It goes with the Territory!

The views of ACT Women from CALD Backgrounds 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
June 2011

whm!
women's centre for health matters

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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 the ACT Health Directorate. The findings and recommendations of this report are those of WCHM and not necessarily those of the ACT Health Directorate.

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EXECUTIVE SUMMARY

Women are the primary seekers of health and wellbeing information in the ACT, not only for themselves, but 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 that research was commissioned by the Women's Centre for Health Matters (WCHM) to explore 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 102 women from Culturally and Linguistically Diverse (CALD) backgrounds who responded to the original health and wellbeing survey (who comprised 15 percent of the total sample) and the views of eleven CALD women who participated in a focus group discussion.

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.[1]

It is WCHM's hope that this companion report will improve the understanding of the needs of women from CALD backgrounds in the ACT in order to facilitate health and wellbeing information provision that is responsive to their needs, and an improved understanding about the barriers that they may face.

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.

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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, p. 8.

RECOMMENDATIONS

The overall recommendations from WCHM's research were:

- WCHM to work with the ACT Health Directorate 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 the ACT Health Directorate 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 the ACT Health Directorate to consider the issues raised by women about the ACT Health Directorate 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; and
  - 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 women from CALD backgrounds in the ACT, WCHM will:

- Advocate with health service providers in the ACT on the importance of services and information provision strategies being responsive to the needs of women from CALD backgrounds.

- Advocate with the ACT Health Directorate and the ACT Community Services Directorate about the need to develop pathways to available, affordable, accessible and appropriate information for women from CALD backgrounds, which address:
  - the availability of health and wellbeing information in different languages and formats, which are also culturally appropriate and recognises the diversity of access issues for CALD groups within the ACT;
  - the need to provide health promotion and illness prevention messages in a way that will reach women from different CALD backgrounds; and
  - the responsiveness of ACT health services to the needs of women from CALD backgrounds.

- Work with partners such as Multicultural Women’s Advocacy (MWA) and the Canberra Multicultural Community Forum (CMCF) to develop links on the WCHM website to ACT specific information and services that is relevant to ACT women from CALD backgrounds.

INTRODUCTION

Women from Culturally and Linguistically Diverse (CALD) backgrounds, 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 and it is well established that women benefit by receiving information from a range of sources[2,3] as it affords them great autonomy and control over the health and wellbeing information they engage with.

CALD women are proactive in seeking out health and wellbeing information; seeking it from a variety of sources, in a variety of media, on a variety of topics. Yet CALD women can face specific cultural and linguistic barriers that make obtaining the health and wellbeing information they need difficult, including not being able to access culturally appropriate services or information in languages other than English. At other times CALD women can access the information they need, but are unable to act upon that information because of restrictions placed upon them by others within their community or because of a lack of available and appropriate services, such as affordable female only exercise spaces.

This report is a presentation of the 102 completed responses received from women from a CALD background who participated in the WCHM Health and Wellbeing Information Survey 2009, and the findings of a focus group conducted with a further 11 CALD 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 102 women in the overall survey sample who reported being from a CALD background.

Section two is a presentation of the focus group findings. It covers the major areas of discussion, which were: the participants' definition of good quality health and wellbeing information, culturally appropriate health and wellbeing information, specific information source and the gaps and barriers that affect CALD women as well as the solutions proposed.

Section three is a discussion of the survey and focus group findings and highlights the differences in health and wellbeing information seeking trends and preferences of CALD women compared to the wider research sample.

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

[3] 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. 6.

The report begins with a brief review of the literature relating to CALD women as health and wellbeing information seekers. A complete literature review was featured in the *It goes with the Territory!* report 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 information. What features here is an abridged version of that literature review which relates specifically to CALD 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 15 percent (n=102) were from a CALD background.

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 Women With Disabilities ACT (WWDACT), 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).[4,5] 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

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[4] 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.

[5] 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.

specific to women. The review focused on local and national research but international studies have also been reviewed.

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.

Participants for the CALD women’s focus group were found through several cultural community organisations in the ACT.

LITERATURE REVIEW

The literature highlighted two issues relating to CALD women as health and wellbeing information seekers, the first being that the health information available to CALD women may not be culturally appropriate or it may be discriminatory. In 2003, Women's Health Victoria (WHV) published an extensive literature review of and survey on women as information seekers, which found that women who had English as a second language were dissatisfied with their access to quality health information, partly because of cultural inappropriateness and partly due to the prejudices of health professionals.[6] Findings from a qualitative study conducted by Reitmanova and Gustafson in Canada on CALD women's access to information about maternity, highlighted the experience of discrimination for migrant women when accessing maternity services. The six Muslim women who participated in the study reported not only a lack of culturally and linguistically appropriate material, but also that they had encountered prejudice and stereotyping when seeking information about services.[7]

The second issue highlighted through the literature was that CALD women prefer information that is tailored to their culture and personal circumstances. When women receive information that discusses the health concerns of other women with similar backgrounds and experiences, it results in a better realisation of health risks and better uptake of health services and screening programs.[8] This type of information is referred to as 'narrative based' and has found to be a very positive way of engaging CALD women with health information, connecting them to services, enhancing peer learning and validating personal experience.[9] The Internet is a popular source of health and wellbeing information for CALD women because it is easier to obtain culturally appropriate and narrative based information.[10]

The literature indicates that immigrants in Australia often have significant unaddressed health needs.[11] Indeed, a study of service utilisation by refugees from East Africa in Melbourne conducted by Cooke et al. found that 77 percent of refugees reported outstanding and unaddressed health problems despite 63 percent already having consulted a health care

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

[7] Reitmanova, S. & Gustafson, D., "'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), 2008, pp.101–111.

