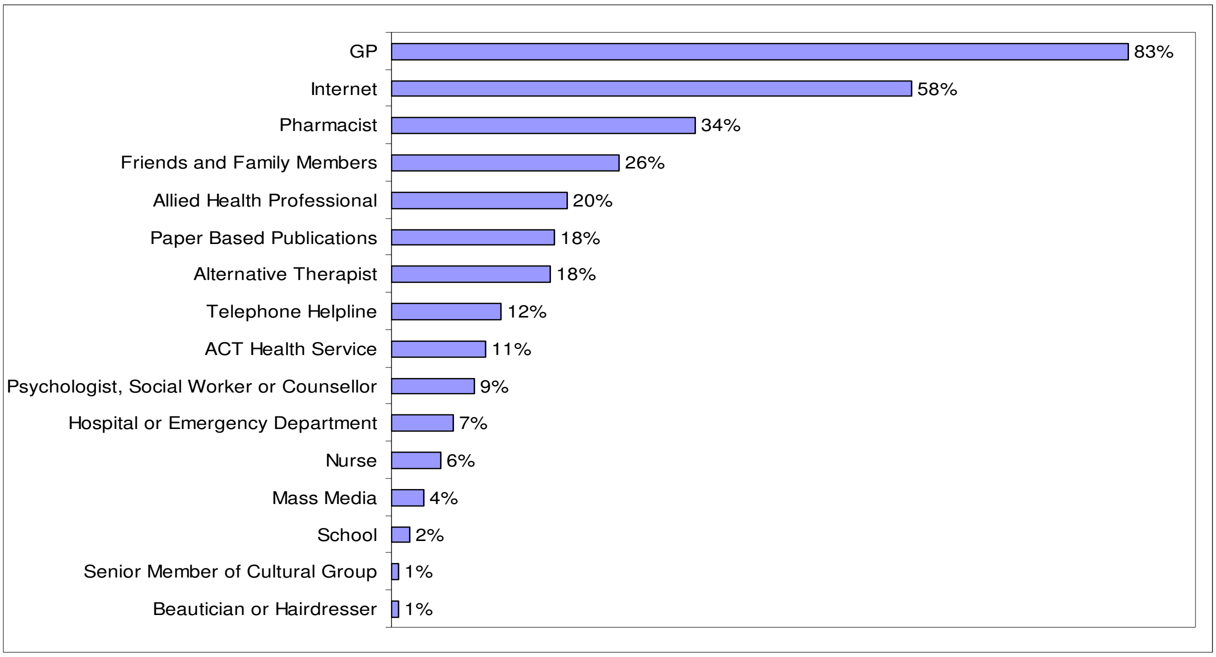
1.2.1 Who Respondents Seek Information For

Ninety-two percent (n=613) of respondents reported looking for health and wellbeing information for themselves. Fifty-three percent (n=354) reported seeking for information for their partner, 48% (n=322) for their children, 30% (n=200) for their friends, 29% (n=197) for their parents, 26% (n=175) for their other family members, 16% (n=107) for other members of their community and 8% (n=50) for another person.

1.2.2 Where Respondents are Most Likely to Obtain Health and Wellbeing Information

Eighty-three percent (n=543) of respondents reported that they are most likely to obtain health and wellbeing information from their GP. This was followed closely by the internet, which is the most likely used information source for 58% (n=383) of respondents. After this, the rates of usage drop by almost half to pharmacists for 34% (n=224) of respondents, family members and friends for 26% (n=168) of respondents, allied health professionals for 20% (n=129), paper based publications for 18% (n=120), alternative therapists for 18% (n=117), and telephone helplines 12% (n=80).

Figure 1: Where respondents are most likely to obtain health and wellbeing information



1.2.3 Actual and Preferred Use of Information Source

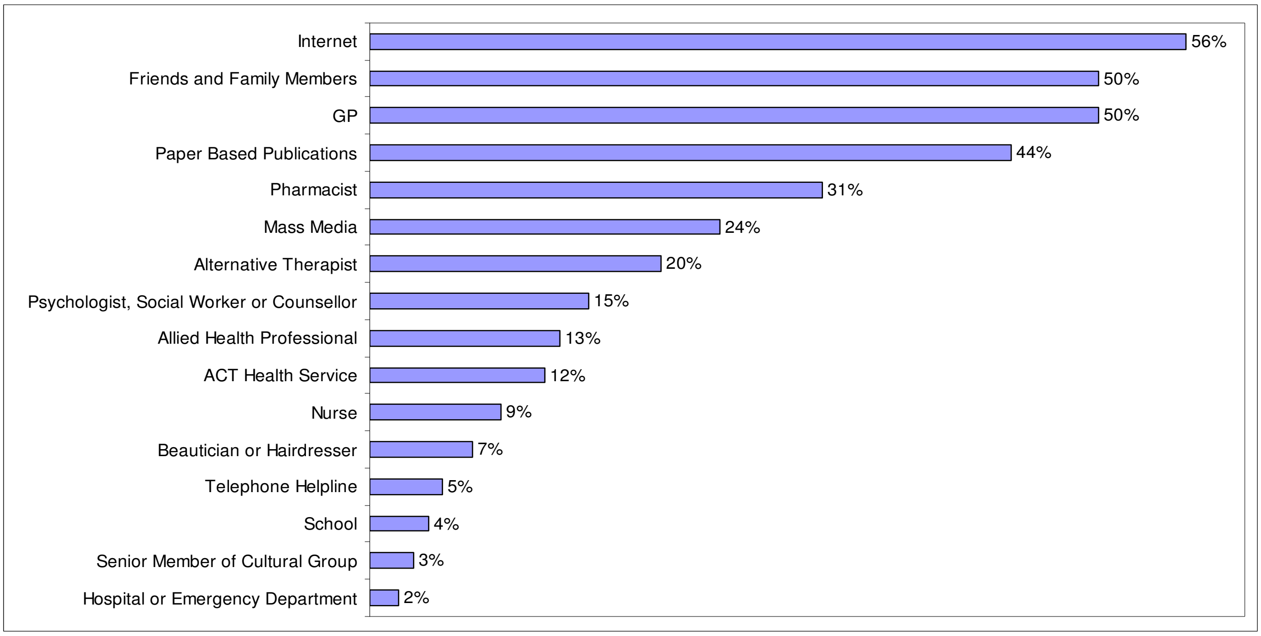
Respondents were asked to identify what type of information they had sought from which information source in the twelve months prior to completing the survey. They were also asked which source they would prefer to seek that information from. Information was broken down into three types: information about general wellbeing; information about minor medical conditions; and information about serious or chronic medical conditions.

1.2.3.1 General Wellbeing Information

In the twelve months prior to completing the survey, the sources most commonly used for general wellbeing information were the internet used by 56% (n=378) of respondents, followed by friends and family members and GPs, which were each used by 50% (n=339) of respondents.

The following graph shows the percentage of respondents who sought general wellbeing information from each source.

Figure 2: Use of source for general wellbeing information in twelve months prior to survey completion



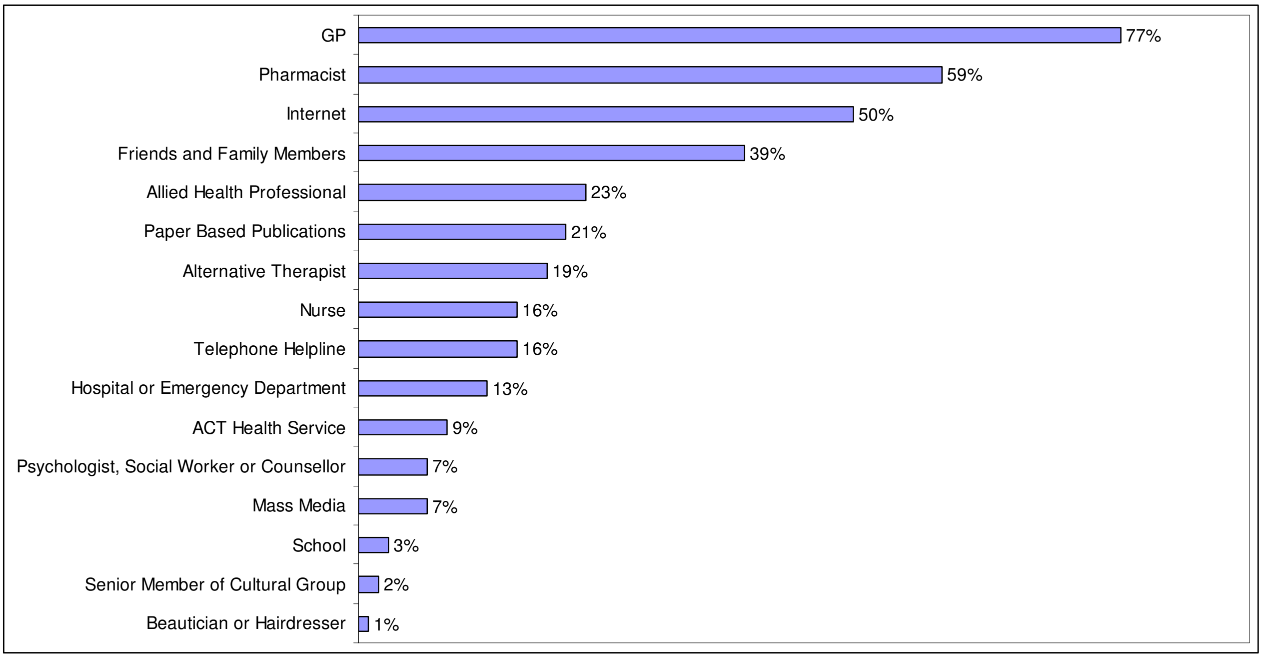
While respondents most commonly used the internet, friends and family members and GPs for general wellbeing information, the three most preferred sources were the internet, preferred by 42% (n=286) of respondents, followed by GPs, preferred by 32% (n=215) of respondents, and then paper based publications, preferred by 17% (n=115).

1.2.3.2 Minor Medical Conditions

In the twelve months prior to completing the survey, the sources most commonly used for information about minor medical conditions were GPs at 77% (n=522) of respondents, followed by pharmacists at 59% (n=394) of respondents, and the internet at 50% (n=335).

The following graph shows the percentage of respondents who sought information about minor medical conditions from each source.

Figure 3: Use of source for minor medical condition information in twelve months prior to survey completion



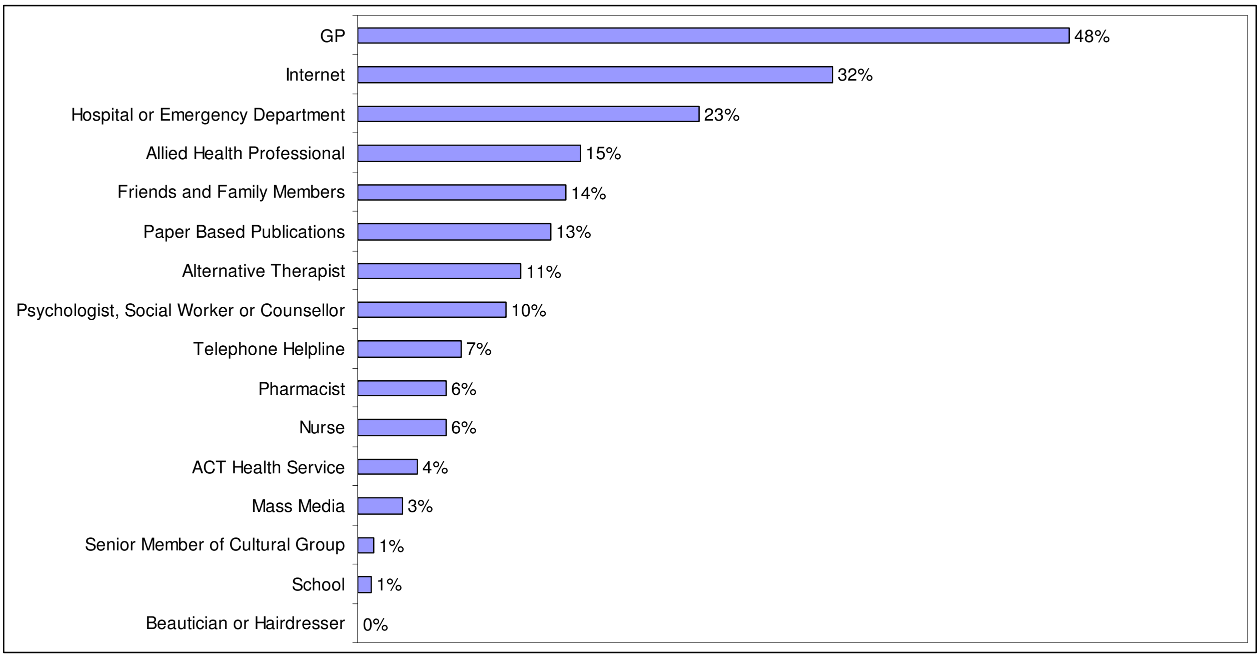
The sources that respondents most commonly used, and most preferred to use for information on minor medical conditions were the same. However, the order in which they were most commonly used — GPs, pharmacists and then the internet — was different to their order of preference, which was GPs, preferred by 62% (n=415) of respondents, the internet, preferred by 28% (n=191) of respondents, and pharmacists, preferred by 14% (n=93).

