It goes with the Territory!

The views of Young ACT Women about Health and Wellbeing Information

A Companion Report to *It goes with the Territory! ACT Women's views about Health and Wellbeing Information (July 2010)*

Angela Carnovale

April 2011

whm!
women's centre for health matters

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ACKNOWLEDGEMENTS

Thanks to The Junction Youth Health Service and the YWCA Lanyon Youth Centre for inviting and supporting young women to participate in the health and wellbeing information survey and focus groups. Thanks also to Youth Coalition of the ACT for taking a keen interest in the research findings. Thanks especially to all the women who gave their time to contribute their insights, experiences and opinions to this research. We hope that through documenting your thoughts and experiences, your health and wellbeing information needs will be better met in the future.

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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.

About the Author

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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.

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. 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.

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.

It is for these reasons the 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 (different groups 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 the *It goes with the Territory!* report were consistent with previous research undertaken by WCHM and demonstrated 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.

Because the data gathered was so rich, WCHM decided to accompany the *It goes with the Territory!* report with companion reports highlighting the needs and preferences of particular groups of women in the ACT, as these companion reports showed that there is as much diversity between different groups of women as there is between women and men.

This companion report represents the views of the 144 young ACT women who responded to the original health and wellbeing information survey (comprising 22 percent of total respondents) and the eight young women who participated in focus group discussions.

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.

However, the factors that influence the level of women's health knowledge and literacy changes according to her health, social and economic circumstances. It is WCHM's hope that this companion report will improve the understanding of the needs of young women in the ACT in order to facilitate health and wellbeing information provision that is responsive to their needs.

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

RECOMMENDATIONS

The overall recommendations from WCHM's research were:

- WCHM to work with ACT Health to identify how to actively promote alternatives to GPs and to explain the tiered levels of intervention that are available in 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 on 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 hospital emergency departments 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 key stakeholders and women) to provide assistance to ACT women 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 to verify 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).

To represent the issues specifically raised in this companion report by young women in the ACT, WCHM will:

- 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, including technologies such as health information lines and Internet sites, which meet young women’s needs.

- Develop its website—in partnership with key stakeholders and women—to provide assistance to young women in using the Internet to source relevant and trustworthy health and wellbeing information.

INTRODUCTION

Young women, like women generally, are often the primary seekers of health and wellbeing information for themselves, their partners, children, parents and other family and community members. They also, again like women generally, rely on a range of sources to satisfy their information needs.

Young women, however, have unique concerns when choosing which source to obtain health and wellbeing information from. Primarily, young women are concerned about confidentiality, and will not use a source if they perceive it as not being respectful of their need for confidentiality, even if the information provided is trustworthy and useful. Secondly, young women want information that is tailored to them as an individual, providing information based on their social, historical and health circumstances. And finally, young women want a one-stop-shop where they can obtain all of the health and wellbeing information they need, or be assisted in navigating the ACT health system in order to identify the most appropriate information source.

This report is a presentation of the survey results of the 144 women who were aged between 15 and 29 years who participated in the health and wellbeing information study and the findings of two focus groups conducted with eight young women.

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. ‘Respondents’ in this section refers only to the 22 percent of women in the overall survey sample who were aged between 15 and 29 years.

Section two is a presentation of the focus group findings. It covers the major areas of importance to the young women who participated: the definition of good quality health and wellbeing information; the Internet; psychologists, social workers and counsellors; GPs; schools; friends and family members; paper based publications; mass media; and the gaps in available information in the ACT.

Section three is a discussion of the major themes and looks more closely at the barriers facing young women in accessing the health and wellbeing information they need.

The report begins with a brief overview of the literature on how and where young women seek health and wellbeing information. A larger literature review featured in the *It goes with the Territory!* report and 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 health and wellbeing information. What features here is an abridged version of the literature review that relates specifically to young 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 from ACT women were collected, of which 22 percent (n=144) reported that they were aged between 15 to 29 years.

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 (WIRC), Citizens Advice Bureau (CAB), Women's Health Service (WHS), 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 key partners such as the ACT Office for Women, Health Care Consumers Association (HCCA), YWCA of Canberra and the Women's Information and Referral Centre (WIRC).

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).[1] [2] 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 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.

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

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

FOCUS GROUPS

The overall survey data was complemented by focus groups held with 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.

WCHM undertook two focus groups with young women, one with five participants and the other with three. Participants for the focus group were recruited through two youth focussed services that encouraged young women to participate and hosted the discussion at their premises.

LITERATURE REVIEW

The international and national literature relating to young women as health and wellbeing information seekers is overwhelmingly dominated by concerns around confidentiality. The most notable domestic example is from 2003 when Women's Health Victoria (WHV) conducted an extensive literature review and survey about women as health information seekers, which highlighted that the main issue for young women seeking health information is confidentiality,[3] and showed that young women relied on family and friends, mass media and the Internet far more than older women.[4]

The *Journal of Medical Ethics* provides an example of the research around confidentiality issues deterring young people from consulting their GPs. They found that as adolescent girls mature they are increasingly concerned about the confidentiality of what they discuss with service providers and are consequently reluctant to consult their physician for health care and information. This is especially true when young women want to discuss sensitive issues such as sexual health, contraception, bullying, depression and the use of illicit drugs.[5] Such research indicates that young women would rather go without quality information than face the risk of having their confidence on sensitive issues broken.

The need for confidentiality determines where young women seek health and wellbeing information.[6] Young women are particularly weary 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.[7,8] The concern for having their confidentiality respected means that young women are less likely to utilise reputable sources such as GPs, relying instead on friends, the internet and mass media.[9] Concern for confidentiality and reluctance to see GPs may contribute to young women being the leading seekers of health information from the internet.[10]

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3 Murphy, M., Murphy, B. & Kanost, D., *A Literature Review of Women as Information Seekers*, Women's Health Victoria, Melbourne, 2003, pp. 44-5.