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

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

[10] Murphy, M., Murphy, B. & Kanost, D., *op cit.*

[11] Cooke, R., Murry, S., Carapetis, J., Rice, J., Mulholland, N. & Skull, S., "Demographics and utilisation of health services by pediatric refugees from East Africa: implications for service planning and provision", *Australian Health Review*, 27 (2), 2004, pp. 40-45.

provider in Australia. This was attributed to a lack of interpreters and lack of appropriate information on available and appropriate health services.[12]

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[12] *Ibid*.

SURVEY FINDINGS

1.1 Demographic Characteristics of the Survey Respondents

There were 102 complete survey responses from CALD women, making up 15 percent of the total survey sample. Women from culturally and linguistically diverse backgrounds make up 31 percent of the female population in the ACT 15 years and older.[13]

Age: Twenty-one percent (n=21) of respondents were 15-29 years; 24 percent (n=24) were 30-39 years; 31 percent (n=32) were 40-49 years; 19 percent (n=19) were 50-59 years; 6 percent (n=6) were 60 years or older.

Educational Attainment: Nine percent (n=9) of respondents had completed a high school qualification; eighty-eight percent (n=90) had completed some post high school study (Certificate I-IV, Diploma, Advanced Diploma, Bachelor's Degree, Postgraduate Degree).

Household Composition: Nineteen percent (n=19) of respondents were single (including separated or widowed) with no dependent children; 33 percent (n=34) were partnered with no dependent children; 10 percent (n=10) were single (including separated or widowed) with dependent children; 30 percent (n=31) were partnered with dependent children; 8 percent (n=8) listed their household composition as other.

Household Income: Fourteen percent (n=14) of respondents reported a total household income of $41,599 or less; 31 percent (n=31) reported a total household income between $41,600 and $88,399; 43 percent (n=44) reported a total household income of $88,400 or more; 13 percent (n=13) preferred not to answer.

Location: Twenty-one percent (n=21) of respondents were living in Canberra's Inner North; 10 percent (n=10) were living in Canberra's Inner South; 22 percent (n=22) were living in Belconnen; 8 percent (n=8) were living in Gungahlin or Hall; 12 percent (n=12) were living in Woden Valley or Weston Creek; 22 percent (n=22) were living in Tuggeranong; 7 percent (n=7) were living in Queanbeyan, Jerrabomberra or Other NSW.

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[13] Australian Bureau of Statistics, *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, 2006.

Work Status: Sixty-five percent (n=66) of respondents were working full-time; 24 percent (n=24) were working part-time or casual; 8 percent (n=8) were not working (studying full-time, not currently in paid employment, or full-time mother or carer); 4 percent (n=4) of the respondents were retired.

Carer Responsibilities: Of the respondents, 15 percent (n=15) reported having carer responsibilities for someone other than a dependent child.

Women with Disabilities: Thirty-one percent (n=32) of respondents reported having a disability or a chronic or long-term health condition.

1.2 Sources of Health and Wellbeing Information

1.2.1 Who Respondents Seek Information For

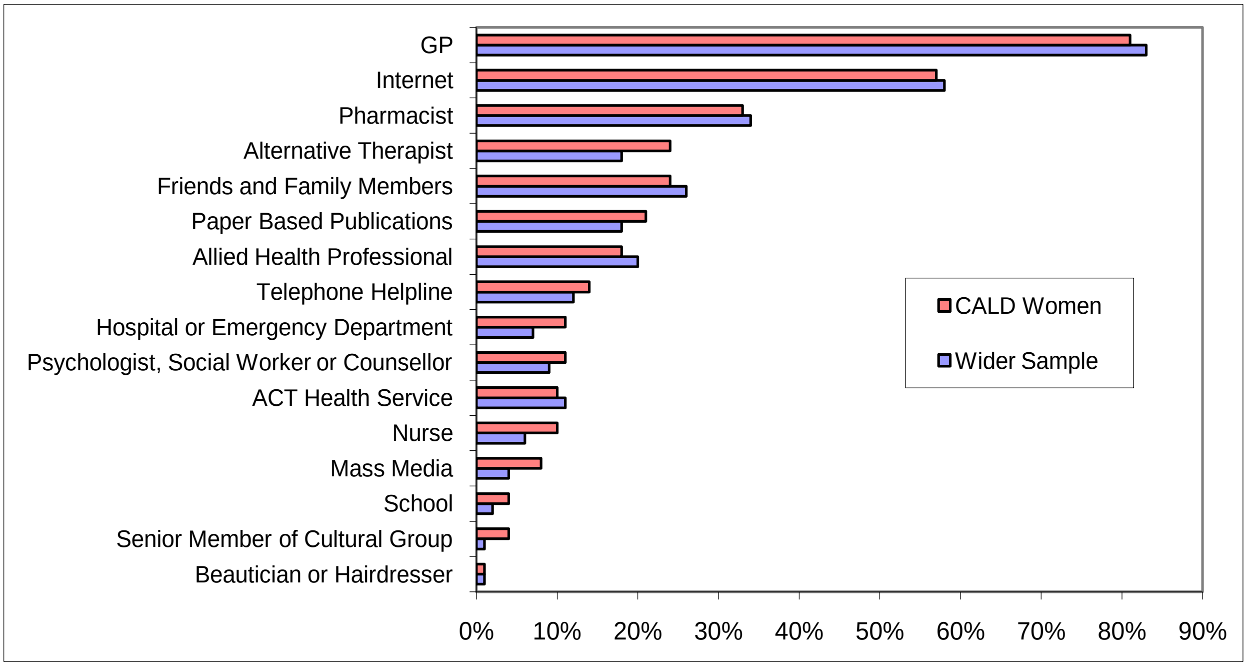
Eighty-seven percent (n=87) of respondents reported seeking health and wellbeing information for themselves, 5 percentage points lower than the wider survey sample; 51 percent (n=51) reported seeking information for their partner and 46 percent (n=46) for their children, both comparable to the wider survey sample; 34 percent (n=34) reported seeking information for their parents and 31 percent (n=31) for other family members, both five percentage points higher than the wider survey sample; 26 percent (n=26) reported seeking information for their friends; 22 percent (n=22) for other people in their community; and 11 percent (n=11) for another person.