1.2.3.3 Serious or Chronic Medical Conditions

In the twelve months prior to completing the survey, the sources most commonly used for information about serious or chronic medical conditions were GPs used by 48% (n=321) of respondents, followed by the internet used by 32% (n=214) of respondents, and hospitals or emergency departments used by 23% (n=153).

The following graph shows the percentage of respondents who sought information about serious or chronic medical conditions from each source.

Figure 4: Use of source for serious or chronic medical condition information in twelve months prior to survey completion

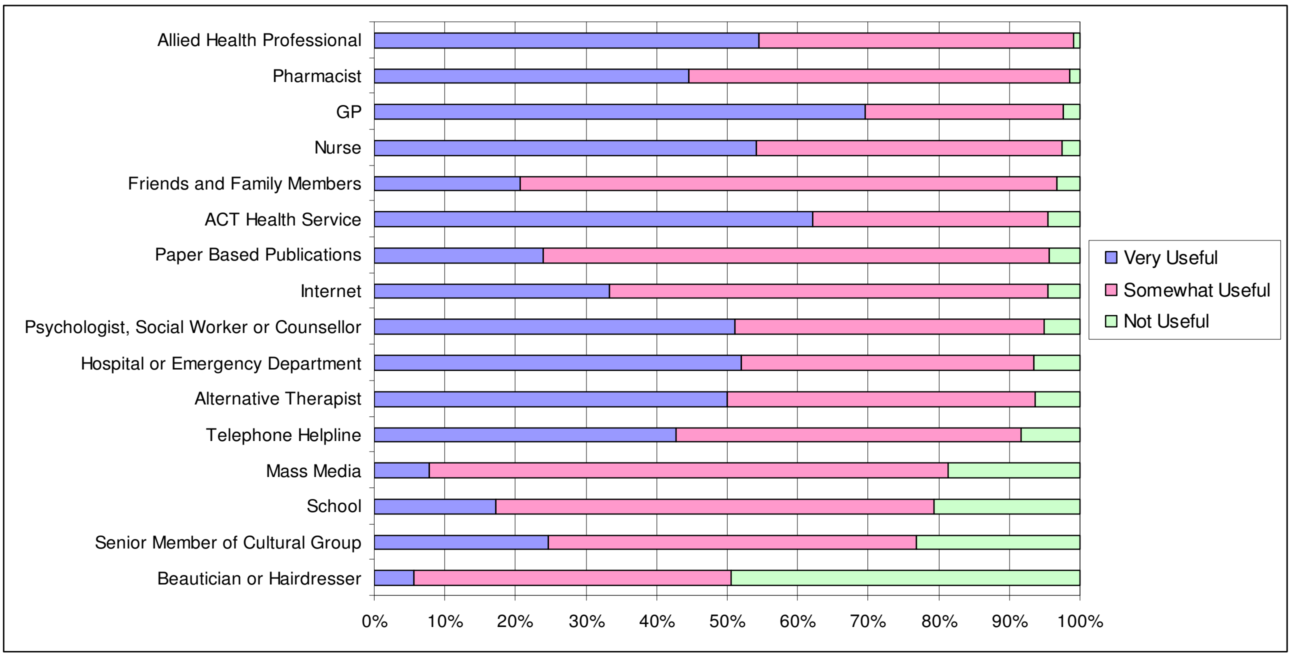


While respondents most commonly used GPs, the internet and hospitals or emergency departments for information on serious or chronic medical conditions, 77% (n=520) reported preferring GPs, 23% (n=152) preferred medical specialists and 14% (n=95) preferred the internet.

1.2.4 Usefulness of Health and Wellbeing Information from Sources

Respondents were asked to assess the level of usefulness of the information they obtained from each source; useful meaning the information that is helpful to individuals and meets their needs. The respondents were asked to identify if the information they obtained was very useful, somewhat useful or not useful. The graph below shows the results for each information source.

Figure 5: Level of usefulness attributed to the health and wellbeing information obtained from sources

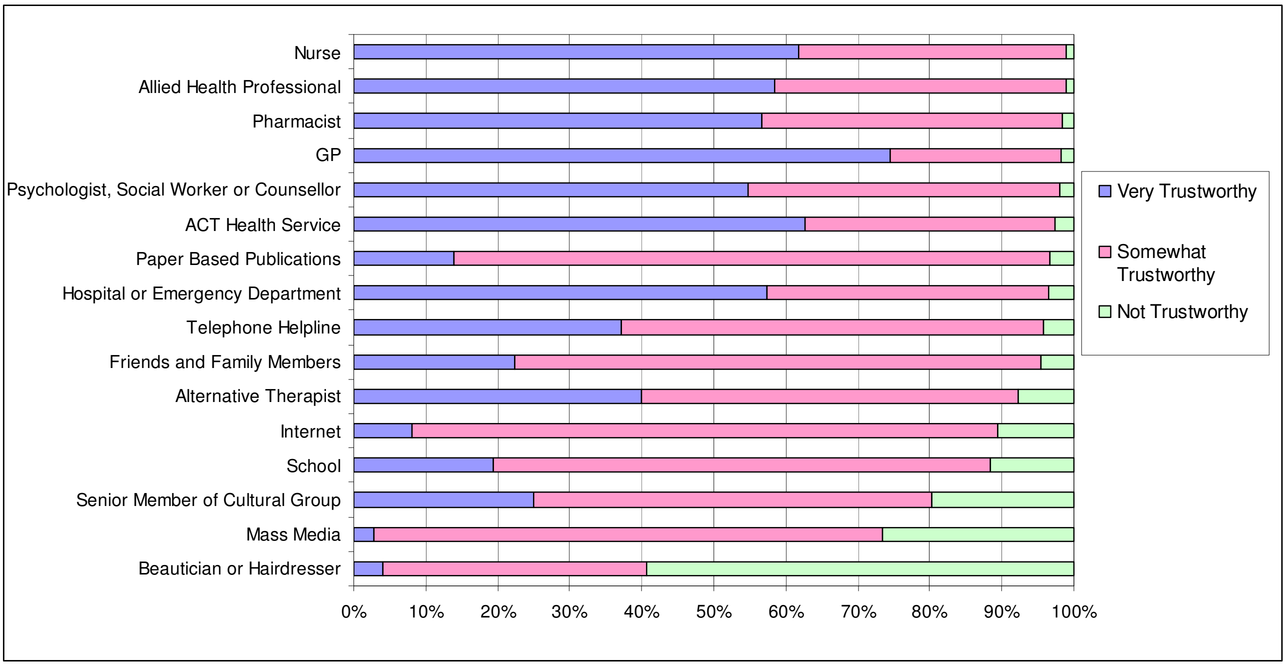


Unsure/don't use responses have been filtered out in order to present the level of usefulness of information from each source only for those respondents who used them. Many chose not to answer the question at all, therefore the figures in the graph represent 100% of those respondents who rated the information source as very useful, somewhat useful or not useful and not 100% of the survey sample.

1.2.5 Trustworthiness of Health and Wellbeing Information from Sources

Respondents were asked to assess the level of trustworthiness of the information they obtained from each source; trustworthy meaning that the information is reliable and/or that the individual has confidence in it. The respondents were asked to identify if the information they obtained was very trustworthy, somewhat trustworthy or not trustworthy. The graph below shows the results for each information source.

Figure 6: Level of trustworthiness attributed to the health and wellbeing information obtained from sources



Unsure/don't use responses have been filtered out in order to present the level of trustworthiness of information from each source only for those respondents who used them. Many chose not to answer the question at all, therefore the figures in the graph represent 100% of those respondents who rated the information source as very trustworthy, somewhat trustworthy or not trustworthy and not 100% of the survey sample.

1.2.6 Contributing Factors for Deciding Where to Seek Information

The five most important factors that respondents reported considering before deciding where to seek health and wellbeing information were:

The source is easily available (suitable waiting times)	61% (n=407)
The information provided is of high quality	55% (n=364)
The source is easily accessible (suitable location)	53% (n=353)
I have already established a trusting relationship with the source	42% (n=281)
The cost is affordable	38% (n=252)

1.3 BARRIERS TO OBTAINING HEALTH AND WELLBEING INFORMATION

1.3.1 Barriers to Obtaining Health and Wellbeing Information from Particular Sources

Alternative Therapists: Of the survey respondents, 72% (n=485) reported that they have considered obtaining health and wellbeing information from an alternative therapist. Being unsure of the quality of information provided by alternative therapists was identified as the most significant barrier, selected by 29% (n=139) of respondents. The high cost of using alternative therapists was identified as the second most significant barrier, selected by 24% (n=116) of respondents. Not trusting the information obtained from alternative therapists was the third most significant barrier for 5% (n=24) of respondents.

Internet: Of the survey respondents, 91% (n=613) reported that they have considered obtaining information from the internet. Being unsure of the quality of the information available on the internet was identified as the most significant barrier, selected by 62% (n=382) of respondents. Not feeling that the information provided to the internet is treated as confidential was the second most significant barrier, selected by 14% (n=85) of respondents. Not trusting the information obtained from the internet was the third most significant barrier for 10% (n=59) of respondents.

Paper Based Publications: Of the survey respondents, 89% (n=599) reported that they have considered obtaining information from paper based publications. Being unsure of the quality of the information available from paper based publications was identified as the most significant barrier, selected by 38% (n=226) of respondents. The cost of buying paper based publications was the second most significant barrier, selected by 9% (n=53) of respondents. Not trusting the information obtained from paper based publications was the third most significant barrier for 2% (n=14) of respondents.

Psychologists, Social Workers and Counsellors: Of the survey respondents, 73% (n=490) reported that they have considered obtaining health and wellbeing information from a psychologist, social worker or counsellor. The high cost of using psychologists, social workers or counsellors was identified as the most significant barrier, selected by 23% (n=114) of respondents. Being unsure of the quality of information provided by psychologists, social workers or counsellors was identified as the second most significant barrier, selected by 13% (n=63) of respondents. Not having access to psychologists, social workers or counsellors was the third most significant barrier for 2% (n=10) of respondents.

Telephone Helplines: Of the survey respondents, 55% (n=368) reported that they have considered obtaining health and wellbeing information from telephone helplines. Being unsure of the quality of information provided by telephone helplines was identified as the most significant barrier, selected by 27% (n=100) of respondents. Not feeling that the information provided to the telephone helpline is treated as confidential was the second most significant barrier, selected by 5% (n=18) of respondents. Not trusting the information obtained from telephone helplines was the third most significant barrier for 3% (n=11) of respondents.

1.3.2 Gaps in Health and Wellbeing Information

Of the survey respondents, 13% (n=89) reported there was health and wellbeing information they were not able to obtain.

This includes information about specific health conditions; comprehensive information on specific health issues; information that is neither too basic nor too difficult; personalised information that is not costly; thorough diagnoses; product information; information about where to access female service providers; age related health information; information about chronic pain; preventative health information; access to personal records, including from parent countries; sexual and reproductive health information; mental health information; and information about integrative health treatments.