4 Murphy, M., *Access to women's Health information: Research Summary*, Women's Health Victoria, Melbourne, 2003, p. 11.

5 Carlisle, J., Shickle, D., Cork, M. & McDonagh, A., "Concerns over confidentiality may deter adolescents from consulting their doctors. A qualitative exploration", *Journal of Medical Ethics*, 23(3), 2006, pp. 133-137.

6 *Ibid*.

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

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

9 Murphy, M., *Access to Women's Health Information: Research Summary*, Women's Health Victoria; Melbourne, 2003, p. 7.

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

SURVEY FINDINGS

1.1 DEMOGRAPHIC CHARACTERISTICS OF THE SURVEY RESPONDENTS

There were 144 complete survey responses from women aged 15 to 29 years, making up 22 percent of the total survey sample. In the ACT, women aged between 15 and 29 make up 22 percent of the female population.[11]

Educational Attainment: Twenty-one percent (n=30) of respondents had completed a high school qualification; 78 percent (n=112) had completed some post high school study (Certificate I-IV, Diploma or Certificate, Advanced Diploma, Bachelor’s Degree, Postgraduate Degree).

Household Composition: Twenty-eight percent (n=40) of respondents were single (including separated or widowed) with no dependent children; 42 percent (n=60) were partnered with no dependent children; 4 percent (n=6) were single (including separated or widowed) with dependent children; 12 percent (n=17) were partnered with dependent children; 15 percent (n=21) listed their household composition as other.

Household Income: Seventeen percent (n=24) of respondents reported a total household income of $41,599 or less; 41 percent (n=59) reported a total household income between $41,600 and $88,399; 34 percent (n=49) reported a total household income of $88,400 or more; 8 percent (n=12) preferred not to answer.

Location: Thirteen percent (n=17) of respondents were living in Canberra’s Inner North; 3 percent (n=4) were living in Canberra’s Inner South; 21 percent (n=28) were living in Belconnen; 14 percent (n=19) were living in Gungahlin or Hall; 14 percent (n=19) were living in Woden Valley or Weston Creek; 27 percent (n=37) were living in Tuggeranong; 8 percent (n=11) were living in Queanbeyan, Jerrabomberra or elsewhere in NSW.

Work Status: Seventy-one percent (n=102) of survey respondents were working full-time; 13 percent (n=18) were working part-time or casual; 17 percent (n=24) were not working (studying full-time, not currently in paid employment, or full-time mother or carer); no respondents were retired.

Aboriginal or Torres Strait Islander: Of the survey respondents, 8 percent (n=11) identified as a woman of Aboriginal or Torres Strait Islander descent.

Carer Responsibilities: Of the survey respondents, 3 percent (n=4) reported having carer responsibilities for someone other than a dependent child.

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

Culturally and Linguistically Diverse: Of the survey respondents, 15 percent (n=21) identified as a women from a culturally and linguistically diverse background.

Women with Disabilities: Of the survey respondents, 21 percent (n=30) reported that they have a disability or a long-term or chronic health condition.

1.2 SOURCES OF HEALTH AND WELLBEING INFORMATION

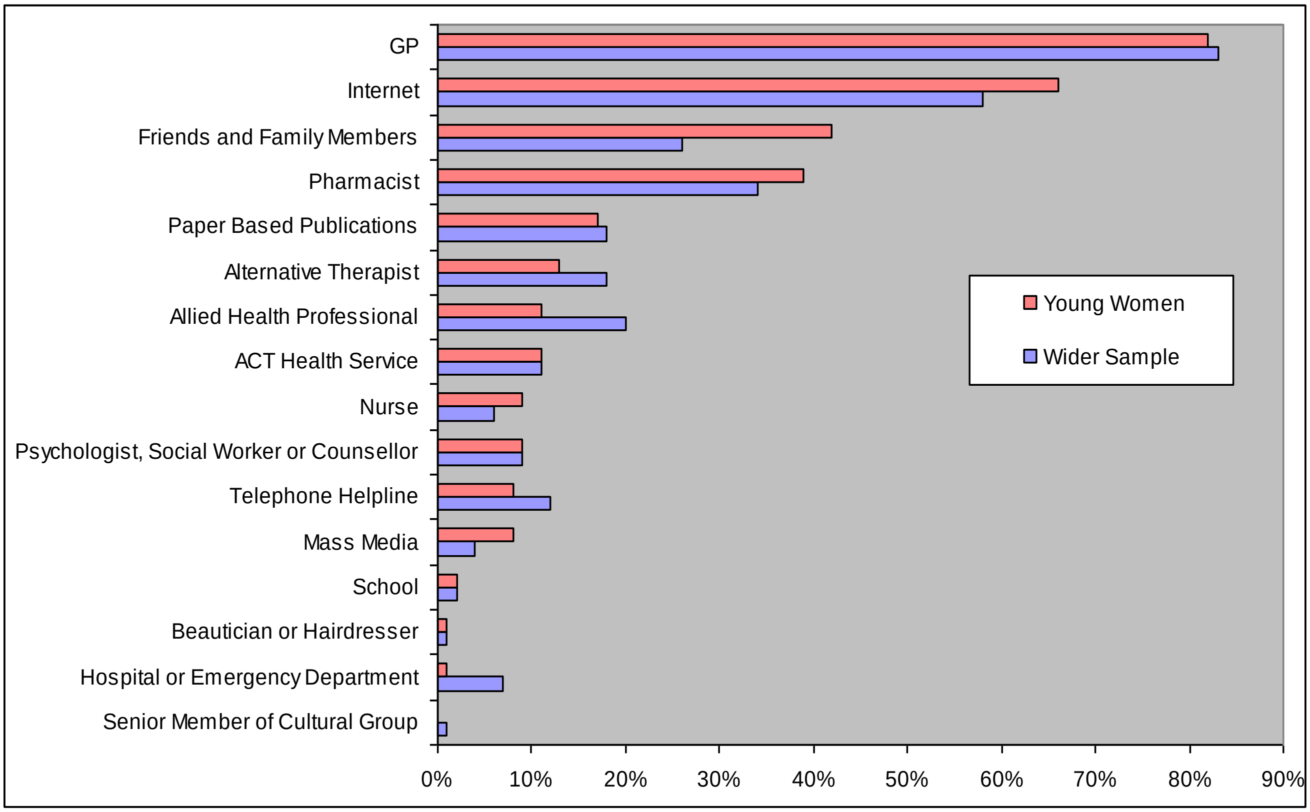
1.2.1 Who Respondents Seek Information For