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

Eighty-one percent (n=79) of respondents reported that they are most likely to obtain health and wellbeing information from their GP; 57 percent (n=56) reported that they are most likely to obtain information from the Internet; and 33 percent (n=32) would most likely obtain information from a pharmacist, all similar to the wider survey sample.

Following these top three sources, 24 percent (n=23) of respondents would most likely obtain information from an alternative therapist or from friends or family members; 21 percent (n=21) from paper based publications; 18 percent (n=18) from allied health professionals; and 14 percent (n=14) from telephone helplines.

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 respondents for general wellbeing information were paper based publications, used by 55 percent (n=56) of respondents; family members and friends, used by 54 percent (n=55); and the Internet, used by 51 percent (n=52).

The sources that the respondents most commonly used and the sources they prefer to use for general wellbeing information were slightly different. Thirty-seven percent (n=38) of respondents prefer to use the Internet to obtain general wellbeing information; 31 percent (n=32) prefer to use a GP; and 17 percent (n=17) prefer family members and friends.

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, used by 76 percent (n=78) of respondents; pharmacists, used by 53 percent (n=54) of respondents; and the Internet, used by 46 percent (n=47).

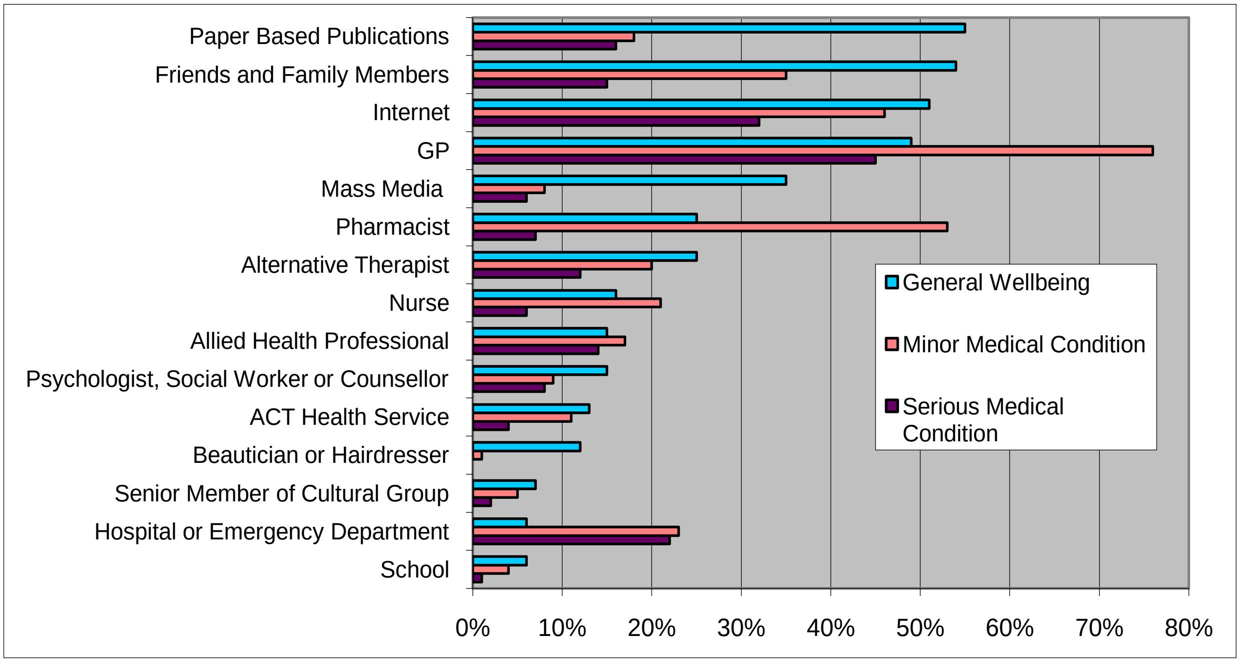
The sources that the respondents most commonly used and the sources they prefer to use to obtain information about minor medical conditions were again slightly different. Sixty percent (n=61) of respondents prefer to use a GP or medical doctor; 27 percent (n=28) prefer to use the Internet; and 7 percent (n=7) prefer either a pharmacist or family members and friends.