Some comments from the survey included:

> *I think that sexual health issues for women over about 30 - 40 are more difficult to get information advice on. My GP appears shocked that I have an active sex life, I'm 47 and until recently single but with casual partners. It's embarrassing to discuss with someone so much younger who seems to think I'm past it. He even assumed I was post menopausal when the change hasn't even started for me yet!*
>
> *I would prefer to have a female GP but as my long-standing GP retired from practice I was unable to locate another female GP in the Belconnen area who was taking patients.*
>
> *Getting objective information about possible side effects or risks for gynaecological procedures seems to be very difficult. I know my doctor isn't telling me the full story, but I don't know where else to get information and it's embarrassing to ask friends for such personal advice.*
>
> *Hard to know where to go for general information on women's issues such as menopause - lots of anecdotal and general information about, but accuracy etc is always an issue for me.*
>
> *It seems that not all Health Professionals are of the opinion that an individual has a right to all the information about themselves and the impact upon them. Too often it is left to the individual to find out what questions they need to ask to get the information.*
>
> *I find it difficult to obtain info which reflects a holistic approach to my h&wb, rather I end up having the immediate issue resolved rather than a search for underlying issues.*

1.3.3 Barriers to Obtaining Health and Wellbeing Information

Of the survey respondents, 41% (n=273) reported experiencing significant barriers in obtaining the health and wellbeing information they require.

The three most common reasons given for this were: the high cost associated with some information sources; not having enough time to seek the required information they; and not being able to get into see a health professional due to waiting times.

> *Barriers are the inability to get a doctors appointment at a convenient time, location and without ridiculous waiting periods. Minor ailments or general feelings of malaise are left untreated or ignored until more severe symptoms emerge because it is simply too hard to get an appointment.*

Some other common barriers identified by the survey respondents were having to rely upon a GP because of not knowing where else to get reliable information; “lack of truly reliable sources”; embarrassment around particular health issues; lack of understanding from health professionals; and “lack of trusted and appropriate service for Aboriginal women in ACT”.

Other comments from the survey included:

> *Access to relevant information without paying a high cost of going to the GP etc. While the cost is not a particular problem of mine, I often wonder what I would do/what other options there are, if I didn't have the necessary funds to do what I needed to do.*
>
> *I am gay, and find it difficult to go to new health professionals without fearing that I will be judged or given different treatment because of this. I find that either people become very cold, or make assumptions of who I am and what I need/want based on my sexuality rather than what I am saying or what conditions I am presenting with.*
>
> *Lack of clear information about entry points and pathways. eg. I recently became pregnant for the first time, and found it hard to get comprehensive info about all options available. I think people fall into the natural or medical care models depending purely on whether their first appt is with a GP or a midwife. They don't have info to make an informed decision of all options.*
>
> *'Shame' factor. Not knowing where to go for particular kinds of assistance.*
>
> *Deciding on accuracy of information received and relevance to me when obtaining information about more general topics as above and having access to relevant professionals*
>
> *Understanding where exactly to go to get the best information relating to the specific concern*

1.4 BARRIERS TO ACCESSING GENERAL PRACTITIONERS

1.4.1 Respondents Who Do See a General Practitioner

Of the survey respondents, 94% (n=634) reported seeing a GP.

The three most significant barriers to accessing GPs identified by respondents were:

Difficulties getting in to see a GP due to waiting times	52% (n=316)
The high cost of seeing a GP	40% (n=242)
Not being able to find a GP who bulk bills	20% (n=124)

In terms of the gender preferences for GPs, 7% (n=46) of respondents always insist on seeing a female GP, 45% (n=275) prefer a female GP but will see whoever is available, 46% (n=285) do not care if the GP is male or female, and 2% (n=10) prefer a male GP but will see whoever is available. Two respondents (0.3%) insist on seeing a male GP.

In terms of preference for the cultural background of GPs, 2% (n=13) of respondents insist on seeing a GP from their own cultural background, 28% (n=171) prefer a GP from their own cultural background but will see whoever is available, 69% (n=427) do not care what cultural background their GP is from, and 2% (n=9) prefer not to see a GP from their own cultural background but will take whoever is available.

In terms of GP location, 28% (n=172) of respondents always insist on using their local GP, 28% (n=173) prefer to use a local GP but will go wherever they can get an appointment, and 44% (n=276) do not mind travelling if they find a GP that they like.

1.4.2 Respondents Who Do Not See a General Practitioner

Twenty respondents (3%) reported that they do not see a GP.

The three main reasons provided for not seeing a GP were:

Not trusting the information they get from GPs	45% (n=9)
Not being able to find a GP taking new patients	40% (n=8)
The high cost of seeing a GP	40% (n=8)

FOCUS GROUP FINDINGS

2.1 INFORMATION SOURCES

The focus group discussions concentrated on health and wellbeing information sources where there were issues for the participants. If a source was not discussed in great detail it was either because the participants did not use it or because they were satisfied with it. As a result, there will be some information sources for which there is little written discussion.

2.1.1 General Practitioners

The research showed that GPs are the most preferred, most used and most trusted source of health and wellbeing information for women in the ACT. For this reason the discussion about GPs is a complex one and takes place within the confines of national changes in primary healthcare, GP availability in the ACT, and the expectations of health care consumers.

That "the community places a great deal of trust in doctors" is an understatement when it comes to women in the ACT, with 82.5% (n=543) of respondents reporting that they are most likely to seek health and wellbeing information from a GP, and 74.5% (n=494) reporting that they find GPs very trustworthy.

Many respondents throughout the study indicated that, despite the difficulties they sometimes experience in accessing GPs, they prefer and trust them for health and wellbeing information. In response to this, one respondent of the follow up survey for women with disabilities said…

> *Yes, in most cases GPs are properly trained, have access to up to date information, and are able to answer my questions, and give me a measure of confidence [that] I have been seen by a properly trained physician.*

For many other participants the preference is partly because of the perception that "you do need to have that history with a GP to get onto further things in the medical system", and partly because they had explained their history to and built a relationship with their GP. The participants of the older women's focus group expressed a desire to have a constant and caring relationship with a health care provider. They seemed to invest energy into these relationships, as is demonstrated by the following exchange…

> *Participant One: I'm 55 and I don't remember ever, ever having a GP who I felt close to or who I could trust and I've had both male and female… Even my vet looks after my pets with more care and attention…Therefore I've built up this barrier towards my doctor and [when] she moved…she's been my doctor for about six years, I breathed a sigh of relief.*
>
> *Participant Two: But you had a choice to change her. I mean, you don't have to go to her"*

> *Participant One: Yeah, but I've been quite sick over the past five years and sometimes those choices are too hard.*
>
> *Participant Three: You don't want to start another relationship.*

This exchange, coupled with the rates of preference for GPs as an information source reported by the survey respondents suggests that the relationship built between a woman and her GP is important to her general wellbeing and health. Whether the health professional with whom a woman builds a relationship needs to be a GP is questionable, and will be discussed in greater depth later in this report.

There were a few participants throughout the focus groups who insisted on having a female GP. "There's an understanding from a female to another female. I think the approach is different, perhaps." This participant from one of the young women's focus groups, as well as several from the mental health consumers focus group, thought that only a female GP could provide a safe and comfortable environment to explore their health and wellbeing needs. Participants of the CALD women's focus group acknowledged that the shortage of female GPs and specialists in the ACT limited women's choices and in the case of some of the women in their communities, prevented them from seeking health treatment at all.

A more common view among the participants was that they would be happy to see a male GP for general health issues but would insist upon a female practitioner for sexual, reproductive and mental health. A participant of the older women's focus group summed this up…

> *If it's the flu shot or a rash or something, I don't care. But if it's anything to do with your emotions or your private bits then definitely female. They [male GPs] just don't see it the same way we do. I can say something to another woman and she instantly knows exactly what I'm feeling and where I'm coming from. You say it to a man and they look at you as it you're stupid…you haven't got time to go sifting through to find the one in a million whose gonna be different.*

Sheer pragmatism was demonstrated in the preferences of some, with one participant from the older women's focus group arguing, "it boils down to who you can see as quickly as possible".

That a GP was sensitive of women's needs was more important than the GP being female for a number of participants throughout the focus groups. They felt that women practitioners could be as insensitive as the most insensitive male practitioner, as highlighted by a participant of the older women's focus group…

> *that's not to say that every female doctor has a good bedside manner and is supportive, they're not. I had one for five years who…came across as very uncaring.*

Several of the participants in the young women's focus groups had experienced considerable difficulty in finding a GP who understands young women's health issues. As a result they felt that quality of the service mattered a great deal more than the gender of the practitioner. They valued a GP who had time to listen, was not judgemental, and provided an affordable service. One participant added "I would really like someone who doesn't dismiss your problems…" to which another participant agreed, "when they do that it just makes you feel worse because it makes you feel like you're complaining about nothing and then you feel pathetic." One participant added that a GP should not reduce a woman's health concerns to hyper-emotionality or pre-menstrual stress.

The participants of the mental health consumers and Aboriginal women's focus groups were also more concerned with gender sensitivity than with the gender of the practitioner. These participants listed the following characteristics of a gender sensitive GP: tact; ability to discuss issues with the appropriate gentleness; manners; being able to know how things need to be said to different clients; and apologising for waiting times. Some participants felt that some GPs spoke down to them, making them feel "dumb" or "unwelcome". The language adopted by GPs in consultation is a significant barrier for many participants, one of whom commented that "some doctors are only able to communicate at a medical level, and they forget that us ordinary people don't use medical terms".

A participant of the older women's focus group summarised the principles of gender sensitive health service delivery by using an example of the way her vet treats her three pets. He remembers her and her husband's name as well as the names and conditions of the three animals and asks after the animals even if he is not treating them. He also prepares long term health care plans for each of the animals, encouraging the participant to think about their long-term needs and risks. She concluded…

> *Why can't I clone him and whack him in the GP's office…Now is this just a personal thing with this guy or is there something in the training that the vets do that somehow seems to meet the needs well on a personal level, on an expertise level.*

Several participants of the Aboriginal women's and CALD women's focus groups agreed that if they had the option to see a health professional from their own cultural background they would; while others thought it as important to have culturally sensitive practitioners, regardless of cultural background, as having a practitioner from their community. Indeed it was the cultural ignorance or insensitivity that angered the participants. One participant explained, "GPs are more concerned about health than cultural background…they can see now, at the moment. Not yesterday and not last year." By this she meant that many GPs do not acknowledge the impacts of culture upon health and wellbeing, or the affects of migration. Another participant expressed frustration at being spoken to inappropriately by both practitioners and the staff in the surgeries…

> *I don't know what it is with staff that they think that if you don't answer them they have to shout at you. And it is because you don't understand what they're saying, not because you're deaf.*

One participant highlighted that there can be confidentiality issues when seeing a health professional from one's own community. She said that providing she found a health service and professional who cared well for her, it did not matter whether they were from her cultural background or not.

A participant from the CALD women's focus group was particularly angry about her experience with GPs and named several significant barriers. She said that because GPs are almost always running late, clients spend quite a long time waiting before their appointment, often with sick and grumpy children. If the client wants to find out if the doctor is running late they must get up and ask the receptionist. The GPs are then very strict with their time, giving just ten minutes on the standard fee before raising it. She concluded that "it's actually quicker for us to ring our family back in the UK" and ask them about symptoms and treatment options. She continued that much of the time GPs are checking symptoms on what appears to be internet search engine. She concluded that clients are…

> *better off doing that at home yourself…Cause first of all, you've sat in the waiting room for hours, you've gone in, you've paid your 60 to 80 bucks and then you've kind of been rushed out of that door because they're waiting to get the next patient in, you know, so it's not worth it half the time.*

This participant said that she only goes to see a GP when she needs a referral.

A participant from the older women's focus group was equally disenfranchised by her experience with GPs and said she no longer considered them a useful source of health and wellbeing information. However she did qualify this by saying it is…

> *not because I don't want that person, but because I just can't possibly think of anyone who could fulfil that role for me in an understanding and sensitive way. I told you my GP had moved and I'm using her boss now and he'll do anything I tell him…He just writes out this stuff and hands it to me and hardly says anything. I think, well ok, it's handy to have one [a GP] like that, but I feel like I'm 'number 48 come in now'.*

A few participants from the young women's focus groups were equally dissatisfied. They felt that GPs do not have time to look at a client's health issue in the context of their background, medical history and current circumstances. "They [GPs] deal with the problem that you talk about, but not with the problem that's within." One participant said that she would value a GP who could "spend that extra fifteen minutes asking questions…to see if there is anything else behind the scenes". She added that she wants to walk away from a consultation "feeling like I've been listened to, I've been understood, that action has been taken, and…[of] having been taken care of." She wanted a GP service that could provide her with "all sorts of information from general health matters to…your wellbeing, mental health, sexual health…pregnancy", but worried that such services do not exist in the ACT as many GPs “don’t have enough time to fully get to know you, assess all that about your life.”