Ninety-one percent (n=130) of respondents reported seeking health and wellbeing information for themselves, which was consistent with the wider survey sample; 57 percent (n=81) reported seeking information for their partner, 43 percent (n=62) for their parents and 40 percent (n=57) for their friends, which were all higher than the wider sample; 27 percent (n=39) sought information for other family members; 12 percent (n=17) for their children; 11 percent (n=16) for other people in their community; and 4 percent (n=6) for another person.

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

Eight-two percent (n=117) of respondents reported that they are most likely to obtain health and wellbeing information from their GP, consistent with the wider survey sample; 66 percent (n=95) reported that they are most likely to obtain information from the Internet, eight percentage points higher than the wider sample; and 42 percent (n=60) would most likely obtain information from their friends or family members, 15 percentage points higher than the wider sample. Following these top three sources, 39 percent (n=55) of respondents would most likely obtain information from a pharmacist; 17 percent (n=24) from paper based publications; 13 percent (n=19) from an alternative therapist; and 11 percent from an allied health professional (n=16) and an ACT health service (n=15). Only 2 percent (n=3) reported that they would obtain information from school.

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



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 by young women for general wellbeing information were friend and family members, used by 71 percent (n=102) of survey respondents; the Internet, used by 69 percent (n=100) of respondents; and GPs, used by 53 percent (n=77).

The sources that the respondents most commonly used, and the sources they preferred to use to obtain general wellbeing information were the same. However, the order in which they were most commonly used—friends and family members, the Internet and GPs—was different to their order of preference, which was the Internet preferred by 50 percent (n=72) of respondents, GPs preferred by 27 percent (n=39) of respondents and friends and family members preferred by 23 percent (n=33).

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 80 percent (n=115) of respondents; followed by pharmacists at 69 percent (n=100) of respondents; and the Internet at 55 percent (n=80).

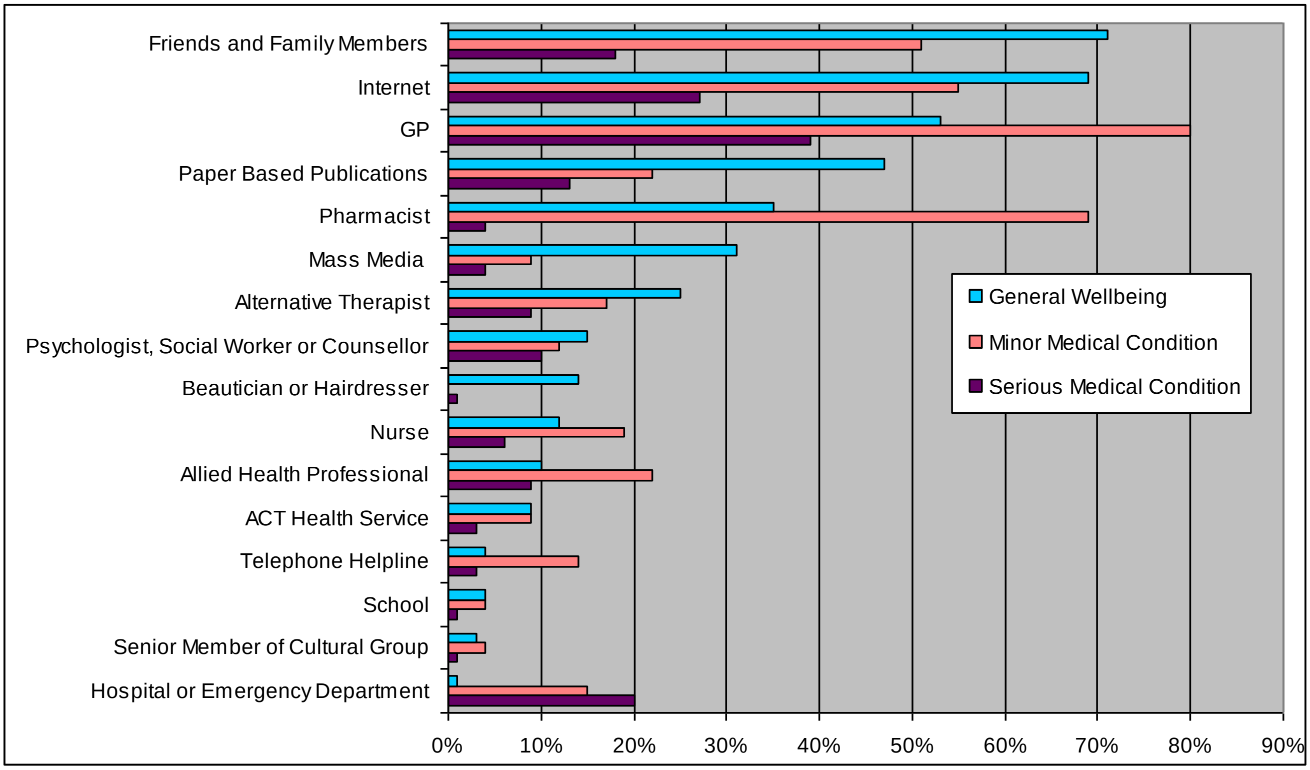
The sources that the respondents most commonly used, and the sources they preferred to use to obtain minor medical condition information were the same. However, the order in which they were most commonly used—GP, pharmacist and then the Internet—was different to their order of preference, which was GPs preferred by 67 percent (n=97) of respondents, the Internet preferred by 32 percent (n=46) of respondents and pharmacists preferred by 12 percent (n=17).