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 45 percent (n=46) of respondents; the Internet, used by 32 percent (n=33) of respondents; and hospitals or emergency departments, used by 22 percent (n=22).

The sources that the respondents most commonly used and the sources they prefer to use to obtain information about serious or chronic medical conditions were again slightly different. Seventy percent (n=71) of respondents prefer to use a GP or medical doctor; 21 percent (n=21) prefer to use a specialist; and 13 percent (n=13) prefer to use the Internet.

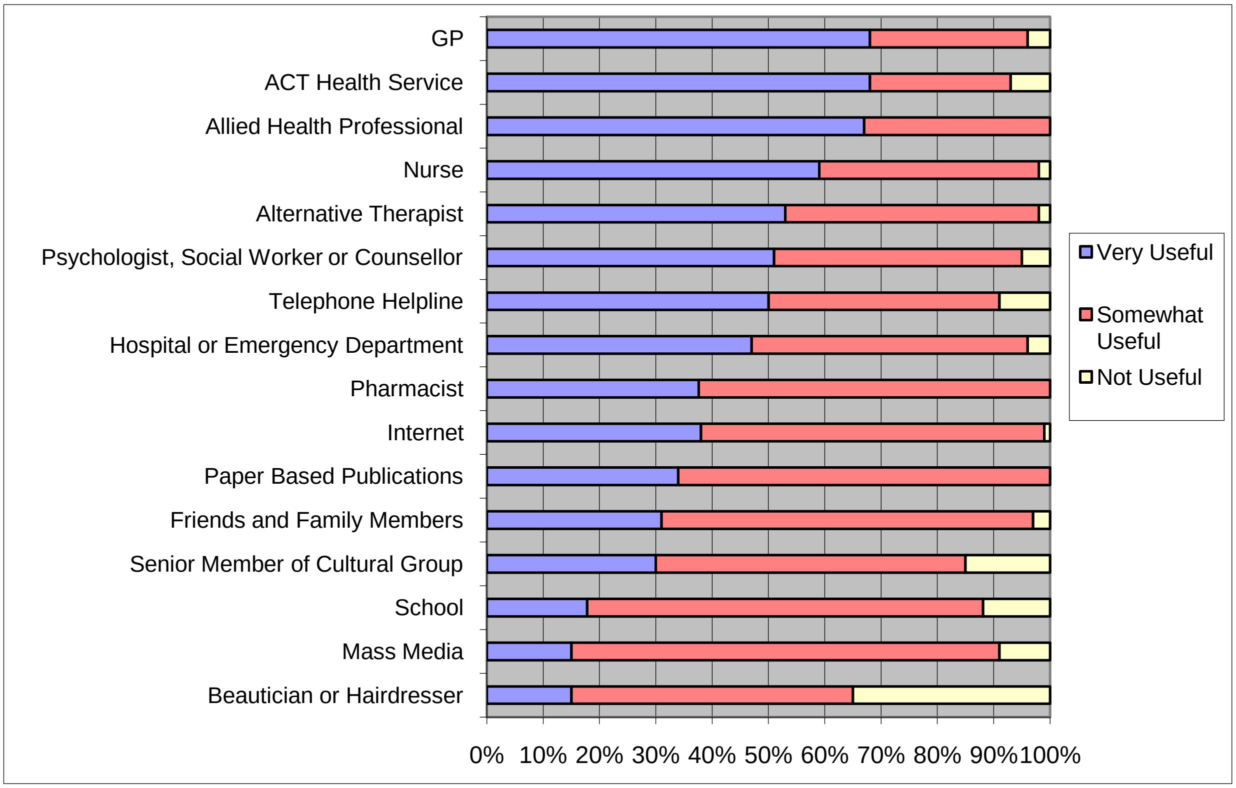
Figure 2: Use of source for general wellbeing information in twelve months prior to survey completion



