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# It goes with the Territory!

## The views of Older 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)*

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**Angela Carnovale**

April 2011

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# ACKNOWLEDGEMENTS

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Many thanks to all the community sector organisations that assisted WCHM throughout the research process, particularly for disseminating the survey widely to women across the ACT. Thanks especially to Judy Croston for her enthusiasm for the project and support to women to participate in the focus group. And last but not least a very warm thanks to all the women who participated in our research—either as survey respondents or focus group participants—and who encouraged other women to participate as well. It is your valuable experiences and insights that inform our mission for a health system that meets the needs of all women well.



## **Publication/Copyright Information**

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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**

Angela is the Social Research Officer at WCHM and has completed a Bachelor of Arts and Asian Studies at the Australian National University.

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# EXECUTIVE SUMMARY

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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 89 women aged 60 years or older who responded to the original health and wellbeing survey (who comprised 14 percent of the total sample) and the views of nine older 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.<sup>1</sup>

However, the factors that influence the level of women's health knowledge and literacy changes according to her health, social and economic circumstances. With an ageing population, disability levels and chronic illness are likely to increase in the ACT and increases in life expectancy will result in increases in the number of women with age-related chronic conditions. There is therefore a need for an improved understanding about the barriers that older women face.

It is WCHM's hope that this companion report will improve the understanding of the needs of older 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.

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<sup>1</sup> Murphy, M., Murphy, B. & Kanost, D., *Access the Women's Health Information: A Literature Review of Women as Information Seekers*, Women's Health Victoria; Melbourne, 2003, p. 8.

# RECOMMENDATIONS

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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 older 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 older women's needs.
- Develop its website—in partnership with stakeholders and women—to provide assistance to older women in using the Internet to source health and wellbeing information.



# INTRODUCTION

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In 2008 the YWCA Canberra undertook a study into the issues facing older women in the Canberra community. Within this study they looked at older women's information needs and found that only 30.7 percent were satisfied with information available about activities, services and support for older women. A further 12.8 percent of their respondents reported needing more assistance or support with getting information, with one in three reporting that they receive most, if not all of their information from social networks. When asked what the focus of a major project designed to respond to an ageing population should be, 80 percent of participants felt that it should focus on access to information.<sup>2</sup>

Older women are more likely to seek health and wellbeing information from a health professional—particularly a GP—than any other group who responded to the WCHM Health and Wellbeing Information Survey 2009. This is not because older women find health professionals to be more useful and trustworthy than other health and wellbeing information sources, but because they value the trusting and safe relationship that can be built with a health professional overtime that cannot be built with other sources. Nevertheless, older women are conscious of the increasing difficulty of achieving and maintaining such a relationship in the ACT's primary healthcare environment and are pragmatic about having to look to other sources to find the information they need.

This report is a presentation of the 89 completed responses received from women aged 60 or over who participated in the survey and the findings of a focus group conducted with a further nine older 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 89 women in the overall survey sample who reported being aged 60 years and over.

Section two is a presentation of the focus group findings. It covers the major areas of discussion which were: the definition of good quality health and wellbeing information, information specific to older women, GPs, the Internet, family members and friends, and the gaps and barriers that affect older women as well as the solutions proposed.

Section three is a discussion of the major themes that emerged through the study findings.

The report begins with a brief review of the literature relating to older women as health and wellbeing information seekers. A complete literature review was featured in the *It goes with the*

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<sup>2</sup> Alison Barclay (ed.), *Exploring the Needs of Older Women in the Canberra Community*, YWCA of Canberra, 2009, p. 28.

*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 older women.

# METHODOLOGY

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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 14 percent (n=89) were aged 60 years or older.

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).<sup>3 4</sup> 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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<sup>3</sup> 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.

<sup>4</sup> 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.

Participants for the older women's focus group were found through one woman in the ACT who works closely with older Canberrans.