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 at 39 percent (n=56) of respondents; followed by the Internet at 27 percent (n=39) of respondents; and hospitals or emergency departments at 20 percent (n=29).

While respondents most commonly used GPs, the Internet and hospitals and emergency departments for information on serious or chronic medical conditions, their preferred sources differed slightly. Seventy-seven percent (n=111) of respondents preferred to obtain information about serious or chronic medical conditions from GPs, 17 percent (n=25) from medical specialists, and 16 percent (n=23) from the Internet.

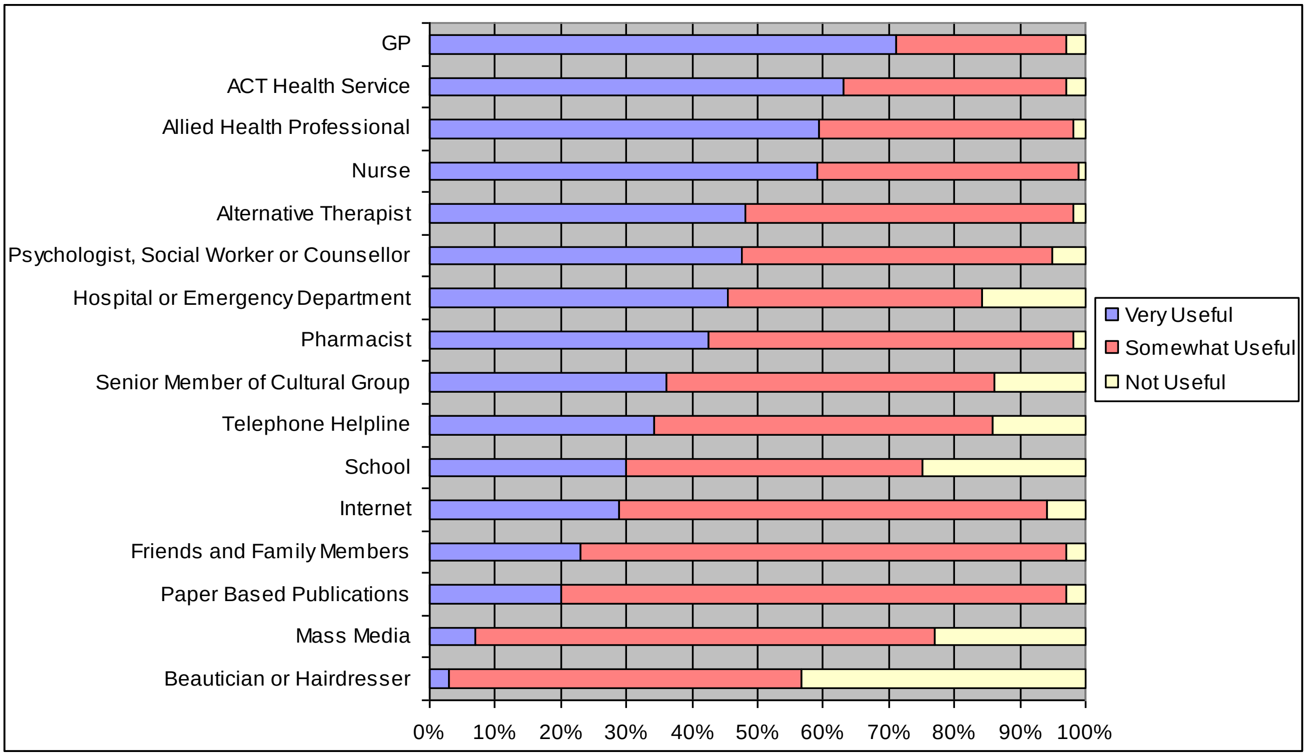
Figure 2: Use of source for general wellbeing, minor medical condition and serious medical condition information in twelve months prior to survey completion



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 that the information 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 3: Level of usefulness attributed to the health and wellbeing information obtained from sources