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

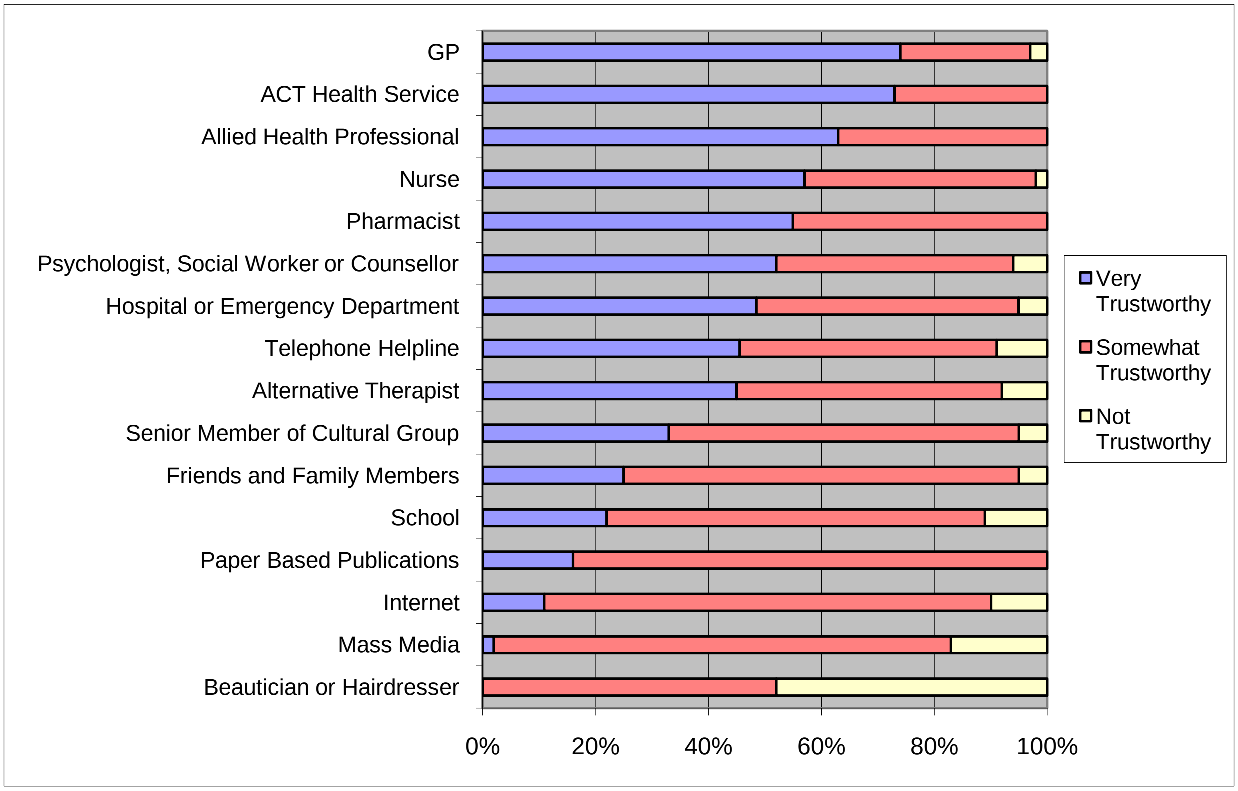


Unsure/don't use answers have been filtered out in order to present the level of usefulness of information from each source only for those respondents who used them. Many chose not to answer the question at all; therefore the figures in the graph represent 100% of those respondents who rated the information 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 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 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 information provided is of high quality	58 percent (n=59)
The source is easily available (suitable waiting times)	55 percent (n=56)
The source is easily accessible (suitable location)	52 percent (n=52)
The cost is affordable	45 percent (n=45)
I have already established a trusting relationship with the source	44 percent (n=44)

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, 79 percent (n=81) reported that they have considered obtaining health and wellbeing information from an alternative therapist. Of these, 31 percent (n=25) listed being unsure of the quality of information obtained from alternative therapists as the most significant barrier, while the cost of using alternative therapists was a concern for 24 percent (n=19). Fifty-two percent (n=42) reported no barriers to obtaining health and wellbeing information from alternative therapists.

Internet: Of the respondents, 96 percent (n=98) reported that they have considered obtaining health and wellbeing information from the Internet. Of these, 61 percent (n=60) listed being unsure of the quality of the information obtained from the Internet as the most significant barrier. Thirty-one percent (n=30) of respondents reported no significant barriers to obtaining health and wellbeing information from the Internet.

Paper Based Publications: Of the respondents, 94 percent (n=96) reported that they have considered obtaining health and wellbeing information from paper based publications. Being unsure of the quality of the information obtained from paper based publications was the most significant barrier for 36 percent (n=35) of these respondents. Fifty-five percent (n=54) reported no barriers to obtaining health and wellbeing information from paper based publications.

Psychologists, Social Workers and Counsellors: Of the respondents, 79 percent (n=81) reported that they have considered obtaining health and wellbeing information from a psychologist, social worker or counsellor. The cost of using psychologists, social workers or counsellors was identified as the most significant barrier by 20 percent (n=16) of these respondents, while being unsure of the quality of the information obtained from psychologists, social workers or counsellors was a concern for 14 percent (n=11). Sixty-five percent (n=53) reported no barriers to obtaining health and wellbeing information from these sources.

Telephone Helplines: Of the respondents, 64 percent (n=65) 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 a significant barrier for 35 percent (n=23). Sixty percent (n=37) reported no barriers to obtaining health and wellbeing information from telephone helplines.

1.3.2 Gaps in Health and Wellbeing Information

Seventeen percent (n=17) of respondents reported that there is information regarding their health and wellbeing that they are not able to obtain. This includes: information about specific health conditions; comprehensive information; personalised information about general wellbeing; general wellbeing information that is not costly; and thorough diagnoses.

Some comments from the survey:

> *I get very conflicting advice from the Internet sometimes. Also info is either too basic or too difficult to understand (unless you are a doctor) - somewhere in between would be good.*
>
> *Information regarding some specific issues is hard to find. I have injury related depression and apart from the little my GP tells me I cannot find additional information.*
>
> *I wish I could see a counsellor, for myself and for my relationship, but it's a bit embarrassing and difficult to do.*

1.3.3 Barriers to Obtaining Health and Wellbeing Information

Thirty-seven percent (n=38) of respondents reported experiencing significant barriers in accessing the health and wellbeing information they need. The major barriers for respondents were: high cost; long waiting times; GPs not accepting new patients; difficulty sorting good information/health professionals from bad information/health professionals; racism; difficulty finding culturally sensitive health professionals; and time poverty.