# LITERATURE REVIEW

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Much of the research on older women and health information indicates that they rely more heavily upon their primary health care provider—predominantly GPs—for their health and wellbeing information needs; more so than any other group of women. The research also suggests that older women are less autonomous in regard to health decision-making and less assertive in delineating what they want from health services. As a result, once they have built a relationship with a health provider, they incline toward that health provider to meet the majority of their health and wellbeing needs.<sup>5, 6</sup>

It is also true, however, that older women frequently turn to family, friends and other women who share health issues to find health information from a trustworthy sensitive source when they cannot find it from mainstream sources.<sup>7,8</sup> The process of sharing information through sharing experience is not unique to older women, but was a feature of the older women’s focus group discussion, which will be explored below.

In 2003 Women’s Health Victoria (WHV) published an extensive literature review of and survey on women as information seekers. This report found that older women reported significant problems with, and concerns around accessing health information, especially on issues specific to their needs such as menopause (and hormone replacement therapy).<sup>9</sup> Being unable to access the information they needed was particularly difficult for older women who did not have dependent children (to help them access the Internet) or who were unwell, living alone, or less educated.<sup>10, 11</sup>

According to the ACT Government’s *ACT Strategic Plan for Positive Ageing 2010-2014*, the ACT has one of the fastest-growing populations of people aged 60 years and over in Australia, and this is expected to grow from 15.8 percent in 2010 to 19.6 percent by 2020, and to 22 percent by 2030.<sup>12</sup> These statistics, coupled with the knowledge that one in four older people in the ACT are living in lone households, with the majority of these being female households, indicates that removing the barriers to access of health and wellbeing information for older women needs to be a priority for the ACT.

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<sup>5</sup> Murphy, M., Murphy, B. & Kanost, D., *A Literature Review of Women as Information Seekers*, Women’s Health Victoria, Melbourne, 2003, p. 45.

<sup>6</sup> Murphy, M. & Murphy, B., *Access to Women’s Health information: A survey of Victorian women as Information Seekers*, Women’s Health Victoria, Melbourne, 2003 pp. 15 & 29.

<sup>7</sup> Wathen, C. & Harris, R., “I try to take care of it myself” How rural women search for health information”, *Qualitative Health Research*, 17(5), 2007, pp. 639-651.

<sup>8</sup> Murphy, M., Murphy, B. & Kanost, D., *A Literature Review of Women as Information Seekers*, Women’s Health Victoria, Melbourne, 2003, p. 45.

<sup>9</sup> *Ibid.*

<sup>10</sup> *Ibid.*

<sup>11</sup> Murphy, M., *Access to women’s Health information: Research Summary*, Women’s Health Victoria, Melbourne, 2003, p. 12.

<sup>12</sup> ACT Department of Disability, Housing and Community Services, *ACT Strategic Plan for Positive Ageing 2010-2014*, ACT Government, Canberra, 2010.

However, considering the GP shortage in the ACT it will be increasingly difficult for older women to build and sustain a relationship with a single health provider for all of their health and wellbeing needs. It is therefore essential that older women have the opportunity to develop sound health literacy so that they can locate, assess, understand and apply the information that they obtain.

The Department of Health and Ageing recently reported that 60 percent of Australians lack the basic health literacy skills to acquire, understand and use health information needed to meet everyday needs.<sup>13</sup> In terms of improving the national level of health literacy, and applying it, Australia trails behind other western countries.<sup>14</sup> Therefore, programs to improve individual's health literacy through education need to be developed.

Improved health literacy does not just mean providing women with more health information, as information alone will not promote lasting behaviour changes.<sup>15</sup> Instead, health literacy is needed to engage with the health information, empower women to understand it, make decisions that promote health, engage in health prevention strategies, access health services and encourage a positive and healthy attitude.<sup>16</sup>

Practical applications of health literacy include being able to read medical documents (such as consent forms or medication instructions),<sup>17</sup> knowing when and how one should go about being screened for disease,<sup>18</sup> knowing when bodily functions are symptomatic of ill health, and knowing how and where to seek necessary health care assistance.<sup>19, 20</sup> Research shows that low health literacy reduces individual's understanding of their health, compliance with health plans, and results in poorer management of their health.<sup>21</sup>

Good health literacy coupled with access to useful and trustworthy health and wellbeing information is important for an ageing population who may not have family to accompany them to appointments with health professionals and who may have to access information from multiple sources for different health and wellbeing concerns.