Despite these stories about negative experiences with or perceptions of GPs, many participants expressed sympathy for the constraints within which they work.

> *I don’t think that’s got to do with the GP him or her self, but it’s got to do with the system as a whole. They’re just understaffed, don’t have time and have to see so many clients a day.*

2.1.2 Pharmacists

Pharmacists were only discussed in the CALD women’s focus group as a source of information that could potentially take on some of the responsibilities traditionally held by GPs. One participant said that she is more likely to see her pharmacist than any other active source of information. She finds it inconvenient that she cannot get prescriptions and sickness certificates from them, as this would almost eliminate her need to see a GP. Other participants agreed that if a pharmacist could fulfil these functions, they would be happy to not see a GP.

2.1.3 Allied Health Professionals

Allied health professionals were important to the respondents of the survey, with 19.6% (n=129) saying that they are most likely to seek health and wellbeing information from an allied health professional. However they did not come up during any of the focus group discussions.

2.1.4 Alternative Therapists

Alternative therapists were not routinely discussed throughout the focus groups, with the most vibrant discussions taking place in the Aboriginal women’s focus group. The participants thought that many people, irrespective of race, gender or age, would prefer alternative medicine to medication, but that it is a matter of privilege due to cost. Cost and access were identified as the two biggest barriers to utilising alternative health therapies. Participants acknowledged that they may need to save for a month for an appointment with a naturopath, not taking into consideration the tonics or medicines that they may recommend.

2.1.5 Hospitals and Emergency Departments

Many participants of the focus groups revealed that they find themselves in emergency departments when they are unable to access a GP. Usually this is because they require a GP after hours but sometimes it is because they cannot afford to access one during business hours.

The survey respondents that identified as Aboriginal or Torres Strait Islander reported using hospitals or emergency departments for health and wellbeing information more than any other group. The participants of the Aboriginal women’s focus group were asked for their thoughts about this. One participant said that she is likely to go to the emergency department when she requires a GP outside of business hours. A second agreed that the reasons Aboriginal women take themselves or their children to the hospital are lack of access and money. For example, even if a patient is only paying the difference for their doctor's appointment, this may mean that they cannot afford their prescription.

Several participants in both the older women's and CALD women's focus groups said that they would call an ambulance or go to the emergency department if they required medical treatment during the night.

2.1.6 Psychologists, Social Workers and Counsellors

Participants of the mental health carers' focus group discussed at length psychologists, social workers and counsellors as an information source. They discussed the discrepancy between the understanding they had of these health professionals as information providers, and the idea the professionals had of themselves. One participant explained the difficulties she encountered in assuming that the psychiatrist would fulfil the role of information provider. She asked, "I mean I'm not sure what their role is, is their role just to hand out the medication and that's it?" Another participant responded…

> *I must say the social workers at the hospital seem to be much more willing to play that sort of role…I find that social workers are a really good half way house...they seem to be aware of what the shortcomings are and our side of the picture…*

For example, she said social workers know that having a home is integral to good health and that people with mental health issues are susceptible to homelessness. Social workers have a much greater knowledge about Centrelink, legal services and other institutions that affect health in its broader definition.

Several participants of the young women's focus groups had used or sought information from a psychologist, social worker or counsellor, but spoke about "being looked upon as a lost cause." Confidentiality was the first major theme to emerge in the discussions and is one of the most significant concerns for young women generally. Participants felt that schools and school counsellors regularly violated confidentiality. The first example given was when a student needs to see a counsellor or youth worker, a note is sent to the student's class and is sometimes read out by the teacher. The participants felt this to be a serious breach of confidentiality and a stunning example of insensitivity. The second example was that counsellors may "force" mediation between a client and other students, which can make the situation more difficult for the client. One participant felt that school counsellors act in what they consider to be the best interests of the client with or without the client's consent. She added "they think because it's a school they don't need to follow confidentiality".

The participants also cited examples where they felt community and government counselling and psychological services within the ACT had violated their confidentiality. One participant gave the following example…

> *She [the counsellor] always asks me 'do you want me to keep this away from your parents, your mum' and I'll say 'yeah don't tell her' and then she'll always call her up straight away and ask her all these things about me and tell her everything, which I asked her not to.*

The second major theme to emerge in the young women's focus groups was not being able to obtain thorough or relevant information about mental health. One participant shared a story about consulting a psychiatrist. She said the focus remained on giving a diagnosis for her depression, rather than providing information about her illness, management strategies or treatment options…

> *She [the doctor] referred me to a psychiatrist, and I saw the psychiatrist and she said… 'I think you might be depressed', and I'm like, I know that, I've been diagnosed with it many times, I want to know how to stop it, how to help it…*

2.1.7 Nurses

The focus group participants did not raise the topic of nurses for discussion. However, the topic of practice nurses was introduced in each group by the researcher, which garnered some interesting insights from participants.

One respondent of the follow up survey for women with disabilities said that nurse practitioners would not be able to fulfil any of the functions of the GP because "they are not as qualified." This was the only time this view was expressed.

Several other participants felt, with a little reluctance, that nurse practitioners could be useful in some circumstances. One participant from the mental health consumers' focus group said…

> *It depends what it is about. If it's that I've got the flu, or a sore throat, or a chest infection or something then yeah. It depends, it depends what it is. But then you run the risk of what if it is something more serious.*

Another respondent from the follow up survey for women with disabilities felt that nurse practitioners and GPs could be of benefit to her for different health issues…

> *You have to be analytical, and use the right person at the right time. [For example] the nurse could give me better information about pressure sores and continence supplies, but the GP would give me better information about my kidney failure.*

Another respondent felt that in some cases, such as issuing medical certificates, nurse practitioners would be beneficial. She felt that this would overcome the problem of not being able to get an appointment with the doctor on the day it is needed. However, she added that nurse practitioners would "never be a substitute for sufficient numbers of properly trained physicians."

It was a common view throughout the focus group that a nurse could fulfil the role of the GP as the first point of contact for women seeking information. Many participants said that a nurse practitioner could be a woman’s initial point of contact and supply her with information about options. The participants of one of the young women’s focus groups felt that nurses were qualified to provide the health and wellbeing information that young women need. Participants of the CALD women’s focus group commented that they would be happy to see a nurse practitioner rather than a GP, especially for medical certificates and prescriptions.

Participants of the older women’s focus group commented that a nurse practitioner could easily undertake many of the functions of GPs, but felt that GPs are generally unwillingly to allow nurse practitioners to do this and continue to speak out publicly against them. The participants felt that this conflict creates confusion in the community, causing women to doubt the qualifications of nurse practitioners.

2.1.8 ACT Health Services

The participants of the focus groups did not discuss ACT health services in great depth except to say that they were satisfied with them.

The Women’s Health Service was the most widely discussed service in the focus groups. The participants of the young women’s, older women’s and CALD women’s focus groups reported using this service and finding it very useful.

2.1.9 Internet

The WCHM study has demonstrated that in the ACT, age, employment, income or educational attainment make little difference to the high rates of internet use for health and wellbeing information. These findings are similar to those of the WHV study of women as health information seekers conducted in 2002, which found the internet was rapidly surpassing other mediums as a source of health information.[212]

The internet was discussed in each of the focus groups in order to better understand how women use it and what they use it for. The majority of participants in every focus group use the internet to obtain health and wellbeing information. They use the internet for a range of reasons, not all of which are consistent across the focus groups, which is why the reasons are proffered for each of the groups.

Participants of the young women's focus groups said they use the internet to check symptoms; research illnesses or conditions; and follow up advice from health professionals and friends. Not all participants of the focus groups use the internet so broadly. A couple use it only to direct themselves to health services or professionals within the ACT, or to find basic information that they then follow up with a health professional.

Many participants of the CALD women's focus group reported using the internet to self diagnose; self treat; seek information about diet and exercise; keep abreast of alternative therapies; keep up to date with current health issues; and to find information about prescribed medicines. One participant gave an example of a health centre in Auckland she frequently emails to get information for women in her community.

One of the respondents from the follow up survey for women with disabilities said she uses the internet to locate information about bullying and stress, and to find health professionals.

Participants in the older women's, mental health carers' and mental health consumers' focus groups were less specific about what they use the internet for. One of the mental health carers said that she only uses scholarly sites; otherwise there is "too much garbage" that needs to be sifted through.

Across the focus groups, a Google search was the most common way to search for health and wellbeing information on the internet. Google searches were the method of choice for participants from the young women's, Aboriginal women's, CALD women's and mental health consumers' focus groups, as well as for the respondents of the women with disabilities follow up survey. One participant of the Aboriginal women's focus group said that she only uses Australian websites, which she does by selecting the AU only option on a Google search. When asked about specific health sites, one participant from the mental health consumers' focus group

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[212] Michael Murphy and Barbara Murphy, 2003, *Access to Women's Health Information: A Survey of Victorian Women as Information Seekers*, Women's Health Victoria, Melbourne, 25.

said, “you usually just Google it and you get those sites anyway…I assume it would come up if it was relevant”. A respondent from the follow up survey for women with disabilities said “don’t use specific sites, just Google the term and see what happens.” Wikipedia also proved popular among some young women and CALD women participants, although others were quick to point out the unreliable nature of Wikipedia.

Throughout the focus group discussions many participants said they preferred government or well-known organisations websites, but would access them through a Google search. They also said they would like to know about specific health sites, agreeing that awareness of these sites is low.

Participants of the mental health carers and mental health consumers’ focus groups identified a few specific sites. These included: the Victorian Better Health Channel; Blackdog; NIH website; Sane; Beyond Blue; and the psychiatric page of MedScape. The participants liked these sites as they were considered reliable, reputable and included journal articles regarding recent studies and new trials.

The majority of the survey respondents and focus group participants who use the internet were keen to point out that they do so cautiously as they are aware of the dangers of relying on the information. Several participants, particularly from the young women’s, Aboriginal women’s and older women’s focus groups, said that they would verify information from the internet with a health professional. Many more said that they peruse a number of sites and if the information is consistent they take it as credible. This was by far the most common method used to check the reliability of information. Many participants thought that websites endorsed by government, well-known organisations or respected public figures were trust worthier. Participants of the older women’s and mental health carers’ focus groups felt that common sense and a good dose of scepticism were essential when searching the internet; “there is a lot of quackery out there!” one participant cautioned.

There were a small number of participants in the young women’s and Aboriginal women’s focus groups who did not use the internet at all because they found it completely untrustworthy. One participant of the young women’s focus groups explained that young people sometimes sabotage government operated health websites, which can misinform and be dangerous for others. Other participants added that information on the internet cannot be trusted because it is not exhaustive or personalised and you cannot ask questions. There were also half a dozen participants who did not have access to the internet.

There were a few participants who did not care about the trustworthiness of the internet. Two participants in the CALD women’s focus group and one in the Aboriginal focus group said they did not care about reliability of the information, as long as it served their needs. One participant said that she does not check the source of information.

Overall the internet is regarded highly as a convenient and efficient source of health and wellbeing information, as long as the seeker is savvy in her searching. One respondent of the follow up survey for women with disabilities captured well what many participants expressed: "I think all information about everything is obtainable if you have access to the internet, or have contact with someone who has such access."

2.1.10 Telephone Helplines

The findings from the WCHM survey and focus group discussions were consistent with those of the WHV study, that while helplines do not have a very broad appeal, they are found to be enormously useful by the women who use them.[213]

Several participants had found telephone helplines to be a useful and trustworthy source of health and wellbeing information. They were considered particularly useful for women with young children when they do not have access to a GP, or to verify whether they need to visit a health professional.

The participants of the older women's focus group did not use telephone helplines. They indicated two reasons for this. Firstly, helplines are not adequately promoted, and secondly, they were not sure if they would speak to a real person. Another deterrent was the perception they would not be talking to a local person with a good knowledge of the ACT health system. One participant said that she had tried to access a telephone helpline and had encountered an automated answering machine, which infuriated her to such an extent that she will never consider using them again.

The respondents of the follow up survey for women with disabilities said that telephone helplines are not a suitable option for women with a hearing impairment, as they need to rely on a relay service, which can be slow and cumbersome. One participant said…

> *I really dislike telephones as I am hearing impaired — I face difficulty accessing services that expect people to use telephones to access information — I find I waste a lot of time having to go to offices in person to lipread/make appointments etc.*

Another respondent thought that the reassurance of a voice at the other end of the line might make women feel that they are receiving 'gospel truth' information, which she felt may not be the case, depending on the level of expertise of the person taking the call.