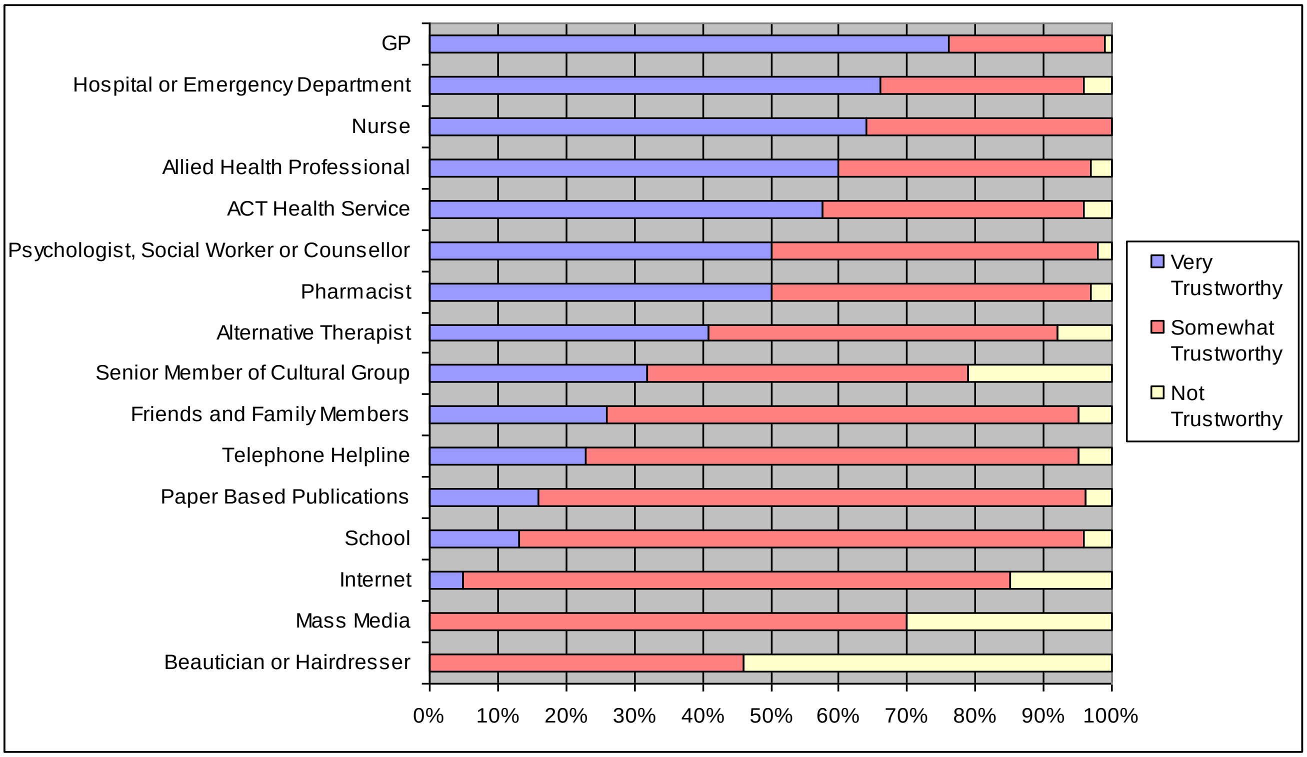


Unsure/don't use answers have been filtered out in order to present the level of usefulness of information from each source only for those respondents who used them. Many chose not to answer the question at all, therefore the figures in the graph represent 100% of those respondents who rated the information obtained from a 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 4: Level of trustworthiness attributed to the health and wellbeing information obtained from sources



Unsure/don't use answers 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 obtained from a 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 the respondents consider before deciding where to seek health and wellbeing information were:

The source is easily available (suitable waiting times)	73 percent (n=105)
The source is easily accessible (suitable location)	63 percent (n=91)
The cost is affordable	54 percent (n=78)
The information provided is of high quality	48 percent (n=69)
I have already established a trusting relationship with the source	33 percent (n=48)

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, 66 percent (n=94) reported that they have considered obtaining health and wellbeing information from an alternative therapist. Of these, the cost of using alternative therapists was identified as the most significant barrier, identified by 27 percent (n=25). Being unsure of the quality of information obtained from alternative therapists was the second most significant barrier, identified by 18 percent (n=17). Fifty-two of the respondents (55 percent) reported no barrier to their use of alternative therapists.

Internet: Of the respondents, 98 percent (n=140) reported that they have considered obtaining health and wellbeing information from the Internet. Of these, being unsure of the quality of the information obtained from the Internet was the most significant barrier, identified by 72 percent (n=101). Not feeling that the information provided to the Internet is treated as confidential was the second most significant barrier, identified by 18 percent (n=25). Not trusting the information obtained from the Internet was the third most significant barrier for 14 percent (n=19).

Paper Based Publications: Of the respondents, 89 percent (n=127) reported that they have considered obtaining health and wellbeing information from paper based publications. Of these, being unsure of the quality of the information obtained from paper based publications was the most significant barrier, identified by 34 percent (n=43). The cost of buying paper based publications was the second most significant barrier, identified by 13 percent (n=17). Seventy-five of the respondents (59 percent) reported no barriers to their use of paper based publications.

Psychologists, Social Workers and Counsellors: Of the respondents, 66 percent (n=93) reported that they have considered obtaining health and wellbeing information from a psychologist, social worker or counsellor. Of these, the cost of using psychologists, social workers or counsellors was identified as the most significant barrier, identified by 25 percent (n=23). Sixty-two of the respondents (67 percent) reported no barrier to their use of psychologists, social workers or counsellors

Telephone Helplines: Of the respondents, 42 percent (n=60) reported that they have considered obtaining health and wellbeing information from a telephone helpline. Of these, being unsure of the quality of the information obtained from telephone helplines was the most significant barrier, identified by 28 percent (n=17). Sixty-five percent (n=39) of respondents reported no barrier to their use of telephone helplines.

1.3.2 Gaps in Health and Wellbeing Information

Of the respondents, 12 percent (n=17) reported there being health and wellbeing information that they were not able to obtain.

The most commonly cited gaps were in information about mental health and sexual health. Other gaps identified were: accurate diagnoses; information about treatment options; and information about general wellbeing.

Here are some comments from the survey:

> *My period stopped for a while and the doctor told me to get a pregnancy test. I was not pregnant but did not know what to do next.*
>
> *Proper tests to investigate whether wellbeing issues are physical or not.*
>
> *It is very difficult to get accurate information from GPs on alternative therapies, or incorporate treatment from both a GP and alternate therapist.*
>
> *A decent counsellor/psychologist to treat my post natal depression.*
>
> *I would like to get information on my health from a trained dietician or nutritionist, but such services are too expensive.*
>
> *Difficulty in fertility treatment.*
>
> *Sometimes there are obscure cases where doctors don't really examine you properly, and they say 'if it comes back, come back to us'... and it comes back, but you don't want to go back to the doctor because you don't feel like they've actually listened to your needs, or examined the actual cause of the problems.*

1.3.3 Barriers to Obtaining Health and Wellbeing Information

Of the respondents, 47 percent (n=67) reported experiencing significant barriers in obtaining the health and wellbeing information they require.

The most commonly reported barriers were: cost of some information sources; waiting times; health professional availability; and personal time constraints. While all of these barriers apply to seeking information from a health professional, several respondents commented that the major barrier for them is not knowing where to go to obtain reliable, affordable and appropriate information. Several respondents felt that their major barrier is locating sources that are non-judgemental, personal and respectful of confidentiality.