Some comments from the survey:

> *Racial, class profiling, negative profiling.*
>
> *1. Cost of services, often wait too long to seek medical assistance or try to 'do it myself' (mental health issues) 2. Transport and time away from work.*
>
> *Sometimes questions from migrant women are not understood in the cultural context and occasionally belittled.*
>
> *To know what to ask, and who to ask it from.*
>
> *Stereotyping by some health care providers who assume that because you come from X background then you must have certain predetermined conditions or you will not understand what they have to say.*

1.4 Barriers to Accessing General Practitioners

1.4.1 Respondents Who Do See a General Practitioner

Of the survey respondents, 95 percent (n=97) 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	50 percent (n=46)
High cost	41 percent (n=38)
Not being able to find a GP taking new patients	27 percent (n=25)

Twenty-nine percent (n=27) of respondents reported that they had not experienced any significant barriers in accessing a GP.

In terms of the gender preferences of GPs, 11 percent (n=11) of respondents always insist on seeing a female GP; 40 percent (n=41) prefer a female GP but will see whoever is available; 41 percent (n=42) don’t care if the GP is male or female; and one respondents prefers a male GP but will take whoever is available. No respondents insist on seeing a male GP.

In terms of the cultural background of GPs, one respondent insists on seeing a GP of their own cultural background; 23 percent (n=23) prefer to see a GP from their own cultural background but will see whoever is available; 68 percent (n=69) are not concerned with the cultural background of their GP; and one respondent would prefer not to see a GP from her cultural background but will see whoever is available.

In terms of GP location, 30 percent (n=31) of respondents always insist on using their local GP; 24 percent (n=24) prefer to use their local GP but will go wherever they can get an appointment; and 38 percent (n=39) don’t mind travelling if they find a GP that they like.

1.4.2 Respondents Who Do Not See a General Practitioner

Only 5 percent (n=5) of respondents reported that they do not see a GP. Their reasons included not trusting the information they get from GPs, not being able to find a GP who bulk bills and the cost of seeing a GP.

FOCUS GROUP FINDINGS

The following are the findings of a focus group that was held with eleven women from different cultural and linguistic backgrounds. The information sources and issues discussed here were chosen because they proved most important to the focus group participants.

2.1 Good Quality Health and Wellbeing Information

The participants felt that WCHM's working definition of good quality health information did not address the needs of culturally and linguistically diverse women. WCHM has defined good quality health and wellbeing information 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.

The participants agreed that good quality health and wellbeing information should reduce anxiety, however, one participant explained that not being able to access information in the relevant language can add to a woman's anxiety, as can having to navigate a health system that she is unfamiliar with. The participants felt that anxiety will prevent CALD women from tending to their health and wellbeing needs, especially if they do not have someone to assist or accompany them.

The participants also felt that very often, information to assist them to make decisions about their lifestyle and health was missing. One participant pointed out that many medicines do not have exhaustive ingredient lists, which does not allow an individual to know if it contains products that are forbidden by their cultural or religious dietary norms. This participant agreed that the ingredients of medicines is less important in matters of serious illness, but that in matters of preventative health care—such as supplements—the ingredients are much more important and may potentially limit the scope of preventative health options for particular groups of women.

2.2 Culturally Appropriate Health and Wellbeing Information

The discussion about good quality health information necessarily led into a discussion about the cultural appropriateness and sensitivity of health and wellbeing information. For example, one participant recognised that while good quality health information is that which assists individuals to make choices about their lifestyle, there may still be an absence of culturally appropriate services or spaces that curb the choices actually available to CALD women. She gave the example of having recently tried to arrange an aqua aerobics class for a group of Muslim women at the public pool, having secured provision from management that the part of the pool being used for the class would be a women only space. Unfortunately, male swimmers continued to enter this space and so, without the support of the staff at the pool, the classes could not continue.

A second participant agreed that women in her community have difficulty using services because of cultural barriers. Speaking on the topic of women in her community and exercise she said…

> *They usually get together themselves because they can't go to the pool unless it's only just a group of women and I think if someone were to get into difficulty the women will just try and help because if it's just a [male lifeguard] there, they're not gonna call him.*

The trepidation with which some CALD women interact with services is not limited to social services, such as gyms and public pools, but to health services as well. The previous participant continued…

> *We have a male doctor here (from the participant's country of birth) and women still can't go to him for certain feminine things because they don't feel comfortable in front of a male doctor. That problem around female stuff and inhibitions and prohibitions in the communities; it's a really difficult one.*

This participant touched on one of the most significant issues for services providers; understanding the inhibitions and prohibitions of particular groups of women and creating not only a service but a facility that is sensitive to those. The participants agreed that often when services have difficulties attracting CALD women it is because the facilities are inappropriate. A space or service can be culturally inappropriate for many reasons including the clothing that are required for the facility—in the case of a swimming pool—or the fact that the facility is unisex. In addition to this one participant commented that many service providers, or people in the community, do not consider the needs of CALD women who are not Muslim, assuming that only Muslim women have specific needs such as women only spaces.

2.3 Information Sources

The following information sources have been chosen for discussion because they proved significant both for survey respondents and focus group participants. They are discussed in relation to the major themes that emerged in either the data findings or the focus group discussions.

2.3.1 GPs

The participants were not happy about the barriers they experience in accessing a GP in the ACT. Firstly, many of the participants were not only unhappy themselves about the time constraints within which GPs work, but also felt that GPs were unhappy and were offering a lesser service as a result. Secondly, one participant who is an aged pensioner said that she now uses the (previously bulk billing) medical centre, rather than a regular GP, due to cost. And thirdly, several participants had experienced difficulty securing appointments with a GP due to their "books" being closed. The participants felt that it is even more difficult to get in to see female GPs, particularly if they have a very good reputation among women in the community. As a result of these barriers, many participants said that they would go to the emergency department rather than a GP.