There were mixed responses about how well known telephone helplines are in the community. Participants commonly had awareness of the mental health helplines, and less knowledge about general health helplines such as HealthDirect. Several participants of the young women's focus groups thought that helplines were promoted well within the community.

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[213] Michael Murphy and Barbara Murphy, 2003, *Access to Women's Health Information: A Survey of Victorian Women as Information Seekers*, Women's Health Victoria, Melbourne, 26.

> *I think that the community as a whole have knowledge that these [services] exist and I think you could almost go out into the street and talk to anybody and they would say 'oh yeah I've heard of that'. So in regards to having information out there and having something that is accessible I think that the community at large would be aware of those kind of systems in place.*

As previously mentioned, it was predominantly mental health helplines that participants were familiar with, particularly Lifeline and Kids Helpline. Many of the CALD women's focus groups thought helplines were only for mental health and wellbeing information.

A small number of participants of some focus groups thought that HealthDirect was a useful mechanism for achieving peace of mind when they may otherwise have visited the emergency department. Only one of the participants of the Aboriginal women's focus group had used HealthDirect and she found the service useful and accurate. The most enthusiastic endorsement of HealthDirect came from a participant in the CALD women's focus group who said it was a reliable and thorough source of health and wellbeing information. She said HealthDirect is her "first option than anything else…They're giving you a better service than the doctor gives you. So it's better to ring there and get what you want."

Many participants throughout the focus groups were not aware of HealthDirect, but were enthusiastic when they learned about it. Other participants had heard of it but were still unclear about its function; many did not know that they would be able to speak to a real person or that the helpline is operated by trained nurses. Participants from the CALD women's and mental health consumers' focus groups that had used HealthDirect felt that promotion of the service had dwindled over the past few years.

Lifeline was well known among the participants and had been found useful and trustworthy by those who had used it. A participant in one of the young women's focus groups stated that Lifeline is her preference for seeking information as…

> *You are completely and utterly anonymous, it's actual people who know what they're doing and you can call them cause they're trained for any sort of crisis.*

For this participant, Lifeline synthesised her need for confidentiality, her desire to seek advice from a real person and her preference for the source to have health knowledge. Many of the participants expressed similar criteria for seeking health and wellbeing information but were unaware that telephone helplines could meet their needs.

2.1.11 Senior Members of Cultural Groups

Senior members of cultural groups were not discussed as a health and wellbeing information source in any of the focus groups. This does not mean that senior members of cultural groups are not important or trusted figures. Indeed they are, and this was abundantly clear throughout the CALD women's focus group. However, it suggests that the participants of our study do not ordinarily rely upon them for health and wellbeing information.

2.1.12 Beauticians and Hairdressers

Beauticians and hairdressers were not were not discussed as a health and wellbeing information source in any of the focus groups.

2.1.13 Mass Media

Participants of the focus groups did not discuss mass media as a health and wellbeing information source in great depth. Several participants of the young women's focus groups said that it is a "good way to portray messages"*.* The participants of the older women's focus group agreed that mass media, like all passive sources of information (sources from which an individual obtains information without actively seeking it) are excellent for communicating to women information they did not know they needed. One participant thought that passive sources of information are vital for women who do not have family, long standing friendships or established networks in the ACT.

Participants of the mental health consumers' focus group shared some anecdotes from watching *Oprah*. One participant, defending television as an information source said "Oprah's good for women". And indeed she may be.

2.1.14 Paper Based Publications

Paper based publications remain an important source of health and wellbeing information despite the rise in preference for the internet. One of the respondents to the follow up survey for women with disabilities pointed out this is because not everyone has easy access to the internet, nor actively searches it for health and wellbeing information.

Paper based publications were important to participants throughout the focus groups as a means of receiving information they did not know they needed. Again, the participants of the older women's focus group thought that paper based publications, like any passive source of information, were vitally important for women who do not have family, long standing friends or established networks with which to give and receive information.

Many participants felt that pamphlets were an excellent source of health and wellbeing information. One of the benefits was that the author can immediately be identified, something that is not so easy on a website. As a result, participants from several focus groups felt that pamphlets were a more credible source of health and wellbeing information than websites. The participants of the mental health carers' focus group praised pamphlets as a valuable starting point for education. They saw them as an intermediary between not knowing anything about an issue, to locating more specific and comprehensive information. One participant said that they are especially useful for providing information about local organisations, services and support.

She felt that pamphlets were small, concrete pieces of information that people can take away and keep, and were likely to help that person seek out further information in the future.

Pamphlets were not a popular passive source of health and wellbeing information for all participants however. Two participants of one of the young women's focus groups thought pamphlets were not suitable because information cannot be tailored or is not always relevant to the individuals reading them. Pamphlets were equally as unpopular among some of the participants of the Aboriginal women's focus group. One example was the tone of language used in breast-feeding pamphlets and the guilt this encouraged in mothers who could not, or chose not to breast-feed.

Three participants in the young women's focus groups felt that popular magazines were the best medium for information about mental and sexual health. Magazines could include information about contraception, sexually transmitted infections and facts about sex that may be omitted from conversations with friends or school sex education. Magazines are ideal as they can deliver information that young women may or may not be looking for in a non-confrontational and anonymous manner. The participants also felt that magazines can reduce the level of embarrassment young women may feel when they have a sexual or mental health issue. Embarrassment may be a reason why young women do not disclose those particular health issues.

Paper based publications ranked fairly highly among the participants on trustworthiness because it is easy to identify the author and because it is thought more difficult to have writing published than to post it on the internet. Not everyone agreed with this, acknowledging that paper based publications are only as trustworthy as their author and the year in which they were written. As one participant of the older women's focus group said…

> *You've gotta make sure that it's got an authoritative source…it would have to be well known for me to take notice of it. Endorsed by the Department of Health or the Cancer Council…so that you know it's not Doctor X with his dodgy practices.*

One of the respondents of the follow up survey for women with disabilities thought that paper based information provided during a consultation with a health professional along with the opportunity to ask questions would be the most useful. This would need to be coupled with questions from the health professional to check the client's understanding. Another respondent agreed, saying that it makes the information more credible if delivered this way.

2.1.15 Schools

Participants throughout the young women's, mental health carers' and CALD women's focus groups thought that schools were an important source of health and wellbeing information. The young women's groups had very lively and passionate discussions about schools delivering preventative information, particularly on sexual health and drug and alcohol use. The mental health carers' felt that schools are fundamentally important for educating the community about mental health issues. The CALD women felt that health education in schools is an effective way of changing adult attitudes over time. On the importance of schools as a source of information one young woman participant summed, “it’s the only site…it is the beginning site.”

Almost all participants of the young women’s focus group felt strongly that schools can be a site of good quality sexual and reproductive health information provided it is delivered in a single sex environment. They agreed that the embarrassment felt by young women when disruptive students in the class — especially boys — made fun of what was being taught, made it difficult for them to value the information. They felt however, that women’s health should be taught to male students and that men’s health should be taught to female students: “I think that through education comes things like respect”. This participant felt that if boys and girls are aware of the changes each other are experiencing there is more likely to be understanding between the two.

A limitation with sexual health education in schools identified by participants over both focus groups was that it does not *“show you the good side but they also don’t show you the really bad side either.”* Many participants felt that sex education needs to be more encompassing and include information about services for particular situations. A few were concerned that the information provided does not cover broad enough territory of bare facts. One commented that sitting through a frank and honest discussion about sex in school could be a suitable litmus test for young women who think they are ready for a sexual relationship. The discussion should incorporate the physical, emotional, social and mental implications. This same limitation was identified with drug and alcohol education.

One participant of the mental health carers’ focus group felt that education about mental health issues should begin in school. She said that this should not just be facts about mental illness, but the promotion of mental health, mental wellbeing and resilience. The mental health carers’ identified the same limitation with mental health education as that identified by the young women about sexual health and drug and alcohol education in schools. They felt that public education paints too rosy a view of mental health issues. It does not emphasise how debilitating some issues can be, or that mental health issues are episodic and can affect anyone.

The CALD women’s focus group had a similar view about the value of schools as a source of health and wellbeing information. They argued that it is one of the surest and least confrontational means to get information to women, and to change attitudes over time. One participant suggested that when children are taught about health in high school, they often feed information back to their mothers and fathers, which is the best way to change attitudes and behaviours over time. Participants felt that a health and wellbeing curriculum should be standard across public and private schools, to ensure that children in the Catholic education system do not miss out on fundamental information.

Reflecting on the usefulness of schools as a source of health and wellbeing information one young woman said that a good rapport between and teacher and a student can be especially advantageous for the dissemination of health and wellbeing information. She said it improves the likelihood of information being transformed into knowledge for the student.

2.1.16 Family Members and Friends

Many women in the WCHM study sought health and wellbeing information from friends and family members. However each group of women interacts with and regards these sources quite differently from the next, making it near impossible to comment in a general way about how the sources are used.

Participants of the young women's, older women's, and Aboriginal women's focus groups agreed that friends and family members are one of the first places they seek health and wellbeing information; "women talk, that's what we do." As captured by one of the participants of the Aboriginal women's focus group, many women look to their networks first for information, "the first thing I do when something's wrong with me or my son is ring my mum." Most of the participants acknowledged that sharing information through familial and friendship networks is important for receiving information they may not have known they needed. However they agreed it must always be taken with caution and followed up before applying to their lives. Many participants had their ways of deciding if information from a friend or family member could be trusted. The participants of one of the young women's focus groups said they judge the credibility of information provided by friends according to their life experiences and whether they have intimate experience of the knowledge they are sharing.

The participants of the CALD women's focus group agreed that health and wellbeing information from family and friends was valuable, but that in their communities this information can be shared without verification from another knowledgeable source. They said that "conversations happen"; people in the community, especially the older women, share their experiences and concerns about health and help diagnose, suggest treatments or reduce anxiety for one another. One participant explained that sometimes women in her community share more than information…

> *I know you shouldn't do this but they go 'oh rather than paying 80 bucks for it how about you just have some of mine, I'll give you a sachet.*

To which another participant added…

> *That happens a lot in my community too…and I say 'you cannot do that with antibiotics, you need to take the whole course'. But it costs money and they don't want to go to the GP and they don't want to go and sit in the hospital.*

The participants agreed that friends and family members are a very good and commonly used source of health and wellbeing information within their communities. They are relationships of trust, which imparts trustworthiness on the information provided. They also agreed that many women in their communities take information from others and do not verify that information or follow up their concerns with a health professional. One participant in particular found this trend worrying and said that she always tells the…

> *women in our communities, 'it's great to talk to your families, it's great to talk to your friends, it's great to share information, but you can't get the right information by talking to your neighbour or your sister. You still need to get the right information'.*

She felt that religious and community leaders, who are the most trusted figures in the community, should encourage women and men to seek professional advice on their health and wellbeing issues, rather than trusting their friends and families alone.

The participants of the mental health carers' focus group had a different experience of friends and family members as sources of information, instead finding that they were the educative source for their friends and family members.

> *I became the source…it became quite oppressive for me because I had to go out and get all the information, come back, not only deal with the client, deal with myself and then deal with my whole family, and then, you know, deal with the widening circle. I became the educative source.*

They fulfilled an educative role for others, particularly for those who had found themselves in similar situations, and this could be demanding and exhausting. Not all of the participants thought that this was a negative experience; one participant said that despite some disadvantages much could be gained through sharing information with others. To which another participant replied…

> *for me too, there still is a delicate balance between the whole keeping the confidentiality of my family too, you now, I find that really a delicate thing because you have this thing where, you know, you want to speak out, you want people to be educated, but, you know, you're talking about your own kids…You have to be that protective shell so that they actually have a space in which they can heal.*

All of these participants agreed that they give and receive health and wellbeing information from their peers in carer organisations, forums and support groups.

Many of the participants of the mental health consumers' focus group did not have a network of family and friends and so relied on support workers, health workers or advocates. Others had negative experiences with family members in regard to their mental health issues and so did not see them as a positive source for information or support.

2.2 SUMMARIES OF THE FOCUS GROUPS

2.2.1 Young Women

The participants of the young women's focus groups issues with seeking health and wellbeing information were different from any other population group. Most commonly they sought information on sexual health, mental health and drug and alcohol use and felt that good quality health and wellbeing information is written simply and comprehensibly for an audience without medical knowledge. The concerns and issues that the participants identified are set out below.