Other comments from the survey included:

> *Financing a trustworthy source.*
>
> *The cost is always a contributing factor, hence why we try to source the information from a free resource such as the Internet.*
>
> *I would not go to the doctors or dentist unless I felt that something was very wrong with me as I have recently moved here from interstate (6 months ago) and have found it extremely difficult to find a dr (I called 5 places and only 1 of those were accepting new patients), my doctor that I did manage to get into see is unfriendly and seems to care much more about getting paid than about her patients wellbeing, and the cost is far too much to justify going most of the time (I had a choice of a few dr's interstate and they all bulk billed). There is a severe shortage of quality dr's in the ACT as many of my friends have had very similar experiences. (one of my friends rang 9 different drs and only got in to see one when she started to cry on the phone out of sheer frustration!)*
>
> *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.*
>
> *Availability of the right resource to provide the information.*
>
> *Knowing where to look/who to speak to for the right information [and] assessing whether information is tailored to my situation—particularly in the case of books/Internet/phone helpline.*

1.4 BARRIERS TO ACCESSING GENERAL PRACTITIONERS

1.4.1 Respondents Who Do See a General Practitioner

Of the survey respondents, 97 percent (n=139) reported seeing a GP.

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

High cost	57 percent (n=78)
Difficulty getting in to see a GP due to waiting times	53 percent (n=72)
Not being able to find a GP who bulk bills	27 percent (n=37)

In terms of the gender preferences of GPs, 10 percent (n=14) of respondents always insist on seeing a female GP; 51 percent (n=70) prefer a female GP but will see whoever is available; 38 percent (n=52) don’t care if the GP is male or female; and 1 percent (n=2) prefer a male GP but will take whoever is available. No respondents insisted on seeing a male GP.

In terms of the cultural background of GPs, 4 percent (n=5) of respondents always insist on seeing a GP from their own cultural background; 19 percent (n=26) would prefer to see a GP from their own cultural background but will see whoever is available; 76 percent (n=105) don’t care about the cultural background of their GP; and 1 percent (n=2) would prefer to see a GP who is not from their cultural background but will see whoever is available.

In terms of GP location, 25 percent (n=34) of respondents always insist on using their local GP; 32 percent (n=44) prefer to use their local GP but will go wherever they can get an appointment; and 43 percent (n=59) don’t mind travelling if they find a GP that they like.

1.4.2 Respondents Who Do Not See a General Practitioner

Only 4 percent (n=5) of respondents reported that they do not see a GP. Their reasons included not being able to find a GP who is taking new patients, not being able to trust the information they obtain from a GP, and the cost of seeing a GP.

FOCUS GROUP FINDINGS

Confidentiality is the key factor governing where young women source health and wellbeing information; the perception of a confidentiality breach will see young women seek information elsewhere even if that means from less credible or trustworthy sources.

Good quality health and wellbeing information was understood as information that is personalised for the individual and provided by a central source that respects young women's need for confidentiality. Almost all of the participants in the young women's focus groups thought that the highest quality health and wellbeing information is that which is tailored to an individual's current heath needs in a confidential manner. This point was illustrated by a brief discussion between a couple of the participants on the effectiveness of a poster for *Headspace*—complimenting the use of colour, image and catch phrase. One of the participants added, "it says 'your headspace' it's about you". Both of the participants thought it valuable that the poster provided contact details, which would allow individuals to source more personalised information.

The participants also expressed a preference to obtain health and wellbeing information from an inexpensive and centralised source. The participants of both focus groups commended the Junction Youth Health Service for meeting the needs of young women in this respect.

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

The participants liked the idea of a 'one-stop shop' where they could access written materials, the Internet and health professionals—not only GPs but nurse practitioners, mental health workers or allied health professionals. The 'one-stop shop' could also have other individuals, such as youth workers, with a sound grasp of the ACT health system to help individuals navigate the health system and make decisions about their health and wellbeing based upon a range of options. The qualities of the Junction Youth Health Service could be reproduced in the 'one-stop shop', summed by one participant as "easy access, free, confidential and personal".

2.1 INFORMATION SOURCES

2.1.1 Internet

Of the sources that are currently available to the participants in the ACT, the Internet was the most discussed in the focus group. The young women respondents of the survey reported higher use of the Internet for health and wellbeing information than any other group of women, however, the difference was not significant and in fact, young women used the Internet at the same rate for minor medical conditions as women in other age groups and less than all other age groups for serious or chronic medical conditions.

Perhaps contrary to assumptions, more young women respondents found the Internet not useful as a source of health and wellbeing information than women in other age groups, and fewer young women respondents found the Internet very trustworthy than respondents in all other age groups, except for the 60 years and over age group. Several participants of the focus groups also exhibited great caution around using the Internet as a health and wellbeing information source fearing that Internet sites, including government operated health websites, could be sabotaged by other young people. These participants had concerns about the ease of posting and disseminating false information on the Internet and would therefore be more inclined to use and trust the site of a reputable health organisation. One participant said that she uses the Internet only to obtain phone numbers or addresses to facilitate her obtaining face-to-face health advice; picking up again on the preference among young women for personalised health and wellbeing information.

There is, however, another group of young women respondents and participants who use the Internet without regard for reliability and trustworthiness. These young women included Google and Wikipedia as two sources they may use to locate health information on the Internet. They commented—like many throughout all focus groups—that if the information on a health issue is consistent across a number of sites they consider it reliable.

Irrespective of the usefulness and trustworthiness attributed to the Internet, participants reported using it to: research illnesses or conditions; follow up information they have received from friends or family; gather information prior to a consultation with a health professional; gain further information following a consultation with a health professional; treat simple ailments like a cold; and locate and direct themselves towards an appropriate health professional. Most of the participants, including some of those who care little for reliability and trustworthiness, said that they would verify the information obtained from the Internet with a health professional, again highlighting young women’s preference for personalised health and wellbeing information.