The participants identified more issues with GPs than those relating to access. One participant was particularly angry about her experience of using GPs and identified the following issues: the GP is almost always running late, which means that you spend quite a long time waiting before your appointment, often with sick and grumpy children; if you want to find out if your doctor is running late and how late they are running you must get up and ask the receptionist yourself; and when you do get in to see the GP they are very strict with their time, giving you ten minutes on the standard fee before raising the fee. 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. This participant said that she feels that much of the time GPs are checking symptoms on what appears to her similar to a Google search engine. She thinks, therefore, 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.

Trust was also a key issue for the participants, who reported that they did not feel that they should automatically trust doctors because they are health trained.

> *The doctor know you only for five minutes but your body is your body so you have to study your own health, not relying on the doctor, because the doctor give you medicine, medicine and I'm always suspicious.*

Another participant agreed saying that GPs should be open about not having all of the answers and allow their clients to be their equals; to share in the information gathering and sharing. There was also some skepticism among the women that GPs are too conscious about being sued and too worried about making money, which whether or not true, affects the public image of GPs for some.

2.3.2 Pharmacists

Pharmacists were very popular among the participants all of whom would like to see pharmacists able to perform a role similar to GPs. The participants all agreed that if a pharmacist or nurse practitioner could provide the same services of referral and prescription as the GP they would be happy to not see a GP for these things.

2.3.3 The Internet

Several participants reported using the Internet to search for health and wellbeing information. For these women, the focus was not on the concern about credibility and trustworthiness of information, but on the convenience of being able to obtain information quickly, without having to leave the house and without the burden of having to get in to see a health professional.

Several of the participants who use the Internet to locate health information do so by using the Google search engine. Most will trawl through websites whether Australian or international until they locate information that is appropriate for them, however, one participant said that she prefers sites from Australia or the UK. This participant said that…

> *The thing when you are looking at information is to look at the same things that come up, so you don't rely on just the one source. You need to take a variety of information from a variety of sites to get the information that you need in order to fix up whatever you need to fix up. So you can't rely on just the one [site].*

Like most women throughout the focus groups, the participants use the Internet for a range of reasons which include: obtaining information about medicines, particularly after they have been prescribed by a GP; searching for journal articles; self-diagnosis; self-treatment; seeking information about diet and exercise; keeping up to date with alternative therapies; and keeping up to date with current health issues.

One participant explained that because many women in her community do not use computers, they come to her to search for information for them. She said that there is a wonderful health centre specific to her community in Auckland with whom she frequently liaises via email to get information for women in her community.

2.3.4 Telephone Helplines

Telephone helplines were not used by many of the participants, but are discussed here because one of the participants mentioned that she frequently uses HealthDirect, which the other participants had not heard about but were eager to learn of. The participant explained that calling HealthDirect is...

> *probably the best thing to do…because…if they've got queues of calls waiting what they will do is they will ring you within 30 minutes. They tell you when they're gonna ring you and they will ring you…That's my 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.*

The other participants were very enthusiastic to learn of HealthDirect and felt that it would be an information source that they would use in the future.

2.3.5 Mass Media

Health and wellbeing information campaigns through mass media, whether electronic or print, were considered valuable by the participants. They agreed that mass media campaigns should contain general information that is targeted at all women, rather than needing to be specific to each cultural group. They did suggest, however, that the campaign should feature on prime time television on major commercial networks; on community radio programs; at community events; and in community centres in order to reach as many women as possible. They also thought that having the campaign in several different languages, spoken in a clear voice or written in simple language would be an ideal way to educate isolated women, or smaller or insular communities, about health issues and services. The participants agreed that these campaigns are trustworthy, particularly if they are endorsed by a government agency or a reputable health organisation.

2.3.6 Friends and Family Members

As predicted from the survey findings, family members and friends were important sources of information for the focus group participants as well as for the women in their communities. One participant explained that the older generations in her community share their experiences and concerns about health and, through these conversations, help to diagnose, suggest treatments and reduce anxiety for one another. She said:

> *And 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'.*

This observation was shared by another participant:

> *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*.

This participant was particularly worried about this trend and continued:

> *I also say to 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'.*

The concern for some of the participants, as articulated above, is that many women in their communities take information from their friends and family members and do not follow the information up with a more authoritative source. The participant last quoted explained this trend as being bound up in trust.

2.4 Gaps, Barriers and Solutions

The participants spoke at length about the barriers to obtaining health and wellbeing information for CALD women. They also discussed how these barriers can be overcome so that CALD women, their families and communities can get the health and wellbeing information they need.