The participants felt that health professionals should be aware of the needs of young women as information seekers, which included having their health concerns taken seriously and not belittled. One participant said, "I'd really like someone who doesn't dismiss your problems…" to which another agreed*,* "when they do that it just makes you feel worse because it makes you feel like you're complaining about nothing and then you feel pathetic." Having health concerns belittled, or having emotional or mental health issues attributed to pre-menstrual stress or hyper-emotionality particularly infuriated the participants.

Confidentiality was the guiding factor for participants choosing a source for health and wellbeing information. Several participants from both focus groups said they had experienced difficulties in accessing health professionals who understood the confidentiality needs of young women. They spoke about having their confidentiality violated by mental health workers, particularly school counsellors. This was the main reason why they sought mental health information from friends or the internet instead. Sources that did not have a relationship to the participants' parents were particularly valued.

Participants of both focus groups expressed a clear preference for information that is relevant to them individually. One group identified a preference for a specific "women's health officer" in schools whom students could go to with health and wellbeing questions. The health officer would need to have and maintain awareness of developments in the health sector in order to be an authoritative source of information for female students.

Almost all of the participants in the young women's focus groups thought that highest quality health and wellbeing information was that which is tailored to an individual's current heath needs in a confidential manner. For example one participant commented on the effectiveness of a poster for *Headspace*, complimenting the use of colour, image and catch phrase. Another participant agreed with this adding, "it says 'your headspace' it's about you". What was also beneficial to these two participants was that the poster provided contact details for more personalised information. Summing up an organisation from which one participant felt she obtained high quality health and wellbeing information, she said, "I always walk out of this place feeling like I've been listened to, I've been understood, that action has been taken, and that I feel somewhat loved…and having been taken care of."

The third most common preference identified in the young women's focus groups was the need to obtain health and wellbeing information from an inexpensive and centralised source. The participants of both young women's focus groups commended the Junction Youth Health Service for meeting the needs of young women, particularly because it is a one-stop shop.

> *I think that's the thing is that, in an organisation like this, a system like the Junction, you're provided with all sorts of information from general health matters to…your well-being, mental health, sexual health…pregnancy….*

This participant compared it to the service available from most GPs throughout the ACT where…

> *they don't have enough time to fully get to know you, assess all that about your life…So I think going into the adult system I'm worried that I'm going to have to go to specific organisations for specific…needs. Rather than being able to go to a GP and get that whole box of information in one hit.*

The preference for breadth of information from a singular, preferably personable, source was echoed throughout the focus groups, as was the understanding that GPs do not have time to fulfil this role.

Overall the participants felt that health and wellbeing information is important in assisting them to maintain their own good health and wellbeing and to navigate the ACT health system. They agreed that good information not only empowers individuals, but empowers communities. One participant very eloquently concluded: "Look I think the key is that with more information, people are more educated…and therefore there is less stigma and confusion."

2.2.2 Older Women

Participants of the older women's focus group discussed their information needs and information seeking preferences, and identified issues in synthesising the two, which are set out below.

While the participants felt that ample health and wellbeing information was available, they were not clear on where to access it. They doubted their ability to navigate the ACT health system, and to manage and apply information effectively in their lives. For these reasons they said that they would prefer a centralised source that could personalise information for them. They said that they want an intermediary; a person who can sort through the mass of information and find what is relevant to them as individuals. They agreed that this person should have some degree of health knowledge.

> *For me it doesn't need to be a GP. It needs to be someone that can suggest different avenues. It certainly needs to be a person…Someone with a bit of credibility, not to know everything but to suggest different avenues.*

The participants liked the idea of this person not being a GP as they would be able to recommend "left field stuff" like alternative therapists "not necessarily 'you need to go and see this specialist or that specialist'." The participants thought that this person could be more like a "health agent" who could create action plans to help women through events such as arranging a funeral. One participant said…

> *We take a lot of responsibility for that ourselves, as we should. But isn't it nice to have someone to say 'how are you going on this? Don't forget about so and so and such and such'.*

One participant suggested the notion of a wellness centre, which could facilitate the process of finding information and personalising it. This participant commented that while not a treatment centre, a wellness centre could reduce the need for a GP, especially for women. Talking with a health professional — a nurse in most cases — and being presented with options could reduce anxiety around a health issue; "it's a very safe place to be [and] it's full of information."

The second major theme of the focus group was the negative focus of health information for ageing women. The participants thought that general health and wellbeing information and preventative health campaigns should inform women about possibilities for them at particular ages and life stages, not only about the risks and health conditions associated with a certain age. The negative focus of information, particularly preventative health information was a source of annoyance for participants, one of whom said…

> *all the passive information that's out there is fear tactics. Do you see any information out there that says 'Great your 60 start a new sex life'?*

Other participants said that they would like more preventative information to inform them about what they may need to know at particular life stages. "Coming into your 60s? There's a chance you might need this," was suggested by one participant. She felt that older women could benefit from simple thoughts, ideas or pieces of information they could draw on when presented with a particular health issue, or when they enter a new life stage.

Gender sensitive health and wellbeing information sources were identified by the participants as those which provide the following: a safe space; facilities for children; access to parking or public transport; multiple services available in a short amount of time; and access for women with limited mobility. The participants thought the model of the Gungahlin medical centre — which has a cluster of services available including childcare — invaluable for women with children, elderly women and those with limited mobility.

The participants largely agreed that when an individual of notoriety and credibility endorses information, it is trust worthier because they assume that the public figure would have "sussed it out" before endorsing it. They thought that the public figure would best not be a politician but rather a journalist, radio or TV personality or a prominent woman from the community.

2.2.3 Aboriginal Women

Overall the participants of the Aboriginal women's focus group preferred health and wellbeing information sources that treated them in relation to their social, economic and historical circumstances. They would also prefer a lesser focus on medication. The participants identified a range of issues in obtaining the health and wellbeing information they require, which are set out below.

The high cost of seeing a GP was the first major barrier identified by the participants in seeking health and wellbeing information. Many of the participant use medical centres where it is not possible to make appointments and difficult to see a regular GP. Many of the medical centres no longer bulk bill, applying a fee of $30.00 during the weekdays and $40.00 after hours. For some participants this has a significant affect on their ability to see a GP. In the words of one participant, "if you are on a pension, $30 or $40 is a big whack out of your pension when you are struggling to survive anyway."

The second most significant barrier was the judgmental or overly clinical communication style adopted by some health professionals. Some participants felt that some GPs spoke down to them, making them feel "dumb" or "unwelcome". One participant commented that "some doctors are only able to communicate at a medical level, and they forget that us ordinary people don't use medical terms." Another participant added that not being able to understand the language of a health professional makes her angry and frustrated when discussing her children's health.

The third barrier was not being able to access a health professional, particularly a GP or a pharmacist, after hours. They felt that women in the ACT need regularly updated lists of GP and pharmacy services. This should include details about bulk billing; opening hours; number of female physicians; and the availability of Aboriginal workers. Several participants said they have taken themselves or their children to the emergency department to see a doctor or pharmacist after hours.

The participants discussed Aboriginal health professionals as information sources. Many agreed that they would prefer to see a health professional from their own cultural background if it was an option. One highlighted that there can sometimes be confidentiality issues when seeing a health professional from one's own community and said that if she found a health service and health professional who cared for her health and wellbeing, she would not mind if they were not from her cultural background. Aboriginal people in the ACT have their own medical service, and one participant wondered if the reason other GPs were out of touch with Aboriginal culture and attitudes to health and wellbeing was because they did not have Aboriginal clients.

In conclusion the participants would like to obtain health and wellbeing information from a greater number of sources than they currently do, including alternative therapists, but do not do so because of the barriers mentioned above. Overall, they said they were more likely to go to active sources such as health professionals and family members, where they can ask questions and receive personalised information, rather than passive sources such as paper based publications.

2.2.4 Mental Health Carers

For the participants of the mental health carers' focus group, the mental health issue of the person they care for determined their health and wellbeing information needs, and how easily they could access this information affected their caring role. The participants identified several issues in seeking health and wellbeing information that are unique to them as a population group, which are set out below.

Several participants said that when they first took on the caring role they needed an information source, preferably a health professional, to pre-empt their information needs. One participant had difficulty accessing information in the initial stages and said that she did not know which health professionals could inform her of the breadth of options for treating mental health issues. She described the feeling of walking around in a daze, and needing someone to provide the information that she did not know she was looking for. The participants agreed that obtaining good quality mental health information is a matter of luck. Two of the participants, for example, did not know how to access a social worker, to which one respondent said, "once again, luck. You've just gotta be in the right place at the right time."

Another concern for the participants was that information from one source could be inconsistent or conflict with the information obtained from another, making it difficult to assess the quality of the information. One participant wondered if such a phenomenon was particular to information about mental health; "there is a certain subjective element that makes the information change slightly from one context to another". The participants agreed that when information is consistent across sources it is more trustworthy.

The cost of some information sources was also a significant issue for many of the participants. One participant explained that she had been referred to some very good services that were not covered by Medicare and therefore inaccessible to her. She and the other participants agreed, "there is a dynamic tension between getting the help you want and being able to pay for it." She continued:

> *I think that is why there is such an emphasis on medication isn't there? Because it's sort of like it's a concrete thing, whereas, you know, everything else just sort of seems too open ended to be able to shell out the money for.*

The participants felt that all mental health services in the ACT, including alternative therapists and treatments, need to be indexed by an independent third party One participant added that awareness about mental health issues could be raised in schools and then supported by a one-stop shop, perhaps a helpline. The one-stop shop would need to be Canberra based in order to provide relevant information about local services.

The participants felt they have to be consistently active in seeking information and constantly reassessing it in light of new or conflicting information. "The system is luck," as one participant pointed out. They said that there does not seem to be any clear channels for mental health information that are reliable, trustworthy and constant. A couple of participants explained that they hope that the information they obtain is exactly what they need: “You start off thinking, ‘oh yes, this is the answer.’” But often it is back to the drawing board: “That’s the education; living through it.”

2.2.5 Women from Culturally and Linguistically Diverse Backgrounds

The participants of the CALD women's focus group identified a range of issues specific to them as individuals or to women in their communities. The major points of the discussion are set out below.

Overall, the participants were more active in obtaining health and wellbeing information that kept them away from health professionals than any other population group. Most of the participants said that it is faster for them to go outside Australia, either physically or electronically, to get the information they require than try to find it in the ACT. The internet and telephone helplines were both popular sources of information as they are easily accessible, provide efficient responses, and do not have to be considered for cultural appropriateness in the same way that other information sources do.

Several participants indicated that good quality health and wellbeing information should be available in different languages, and assist women to navigate an unfamiliar health care system. A couple of participants added that information should be culturally sensitive, taking into account social, medical or dietary practices or prohibitions that exist in some cultures.

There were a number of barriers that affected participants' access to health and wellbeing information, the first of which relates to the cultural appropriateness of facilities. One participant felt that good quality health and wellbeing information could provide women with the information they need to make choices, such as exercising regularly, but that the unavailability of culturally appropriate services, such as cheap and female only exercise spaces, curb the choices available to CALD women.

The second significant barrier identified was the lack of female GPs and specialists. One participant argued that from the oncology ward to the maternity ward there is not always the option to be treated by a woman, which she said can deter women in her community from accessing health services. A second participant agreed with this and explained that there is a male doctor from her community to whom women, while happy to go to him for some health issues, still cannot go for women's health matters. "That problem around female stuff and inhibitions and prohibitions in the communities, it's a really difficult one."

The participants were concerned about women in their communities who are isolated and unable to access health and wellbeing information without the assistance of their husbands. They felt that the barriers these isolated women face need to be understood in their cultural context. One participant said…

> *We the women here in this room, we can speak English, we are independent, we can go anywhere we like, we have choices. But there are some women who are isolated, like for example the new migrants. They can't speak English, they've got a husband whose controlling them…I think it is better if the men understand that the women need to be healthy, need a lot of things, not only the woman. If the woman*

> *had the choices they would be fine, but there are women who are really dependent on their husbands, they can't even step outside their house…so how can they get information? That kind of thing, I have seen it often here.*

This participant had extensive experience working with new migrants in the ACT and believed it vital that men are informed on the importance of women's health issues. She said that she used to present women with health information and, to which they commonly replied that they would need to check with their husbands whether they should have a mammogram or pap smear. She concluded: "That is my experience with the new migrants…the husbands say 'what, checking the private parts? No way.' The husbands do not understand…"

The other participants agreed that the best way to get information to isolated CALD women is by working holistically in the community, involving men, other family members and community and religious leaders in the process. Another participant explained that she ran a program in her community, speaking with church leaders and elders about women's health, men's health and domestic violence to open up discussions in the community. She believed the success of this program was a result of working holistically within the community; "we can't work just with our women".