The majority of participants, excepting the most cautious who do not use the Internet, agreed that they would like to know about health websites that are endorsed or operated by government or reputable health organisations. They felt that such sites would be well promoted through eye catching posters in youth centres, shopping centres and schools.

2.1.2 Psychologists, Social Workers or Counsellors

Mental health information, being one of the three most significant areas of interest and need for young women, featured prominently in both focus groups. Several participants have used or sought information from a mental health worker or professional, but are overwhelmingly dissatisfied with mental health services within the ACT, speaking about “being looked upon as a lost cause” by them.

The first issue discussed in relation to obtaining mental health information was confidentiality. Schools and school counsellors were one area where the participants felt that confidentiality was regularly violated. The first example given was that 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, which the participants felt to be a serious breach of confidentiality and, at the very least, a stunning example of insensitivity. The second example was that counsellors may ‘force’ mediation between the client and the other students that they are having trouble with, which can make the situation more difficult for the client. One participant felt that counsellors in the school environment 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”.

However, it as not only within the school counselling environment that participants felt that their confidentiality had been violated; they also cited examples from community and government counselling and psychological services within the ACT. One participant gave the following example…

> *[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.*

At this point, another participant stated that her preference is to use Lifeline 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”.

The second major theme in relation to mental health was the lack of availability of thorough or relevant information. One participant shared a story where even after seeing a psychiatrist the focus remained on giving a diagnosis for her depression, not on giving her information about her illness, management strategies or treatment options…

> *[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…*

A majority of participants felt that there are very few sources providing appropriate, timely and comprehensive mental health information in the ACT.

2.1.3 GPs

Cost was the major concern of the participants in accessing GPs, because many of them do not have steady or regular incomes. They agreed that the cost of seeing a GP coupled with the cost of any required medication, if uncovered by bulk billing or a health care card, would not leave sufficient income for them to maintain other living costs.

Equal to concerns about cost was dissatisfaction with the lack of time GPs have to look at a client’s health issue in the context of their background, medical history and current circumstances. “[GPs] deal with the problem that you talk about, but not with the problem that’s within.” One of the participants 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 then added that she wants to walk away from a consultation with her GP “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”, but worried that such GP 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.”

Several participants felt that not only is it difficult to find a GP with an understanding of women’s health issues, but even more difficult to find a GP who understands young women’s health issues. For this reason, they felt that the quality of the service mattered more than the gender of the GP; valuing a GP who had time to listen, was not judgmental, and provided an affordable service. One participant commented that she would “really like someone who doesn’t dismiss your problems…” to which another participant added, “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.”

Several participants stated that they would be happy to see a male health professional for a range of health issues, but would insist upon a female health professional for sexual and reproductive health matters. For two of the participants, seeing a female GP was imperative: “There’s an understanding from a female to another female. I think the approach is different, perhaps.”

However, a story shared by one of these participants indicates that the pressure to find a female GP may be alleviated if young women were more aware of the health services available within the ACT.

> *Fortunately, I have actually lined myself up with a female GP…and that was a primary concern for me because I have still a lot of issues surrounding women’s health, not general health. However, [I’ve been provided] with information about family planning and what not…specifically for women’s health problems. So that took the stress of having, needing to have a female doctor. Even though now I already have a female GP lined up, having the knowledge that I could go to an area that specifically looked after women’s health relieved me. So whether I have a male or female now is not really relevant.*

2.1.4 Schools

The young women’s focus groups were the site of very lively and passionate discussions around the role of schools in delivering preventative health and wellbeing information. The discussion centred on sexual health information and drug and alcohol use—two of the most important issues for young women.

Almost all participants 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 find any value in the information. They agreed, however, that women’s health should be taught to male students and that men’s health should be taught to female students. One participant said, “I think that through education comes things like respect", meaning that if boys and girls in school are aware of the sorts of changes each other are experiencing there is more likely to be understanding between the two.

The current 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 particular services that students can access should they find themselves in particular situations. That the information provided in schools does not cover broad enough territory in a bare facts kind of way was a particular concern for a few participants. One participant commented that sitting through a frank and honest discussion about sex in school would be a suitable litmus test for young women who think they are ready for a sexual relationship; it should incorporate the physical, emotional, social and mental implications.

The same limitation was identified with drug and alcohol education in schools. One participant felt that education on drug and alcohol use rarely includes hard drugs such as heroin or ice, even though these drugs may be available to or used by students or their friends. By leaving information out, she felt that students are not made aware enough of the consequences of drug and alcohol use.

Students' rapport with workers in the school also affects the quality of information absorption, which is why the school is not only an important site of information but can potentially be a very effective one. One participant thought that a specific women's health officer within the school could be the designated person that students go to when they have health and wellbeing related questions. It would not have to be an external person, but a teacher, or worker in the school, who is in constant contact with developments in the health sector so that they can be an informative and authoritative source of health information. The officer would be a first point of contact and referral, not a nurse capable of diagnosing and treating the students. This would also allow the confidentiality that young women require when seeking information.

Overall the participants felt that a vast array of information should be available in schools but in a manner that is sensitive to young women's needs, such as being positioned thoughtfully to avoid stigma placed on students when they read particular pamphlets or posters. The benefit of having the posters or pamphlets within the school is that while they may be ridiculed or passed around as practical jokes, students are reading the material and taking the information on board, as one participant affirmed: "yes, people do actually read them when they get passed around."

2.1.5 Friends and Family Members

Young women are almost twice as likely to obtain information from friends and family members than any other age group, although it is fair to assume from the information obtained in the focus groups, that it is friends more than family members who provide young women with information.