The participants considered men prohibiting women from accessing certain health services as a major barrier for CALD women, and highlighted the need for working holistically within communities—with both men and women—in order to facilitate good health literacy. A participant who had worked with new migrants stated the following:

> *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…*

This participant argued that it is vital that men are informed on the importance of women's health issues:

> *I think it is better if the men understand that the women need to be healthy, need a lot of things. 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.*

She said that in her experience of working with new migrants, many women say that they require the permission of their husbands to have mammograms and pap smears even after learning of the importance of such testing. She continued:

> *So really in this case the men have to be informed that their wife really needs health because back in their country…they don't care about the health of the women, just give birth, give birth and then that's it. There is not even a doctor for women. They don't believe that a woman should go to the doctor…then they bring that culture here…That is my experience with the new migrants…the husbands say 'what, checking the private parts? No way. The husbands do not understand that…if they want to have ten kids the women need to be [healthy].*

Another participant explained the efforts that have been made in her community to get men involved in talking about health issues:

> *I called on our elders because our elders are very much respected. So I took two of the women with me and we made contact with the men who were leaders of our men's groups and we went into their meeting space.*

She said that this approach is continuing and once every three months she and another two women go to the men's meetings with a gift for them and talk about the latest studies in women’s and men’s health. She concluded: “We had to include the men because the men will say [to the women] ‘yes I’m taking you’, or ‘no I’m not taking you’”.

She further explained that because new migrants from her community generally look for a church group in order to build links to a new community, she does “a lot of work with the church leaders to try and give them information to pass on to the new people.” Individuals, she argued, need to understand that their religious leaders cannot fix everything, as they often tend to think, and this can be achieved if church leaders themselves encourage individuals to seek out appropriate health information and advice.

Several of the participants agreed that the only way to successfully access CALD women is to work holistically within the community, involving men, other family members and community and religious leaders in the process. “We can’t work with just our women.”

Isolation was the second major barrier identified by the participants. The participants said that the most isolated women are literally house bound; economically and socially dependent upon their husbands and probably unlikely to attend community events. One participant explained that some women come from cultures where they are always in the company of other women, particularly when they go out, and yet sometimes have to migrate to Australia without family or friends. She said that these women often refuse to access services because they do not wish to go on their own.

The participants suggested that if health professionals could provide health clinics in cultural community centres, they may be able to access those women who are isolated or who are prohibited by their husbands from accessing mainstream health services. This would provide all CALD women with access to health services without the fear of having to travel to unknown places or use facilities that are inappropriate while being supported by other women in their community using the service at the same time.

Another participant suggested that providing information to children through school is the best way to change attitudes and behaviours over time. She explained, from personal experience and observation, that when children are taught about health in school they often feed information back to their mothers and fathers, ensuring that the information is turned into knowledge for the whole family.

DISCUSSION

Both the survey and focus group findings demonstrate that CALD women in the ACT are more active in obtaining health and wellbeing information from sources that keep them from having to consult a GP. This is not to say that they find GPs not useful or untrustworthy, but that the barriers associated with accessing a GP in the ACT are a powerful deterrent for CALD women, when they can more easily access information from other sources. It is noteworthy that most of the focus group participants agreed that it is faster—and sometimes cheaper—for them to go outside Australia, either physically or electronically, to obtain the information they require than to try to obtain it in the ACT. CALD women were one of the only groups surveyed by WCHM to not use a GP for information about general wellbeing.

The concept of trustworthiness manifests differently in the CALD women's responses than those of the wider survey sample. Throughout the overall research sample, women reported a preference for using health professionals, particularly GPs, to obtain health and wellbeing information because they have health knowledge and can therefore be considered a trustworthy and authoritative source. The CALD participants in the focus group spoke about trust and authority resting with individuals that are respected within the community—such as religious leaders or community elders—or with individuals that the women have had a long and close relationship with—such as friends and family members. The participants were less likely to rate a source as trustworthy simply because the source is health trained. This finding demonstrates that knowledge authority, like concepts of health, wellbeing and the body, are realised differently across cultures.

Aside from this, the responses from CALD survey respondents bore very little difference from those of the wider survey sample. The likeliness of using particular sources or the barriers perceived as limiting the use of particular sources were similar across the two groups.

The findings show that because CALD women are willing to obtain general wellbeing information from sources other than health professionals, it is vital to ensure that good quality health and wellbeing information is available through a variety of media in the places that CALD women frequent. These may include: religious centres, shopping centres, universities, CIT and community centres. The participants also said that health messages delivered via television would best be on commercial television stations as not all CALD women watch SBS.

The findings from the focus group also highlight that there are many differences and similarities between different cultural groups that extend beyond language. It is therefore important that services have an understanding of the different cultural groups that access them to be able to ensure that staff understand and are responsive to the particular needs of those groups.

CONCLUSION

This report has presented the survey responses of the 102 women from a CALD background who participated in WCHM's Health and Wellbeing Information Survey 2009, and the findings of a focus group conducted with a further eleven CALD women.

CALD women are proactive in seeking out health and wellbeing information; seeking it from a variety of sources, in a variety of media, on a variety of topics. Yet CALD women can face specific cultural and linguistic barriers that make obtaining the health and wellbeing information they need difficult, including not being able to access culturally appropriate services or information in languages other than English.

General health and wellbeing information, provided in a place that CALD women frequent, which includes the relevant details—phone number, web address, physical address—that allow access to more personalised information, will ensure that ACT CALD women have access to the good quality health and wellbeing information they need.

Ensuring that CALD women can access the health and wellbeing information they require in a culturally appropriate and understandable way enables them to fully engage with health decision-making for themselves and their families. However, providing culturally appropriate information involves knowing the major cultural groups in the ACT and taking time to understand their particular barriers and enablers to accessing information. This process will ensure that information providers work within families and communities, enabling all individuals to achieve and maintain good health and wellbeing.

Finally, like most groups in the ACT, CALD women need improved health literacy. 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.[14,15] 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.

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 women from CALD backgrounds.

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[14] 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.

[15] 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.

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