Trust was another reason to work within the community. Participants explained that information is trusted when endorsed by a community or religious leader. One participant explained that because people trust the leaders, they will trust the information they provide. "Because there's trust, you're trusting someone you've gone to church with in the last twenty years…The trust issue is really big."

2.2.6 Women with Disabilities

The respondents of the follow up survey for women with disabilities highlighted that they have complex and diverse health and wellbeing information needs that often go unmet. The issues identified are set out below.

The respondents felt that women with disabilities choose the information source and format that is most appropriate for their particular disability. They highlighted the advantages and disadvantages of each information source from their different perspectives. One respondent commented…

> *women who are blind need information to be provided in a format of their choice. Women who are intellectually challenged should have their information in plain English. Deafblind women should have access to an interpreter in face to face information sessions.*

Another respondent added that women with disabilities are more likely to have complex and specific health information needs, because they have both health and disability issues. She said that specific information is rarely available from any one source because of the lack of expertise in the complex interrelation of health and disability issues. Conversely, she said that specialists may have expertise that is too narrow.

The need for information to be available in a range of formats was raised by three of the respondents. The first respondent felt that that those who create brochures often do not "make allowances for the information to be provided in alternate formats." The second commented on the risks posed to women with disabilities when information about medications — the purpose, dosage, allergic reactions and side effects — are not available in alternate formats. The third pointed out that many deaf people in the ACT miss out on vital health information, especially those who require interpreters. She felt that support should continue for interpreters for hospital admissions and consultations with allied health professionals. This would ensure women get the health information they require in a way they understand, thereby not "endangering their health and wellbeing through missing vital information."

Gaps in the information available for women with disabilities were identified by the respondents. One respondent highlighted a gap in information about products to assist people with hearing impairment. She said, "most audiologists have vested interests in supporting one supplier — it's hard to make a choice that is genuinely best for me." Another respondent added that little is known about the interaction of various medications, meaning that women with disabilities are at risk of being prescribed medication for a health issue that could react negatively with the medication they take routinely for their disability.

2.2.7 Women Living with Mental Health Issues

The participants of the focus group for women living with mental health issues did not identify many issues in accessing health and wellbeing information. However, they did experience cost as a significant barrier.

Participants were primarily concerned with being able to access health and wellbeing information from affordable and non-judgmental sources. Two of the participants felt that women should not have to dig too deeply to get information from health professionals, especially about flexible treatment payment options and subsidies for treatment such as dental and mental health care. Cost was a significant barrier for one of the participants in particular. She said that she had seen a GP about her depression for the previous ten years, as she could not access free psychological services. She stressed that her GP is a fantastic doctor but that…

> *she's not a psychologist at the end of the day. She sits there and she listens, and she gives advice, and then she gives me my medication. But my complaint is, you know, that's where the treatment ends. Whereas, you know, there has been no offer of any alternative treatment to try and stem the depression in the first place or at least get to the root of why it's happening.*

She explained that cost sometimes prevented her from being able to see her GP as well…

> *I've been in a position where I've needed to see the GP for depression and anti-depressants but because they don't bulk bill I haven't been able to afford to go and get the care that I needed, even with the Medicare rebate or whatever, you've still gotta [pay] because they don't bulk bill and then you've gotta have the money to get your prescriptions. You come out and you've spent a hundred dollars. Then you think 'I'll just put it to the side' and it gets worse.*

The other participants agreed that the cost of seeing a GP coupled with the cost of required medication, if uncovered by bulk billing or a health care card, would not leave sufficient income for them to maintain living costs.

Overall, the participants were less concerned with the issues that were discussed in the other focus groups, as the challenges in each of their lives were considerably greater than those of the other participants. The felt, however, that sources based in the community which allow women to obtain a great deal of health and wellbeing information from one centralised source were most suitable to their needs. They agreed, that good quality health and wellbeing information is important in helping women manage their health and wellbeing. As one participant beautifully articulated…

> *It's about empowerment. Giving you the tools and the skills and the options and the knowledge to self help.*

DISCUSSION

The research showed that most women in the ACT do not have regular needs for health and wellbeing information. Instead they seek information at particular times in their lives depending on their health situation — when they, a member of their family or a partner become ill or have a health issue.

GPs play a critical role in the provision of health information to ACT women, and were consistently rated as the most trustworthy and useful source. While many women feel dissatisfaction with the accessibility and availability of GPs, there is a common perception that only GPs are qualified to provide useful and trustworthy health information and treatment. However, many respondents and participants said they would be happy to not use a GP for a range of health issues if there was an appropriate alternative, meaning that GPs might not be so heavily relied upon for information if women knew they had other choices.

Women need reliable ways to identify, source and obtain up-to-date and relevant information from the most convenient or visible source. This means that methods of access to local and trusted health and wellbeing information sources need to be promoted over time to be visible to ACT women when they need them. For many ACT women, there is not enough awareness about other sources and services that would be viable substitutes for GPs or pharmacists.

PROMOTION AND AWARENESS OF ALTERNATIVES

The reliance on GPs for general wellbeing or minor health issues may be reduced if there were a better understanding of other sources of information for ACT women. For example nurse practitioners, allied health professionals and health educators have the potential to contribute to and deliver health care and promote wellness. These health professionals are educated, competent and authorised to perform certain services and have diverse perspectives that can greatly increase the quality of services and information. Most professions share some skills or procedures with other professions, and it is no longer reasonable to expect GPs to have a unique scope of practice, exclusive of all others.

ACT women are no longer only concerned about access to information, but also about quality, reliability and currency of the information available overall. There is a need to offer assurance to ACT women that other regulated individuals are competent in providing certain services in a safe and effective manner. This assurance should include the scope of practice of the individual professions, which includes their: range of roles; functions; responsibilities; skills; qualifications; and decision making capacity (such as capacity to prescribe medicines or initiate and receive referrals).

Telephone helplines are one such source that could benefit from greater promotion of their purpose and service. As mentioned earlier, many women would happily use telephone helplines such as HealthDirect for minor health issues if they could be sure that the information would be provided by a real person with appropriate health knowledge. Awareness of the existence of HealthDirect and how it operates is very low, yet the use of this source would considerably reduce difficulties in accessing health advice after hours, or could be an alternative to costly options for minor issues.

The participants who had used the service considered HealthDirect a reliable and accessible source of information:

> *One service I find particularly helpful for my children is Health Direct but I tend to find that a lot of people don't know about this service — a quick call to health Direct can often make the difference between being a very worried parent or making an unnecessary trip to Emergency Department.*

It was felt that better promotion might increase the use of HealthDirect and reduce the use of emergency units by providing advice and after-hours access to skilled primary health care services.

NAVIGATION

Women need navigation tools that assist them to find their way around the ACT health system and to access services both within and outside of this system.

> *I wish it was easier to find out which GPs or medical centres bulk billed and where they are located.*
>
> *I need good quality women's health information with a range of choices and options, information of various referral choices and costs.*

There is also a need for the development of self management support tools to help women find the right information — this will ensure that in the future there is a system ready to support self management of health and wellbeing, particularly with the ageing population.

> *It would be ideal to be able to access a kind of tool (internet, booklet, phone) that could give me an indication on where to find information about my health that I can trust and is good quality.*
>
> *Sometimes it is difficult to know if I can trust the information I find and sometimes I just don't know where to go.*

ACT women highlighted the need for access to wellbeing information and not just medical information. The current response to providing information about health and wellbeing services within the ACT was seen as focused on access to medical-oriented services and GP or hospital based services, rather than information-based services. The options and choices need to recognise the importance of other services, including programs run through community organisations:

> *The problem with ‘wellbeing’ is that it involves so many aspects, diet, exercise, stress management, emotional health, attitudes, etc. and this is not an area generally looked at by the medical or even psychological arena.*
>
> *Everyone seems to be a ‘specialist’ in something but often they don't communicate to each other or contradict each other and do not cross refer to each other. My GP gives me scripts for the pill, assists me with injury and minor illness but I would never go to him for ‘wellbeing’.*
>
> *I think generally the focus is of Health Care is illness, rather than preventative.*

Resources that assist women to make informed decisions about their health care should be better promoted and distributed by ACT government, stakeholders and health providers. This will assist women to understand the options available, know they have choices, know they do not have to go to a doctor for all health and wellbeing issues and information, and make decisions based on trusted and credible information.

TOOLS AND SUPPORT FOR INTERNET LITERACY

The internet is the fastest growing source of health and wellbeing information. It is the most likely used health information source for 58.2% of survey respondents — second only to GPs — and one of the most likely used sources of information for general health and wellbeing, minor health issues and serious or chronic health issues.

The survey respondents and focus groups participants reported using the internet for a multitude of health and wellbeing needs. These included: self-diagnosis and treatment; investigation of a health issue prior to seeing a health professional; investigation of a diagnosis or prescription after seeing a health professional; lifestyle options, including diet, supplements and exercise; to locate and research alternative therapies/therapists; to research particular health issues or conditions for either themselves or a friend or family member; and general knowledge.

Most respondents who used the internet for health and wellbeing information did not use it in isolation from other information sources. They also use the internet with caution, aware of the dangers of relying on the information. This was true of every demographic group of women, except for the most disadvantaged who worry less about the reliability and source of the information.

> *Re internet information — I am careful in my use of this information and am aware there is a lot of inaccurate information on the internet. I limit my use to 'trusted' sites.*
>
> *The internet is an excellent source of reliable information — it is also the source of a lot of utter rubbish. Its usefulness depends on how it's used. It's very useful if used in a discriminating way and for general information only. No information about serious or chronic conditions obtained over the internet should be relied on without the advice of a doctor.*

A number of respondents and participants were not aware of trustworthy health information sites or how to identify them, and wanted this knowledge:

> *The internet is a useful tool for gathering information but I think women need help discerning reputable sites.*

Using the internet for accessing health and wellbeing information with success is as much about internet literacy as health literacy! Enabling women to navigate the internet is essential for better access to appropriate health services.

> *Too much misinformation, not enough synergy between the information from different sources. It can be overwhelming as to what to do, which advice to take. Ultimately one has to be apt at research and seek many opinions on things.*
>
> *I don't know where to find it, and I don't know if what I find is quality information and I can trust it.*

ACT women's internet literacy can be enhanced by assisting women to navigate, obtain and assess health and wellbeing information from the internet and supporting them to understand how to assess and identify trusted sites. This would provide links to more specific information based on their individual needs and circumstances such as pregnancy, menopause, and sexual and reproductive health from a range of perspectives such as age, culture and sexuality.

By enabling women to access trustworthy information they will be able to make rational and informed health decisions without needing to verify it with a GP.

BARRIERS

Cost

Cost was the most significant barrier identified throughout the survey to accessing health and wellbeing information. The cost of sourcing health and wellbeing information can impact on many women's access to the information and services that would best suit their needs. Throughout the study women indicated they were forgoing some things to cover their health costs, or choosing to delay or stop consultations with health professionals, treatment or purchasing medication. This may impact upon women's health and wellbeing and contribute further to costs both for themselves and the health system in the future.

Time

> *I have time issues getting to a GP — and I have a fairly flexible work day! I don't plan to get sick and cannot always plan an appointment a week ahead.*

Waiting times for an appointment, delays at the time of appointment and lack of time for discussion were significant issues throughout the survey responses and focus group discussions. Limited consultation times mean that many women felt they did not have time to ask questions or raise concerns.

> *I speak slowly [and] think slowly but I consider myself intelligent. The problem is that when I go to see a GP, TIME is MONEY! I feel I have to rush and forget some things.*
>
> *The amount of time allowed for each individual person for an appointment and whether the medical professional is familiar with the individual file or notes …... Some patients do not like to ask too many questions as it results in the fee being doubled.*
>
> *A lot of the time it feels like they're trying to rush you out the door due to the volume of clients they have to see, so attention to detail can be lacking and they don't spend as much time listening/asking questions — often doesn't feel like they value the patient's input or take it seriously.*

The time required for women to travel to their appointments was also a significant issue, which impacts upon them in a number of ways — i.e. employment or income in the case of ongoing illness.