Although young women obtain health information from their friends, they do not always think that information to be useful or trustworthy. A couple of the participants said that they decide upon the trustworthiness of information they obtain from friends depending upon that friend's personal experiences. If the friend has already been through the situation themselves then their information is trustworthy, sometimes more so than information from health professionals. If that friend has not been through the situation then their information will likely be verified through the Internet or another health information source.

2.1.6 Paper Based Publications

Three participants felt that popular magazines are an optimal site for information about mental and sexual health. The magazines could include information about: contraception, including ingredient lists; sexually transmitted infections; facts about transmission; 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 particular health issues surrounding sexual or mental health, which may be a major reason why young women do not disclose particular health issues.

2.1.7 Mass Media

Reflecting on health and wellbeing information dissemination overall, the participants agreed that there are some issues that need to be discussed in a general way through public or school education campaigns, such as sexual health, mental health and drug and alcohol use. According to the participants, information presented through mass media would be most effective if the medium, such as a poster, had an eye-catching visual accompanied by a memorable phrase and a contact detail. "Something that's quite general and not shocking but has enough information there that you can then take that away and go down that particular avenue." All participants agreed on the importance of the visual, as it makes clearer the message of the campaign and is useful in turning information into knowledge. What is important here, however, is that even though the participants appreciated the necessity of mass media as a source of health information, they almost always said they wanted the option of gaining more information through contact with a health professional.

2.2 GAPS

In regard to the gaps in the ACT's information landscape, one participant felt that there is a lack of comprehensive general information about mental health and mental illness, which she believes results in many individuals accessing information only at the point of crisis when they find themselves in the middle of the medical or mental health systems. Other specific information which participants thought missing in the ACT included: career advice; job seeking; pregnancy; and information about bulimia, anorexia and obesity that is not conflicting.

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."

DISCUSSION

Confidentiality is the primary concern for young women when sourcing health and wellbeing information. Young women, especially those under the age of 18, are particularly concerned about health professionals passing information on to their parents, teachers or peers that may get them into trouble, be a source of embarrassment or create conflict. The need for confidentiality is so great, that many of the focus group participants would obtain information that is less credible, from sources that are less trustworthy, in order to ensure that their confidentiality is not breached.

Respect for confidentiality is one of the three ways that information sources demonstrate their sensitivity in dealing with young women; treating each individual holistically and creating a safe unintimidating environment are the other two ways. Young women want to be seen and treated as individuals within a social, economic and historical context. They reject a medical mindset that treats diseases and body parts in isolation from the individual and their experience. They equally reject overly sterile environments, which can be intimidating and make them feel uncomfortable and unwilling to talk about their health and wellbeing.

The Junction Youth Health Service was commended as a source of health and wellbeing information because the health professionals there maintain a focus on talking to and treating each individual within their social, economic and historical circumstances, with a lesser focus on medication. Part of the appeal of the Junction Youth Health Service is being able to obtain face-to-face information that is personalised and tailored to each individual.

Not being able to access health services that are sensitive to young women’s needs contributes greatly to young women relying on other sources, such as the Internet, mass media and friends, to obtain health and wellbeing information. In regard to the Internet and mass media, young women prefer these sources over other—perhaps more trustworthy—sources because they reduce the level of embarrassment and judgment associated with seeking information on particular topics.

In regard to young women’s preference for seeking health and wellbeing information from friends, the reason for this is that friends have an understanding that often health professionals cannot; listening to one another’s concerns and treating each situation as unique. As has already been well established throughout this discussion, young women want information from a source that listens to their concerns and circumstances and provides the information relevant to them. So while the information obtained from friends may not be the best quality, the experience of obtaining that information in many ways satisfies what young women want.

Being unable to find sources that are sensitive to young women’s needs made finding relevant, useful and trustworthy health and wellbeing information more difficult for the young women who participated in the research. 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. Having health concerns belittled, or having emotional or mental health issues attributed to pre-menstrual stress or hyper-emotionality particularly infuriated the participants.

While young women prefer to obtain health and wellbeing information from face-to-face sources that personalise the information for them they will not do so if they feel that their confidentiality will be in any way violated. Services wishing to be sensitive to the needs of young women then, may need to understand what young women’s understanding of confidentiality is and why it is so important to them.

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.[12] 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.

This report has presented the survey responses of the 144 women aged between 15 and 29 years who participated in WCHM's Health and Wellbeing Information Survey 2009, and the findings of two focus groups conducted with eight young women.

As mentioned in the introduction, and as explored throughout the report, the greatest barrier for young women in accessing the health and wellbeing information they need, is not being able to find sources that are both trustworthy and sensitive to young women's needs. This means that young women rely on the Internet, mass media and friends more readily than women in other age groups, because while the information may not be as trustworthy, they know they will be able to receive information that is non-judgemental, in a way that they will not feel embarrassed and by a source that will protect their confidentiality.

All aspects of health knowledge and care, however, 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.[13] [14] 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.

Young women in the ACT prefer to receive information from a personalised source that can tailor information to their individual context. While it may not always be possible for young women to

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

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

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

obtain their information from a one-stop shop, it is possible and very necessary to increase awareness among young women in the ACT about the different sources from which they can obtain the information they need, the best source to rely on for particular kinds of information, and how to use the source in a safe, comfortable and effective manner.

It is hoped that this report will provide health and community services in the ACT with a guide to creating information that will meet the needs of young women.

REFERENCES

Astbury, J. and White, D., *Addressing women's health information needs: the adequacy of current and emerging health information systems—A literature review*, Key Centre for Women's Health in Society; Melbourne, 1998.

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

Carlisle, J., Shickle, D., Cork, M. & McDonagh, A., "Concerns over confidentiality may deter adolescents from consulting their doctors. A qualitative exploration", *Journal of Medical Ethics*, 23(3), 2006.

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

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

Murphy, M., *Access to women's Health information: Research Summary*, Women's Health Victoria, Melbourne, 2003.

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

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