Transport and Location

Lack of transport is a barrier to accessing health care and information for many women, which has been exacerbated by closures of local GP practices, the centralisation of GP services and the lack of alternative options available in close proximity. There is limited public transport to many primary health care services and travelling to the GP can be lengthy and difficult, particularly at night or on the weekend.

Coordination and timing of public transport is a problem for those with limited mobility or travelling with children — especially sick children. Women with disabilities and older women may need support or assistance while travelling to and waiting for their appointments, while many others may not be able to access private or public transport.

> *I don't have a car, which makes it very difficult to access GP services outside the inner south, especially when I am sick and don't feel like travelling on public transport or taxi to get to an appointment. My local GPs have waiting lists of 7–10 days for an ordinary appointment. This has been a problem since I can not get a medical certificate for work when I am sick. GPs outside my area do not take new patients, and the emergency department is not appropriate to go to with minor illness.*
>
> *Geographic access to GP and specialist services — this is heavily impacted by public transport,, especially as I (and many others) are poor, limited in mobility, and do not have a car, or a carer with a car.*
>
> *Recently my GP's practice moved out of area due to the high cost of providing local services. I value my long term relationship with my GP and this practice and while I understand the reasons for the move, I dislike the fact that I have to travel further and out of area to access the service.*

> *I was seeing a GP for 5 years — he reached his retirement age and retired from the practice. I went to another place and met a good Dr. and I went back 10 months later and he had moved from Civic to Gungahlin — too far for me if I am feeling unwell, on public transport. So, if I make an appointment at this place I have to wait 10 days. I am currently looking for another GP.*

GAPS

Life-course information was often cited as lacking in the ACT. Many women want information that informs them of what they may need to know at particular life stages. In particular participants felt that there needs to be more comprehensive, non-conflicting and accessible information on sexual health and menopause for older women, having a baby in Canberra, and bulimia, anorexia and obesity.

Women also highlighted the importance of good quality early intervention and life skills information including: nutrition advice; financial counselling; stress management programs; parenting and communication skills programs; physical activity programs; as well as alternative therapies. These programs and services could result in some chronic health conditions being lessened or avoided.

Facilitating access to health information also needs to include a multi-access strategy, or tiered approach, to enhance access to information by a wide range of women including information which has been developed and disseminated in a range of formats, accessible at many access points.

PREFERENCES

Community Based Services and Women's Services

Women want a flexible system, which provides services close to the home and alternatives to GPs and hospitals. Women prefer a holistic approach, including knowledge of and referral to other health and community resources. A community based approach, or access to women's services close to where people live is a preference particularly for older women and women with children. Personal contact, trust and time for women to discuss sensitive health issues are also important.

The system needs to:

- deliver services to individuals and communities, and be organised to address the needs and characteristics of the local population (geographical, social and cultural)
- comprise family doctors, nurses, nurse practitioners and other health care professionals, as well as disease prevention, health education programs, and community pharmacists
- provide access to outreach services and coordinated approaches by a range of complementary workers, services and front line health workers who have well developed generalist skills across a broad range of health and wellbeing issues
- be available 24 hours a day, seven days a week.

This approach, along with better support for and promotion of health information, internet sites and telephone helplines, could reduce the use of emergency departments and GPs by providing a range of services, advice and after-hours access.

The ACT Government is already trialling the use of health nurses in some schools, walk-in-centres, nurse practitioners and practice nurses, and is looking at options such as the Charnwood community centre model.

The ACT Government needs to continue to ensure this provision of community based and coordinated services close to where people live, work and play. But they must also ensure these include access strategies such as assisted and affordable transport, and low or no cost services for the most disadvantaged.

Peer Networks

To be active in their health care, ACT women felt they not only needed access to health information and support, but also to peer networks. For many survey respondents and focus group participants, social networks are the best way to share and receive information, support and referral. Many women highlighted the benefits of this and would like information on relevant consumer networks and self help groups to link them to such supports.

Health consumer organisations and support groups already play an important role in providing some of this advice and need to be resourced to continue do so.

Online support groups are an increasingly popular means for women to obtain information, emotional support and to reduce isolation during illness. Personal stories of others from a similar demographic or who are going through a similar health experience are a useful way to present health and wellbeing information. Listening to personal stories has been shown to help women be more proactive in asking questions of their health providers.[214]

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[214] Sillence, E., Briggs, P., Harris, P. & Fishwick, L. (2007). "How do patients evaluate and make use of online health information?" *Social Science & Medicine*. 64(9). Pp.1853–1862.

Gender Sensitivity from General Practitioners

ACT women highlighted the lack of a trusting and personal relationship with GPs, and the need for gender sensitive approaches by GPs.

> *'Super' clinics are very impersonal. The days of a long, trusting and close relationship between your family and your GP are long gone.*
>
> *It can be difficult to build a relationship with one practitioner due to rushed consultations, feeling like your GP doesn't know your history, moving around a lot and having to use different GPs.*
>
> *The ability to develop an ongoing relationship with a GP….. I currently can see up to five doctors at my local medical centre.*
>
> *They [male GPs] just don't see it the same way we do. I can say something to another woman and she instantly knows exactly what I'm feeling and where I'm coming from. You say it to a man and they look at you as it you're stupid…you haven't got time to go sifting through to find the one in a million whose gonna be different.*

Endorsement of Trusted Sources

Many women felt that health information would be more trustworthy, and therefore more useful, if a well-known and respected individual or organisation endorsed it.

Positively Framed Information

Most focus groups raised the issue that health promotion messages do not work well if they are framed negatively. Older women felt that there was a negative focus on health information for ageing women. They would prefer that general health and wellbeing information and preventative health campaigns inform women about the possibilities for them at particular ages and life stages, not just the risks and health conditions.

> *…all the passive information that's out there is fear tactics. Do you see any information out there that says 'Great! You're 60 start a new sex life'?"*

CONCLUSION

Good quality health and wellbeing information increases women's knowledge about health, wellness, illness and disease; assists them in making choices about their lifestyle and decisions about their health; and reduces anxiety about health issues.[215] In addition, good quality information is comprehensive and comprehensible to a wide audience; is written in clear, non-medical language; is not patronising; does not undermine women as their own best guide in matters of health and wellbeing; and is gender and culturally sensitive.

When women have good quality information that is *available, affordable, accessible* and *appropriate*, they are equipped to maintain their own health and wellbeing, as well as that of their children, partners and other family members. This forms the basis of WCHM's definition of gender sensitive health service delivery.

All aspects of health knowledge and care are affected by an individual's health literacy, which should be developed in coordination with the creation and dissemination of health and wellbeing information. Health literacy assists individuals to engage with and understand health and wellbeing information. It enables them to navigate health systems, access care, and understand their own health risks and needs.[216,217] Improved health literacy in partnership with access to health and wellbeing information can reduce the burden of preventable and chronic illness, reduce reliance on the health system and optimise women's health and wellbeing.

The shortage of GPs in the ACT need not dictate the efforts that can be made to address the barriers ACT women face in accessing health and wellbeing information, or the gaps they identify. The creation and promotion of a tiered health system, for example, can assist women to know the most appropriate source for the information they require, thereby reducing the barriers they face in accessing a GP.

It is hoped that *It goes with the Territory* will provide health and community services in the ACT with a guide to creating information that will meet the needs of the women they serve.

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RECOMMENDATIONS

- WCHM to work with ACT Health to identify how to actively promote other alternatives to GPs, and to explain the tiered levels of intervention that are available within the ACT (in particular Walk-in Centres, pharmacists, nurses, practice nurses, nurse practitioners, CALM services, HealthDirect, and the hospital emergency departments) to increase the awareness of and trust by ACT women, with a particular focus on information for each about:
    - their scope of practice;
    - confirmation of their qualifications and skills; and
    - when to use them or access them.

- WCHM to work with ACT Health in relation to the GP Taskforce recommendation on the development of a GP Register, and to ensure the incorporation of the feedback from ACT women.

- WCHM to work with ACT Health to consider the issues raised by women about the ACT Health website and white pages entries, and the need for better navigation about the range and scope of available services for women in the ACT.

- WCHM to advocate with ACT Government about the need to continue to explore, pilot and evaluate new community based primary care that is supplementary to both GP practices and emergency departments in hospitals, and which meets women's needs, including tiered approaches which also use technologies such as health information lines and internet sites.

- WCHM to develop its website (working in partnership with other key stakeholders and women) to provide assistance to ACT women as health consumers in using the internet and in navigating and assessing the information that is accessed through the internet, particularly through:
    - the provision of tools to support ACT women to understand how to assess and identify trusted sites — by enabling women to access trusted information they will be able to make more rational and informed health decisions without needing to access GPs every time to check information;
    - the use of navigation tools to assist them to find their way around the health system and to access services in and outside the health system that lead to better health outcomes;
    - the development and trialling of a central approach to health and wellbeing information in the ACT for women with a focus on the current gaps identified (Having a baby in Canberra, sexual health and menopause for older women, and young women and eating disorders).

APPENDICES

APPENDIX 1

Breakdown of Usage of Information Sources in Twelve Months Prior to Survey Completion

The following figures show what type of information respondents sought from information sources in the twelve months prior to completing the survey. Senior members of cultural groups, beauticians and hairdressers and schools have not been included because of the small number of respondents who reported using them in the twelve months prior to completing the survey.

General Practitioners Of the 652 respondents who sought information from a GP in the previous twelve months, 336 (52%) sought information about general wellbeing, 522 (80%) about minor medical conditions and 321 (49%) on serious or chronic medical conditions.

Pharmacists Of the 514 respondents who sought information from a pharmacist in the previous twelve months, 206 (40%) sought information about general wellbeing, 394 (77%) about minor medical conditions and 42 (8%) on serious or chronic medical conditions.

Allied Health Professionals Of the 269 respondents who sought information from an allied health professional in the previous twelve months, 86 (32%) sought information about general wellbeing, 155 (58%) about minor medical conditions and 98 (36%) on serious or chronic medical conditions.

Alternative Therapists Of the 239 respondents who sought information from an alternative therapist in the previous twelve months, 134 (56%) sought information about general wellbeing, 125 (52%) about minor medical conditions and 71 (30%) on serious or chronic medical conditions.

Hospitals and Emergency Departments Of the 223 respondents who obtained information from a hospital or emergency department in the previous twelve months, 14 (6%) obtained information about general wellbeing, 85 (38%) about minor medical conditions and 153 (69%) on serious or chronic medical conditions.

Psychologists, Social Workers or Counsellors Of the 186 respondents who sought information from a psychologist, social worker or counsellor in the previous twelve months, 102 (55%) sought information about general wellbeing, 48 (26%) about minor medical conditions and 69 (37%) on serious or chronic medical conditions.

Nurses Of the 172 respondents who sought information from a nurse in the previous twelve months, 63 (37%) sought information about general wellbeing, 106 (62%) sought information about minor medical conditions and 42 (24%) sought information on serious or chronic medical conditions.

ACT Health Service Of the 130 respondents who obtained information from an ACT health service in the previous twelve months, 79 (61%) obtained information about general wellbeing, 57 (44%) about minor medical conditions and 25 (19%) on serious or chronic medical conditions.

Internet Of the 541 respondents who obtained information from the internet in the previous twelve months, 378 (70%) obtained information about general wellbeing, 335 (62%) about minor medical conditions and 214 (40%) on serious or chronic medical conditions.

Telephone Helplines Of the 156 respondents who sought information from a telephone helpline in the previous twelve months, 31 (20%) sought information about general wellbeing, 105 (67%) about minor medical conditions and 44 (28%) on serious or chronic medical conditions.

Mass Media Of the 190 respondents who obtained information from mass media in the previous twelve months, 159 (84%) obtained information about general wellbeing, 45 (24%) about minor medical conditions and 22 (12%) on serious or chronic medical conditions.

Paper Based Publications Of the 363 respondents who obtained information from paper based publications in the previous twelve months, 293 (81%) obtained information about general wellbeing, 138 (38%) about minor medical conditions and 87 (24%) on serious or chronic medical conditions.

Family Members and Friends Of the 447 respondents who obtained information from friends or family members in the previous twelve months, 339 (76%) obtained information about general wellbeing, 261 (58%) about minor medical conditions and 92 (21%) on serious or chronic medical conditions.

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