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<sup>13</sup> Nutbeam, D., "Building health literacy in Australia", *Medical Journal of Australia*, 191(10), 2009, pp. 525-6.

<sup>14</sup> Adams, R., Stocks, N., Wilson, D. & Hill, C., "Health literacy a new concept for general practice?", *Australian Family Physician*, 38(3), 2009, pp. 144-147.

<sup>15</sup> Renkert, S. & Nutbeam, D., "Opportunities to improve maternal health literacy through antenatal education: an exploratory study", *Health Promotion International*, 16(4), 2001, pp. 381-388.

<sup>16</sup> VonWagner, C., Knight, K., Steptoe, A., & Wardle, J., "Functional health literacy and health promoting behaviour in a national sample of British adults", *Journal of Epidemiology & Community Health*, 61(12), 2007, pp. 1089.

<sup>17</sup> Hardyman, R., Hardy, P., Brodie, J., Stephens, R., "It's Good to Talk Comparison of a Telephone help line and website for cancer information", *Patient Education and Counselling*, 57, 2005, pp. 315-320.

<sup>18</sup> 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.

<sup>19</sup> Adams, R., et al., *op cit*.

<sup>20</sup> Renkert, S. & Nutbeam, D., *op cit*.

<sup>21</sup> Torres, R. & Marks, R., *op cit*.

# SURVEY FINDINGS

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## 1.1 DEMOGRAPHIC CHARACTERISTICS OF THE SURVEY RESPONDENTS

There were 89 complete survey responses from women who were aged 60 years or older, making up 14 percent of the total survey sample. Women aged 60 years or older make up 14.9 percent of the female population in the ACT.<sup>22</sup>

**Educational Attainment:** Twenty-two percent (n=20) of respondents had completed a high school qualification; 72 percent (n=64) had completed some post high school study (Certificate I-IV, Diploma or Certificate, Advanced Diploma, Bachelor's Degree, Postgraduate Degree).

**Household Composition:** Forty percent (n=36) of respondents were single (including separated or widowed) with no dependent children; 49 percent (n=44) were partnered with no dependent children; 2 percent (n=2) were single (including separated or widowed) with dependent children; 2 percent (n=2) were partnered with dependent children; 6 percent (n=5) listed their household composition as other.

**Household Income:** Thirty-eight percent (n=34) of respondents reported a total household income of \$41,599 or less; 33 percent (n=29) reported a total household income between \$41,600 and \$88,399; 19 percent (n=17) reported a total household income of \$88,400 or more; 10 percent (n=9) preferred not to answer.

**Location:** Twenty-four percent (n=21) of respondents were living in Canberra's Inner North; 6 percent (n=5) were living in Canberra's Inner South; 19 percent (n=17) were living in Belconnen; 5 percent (n=4) were living in Gungahlin or Hall; 22 percent (n=20) were living in Woden Valley or Weston Creek; 19 percent (n=17) were living in Tuggeranong; 5 percent (n=4) were living in Queanbeyan, Jerrabomberra or Other NSW.

**Work Status:** Twelve percent (n=11) of respondents were working full-time; 21 percent (n=19) were working part-time or casual; 7 percent (n=6) were not working (studying full-time, not currently in paid employment, or full-time mother or carer); 60 percent (n=53) of the respondents were retired.

**Aboriginal or Torres Strait Islander:** Of the survey respondents, 2 percent (n=2) identified as a woman of Aboriginal or Torres Strait Islander descent.

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<sup>22</sup> 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.

**Carer Responsibilities:** Of the respondents, 17 percent (n=15) reported having carer responsibilities for someone other than a dependent child.

**Culturally and Linguistically Diverse:** Of the survey respondents, 7 percent (n=6) identified as a woman from a culturally and linguistically diverse background.

**Women with Disabilities:** Thirty-seven percent (n=33) 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

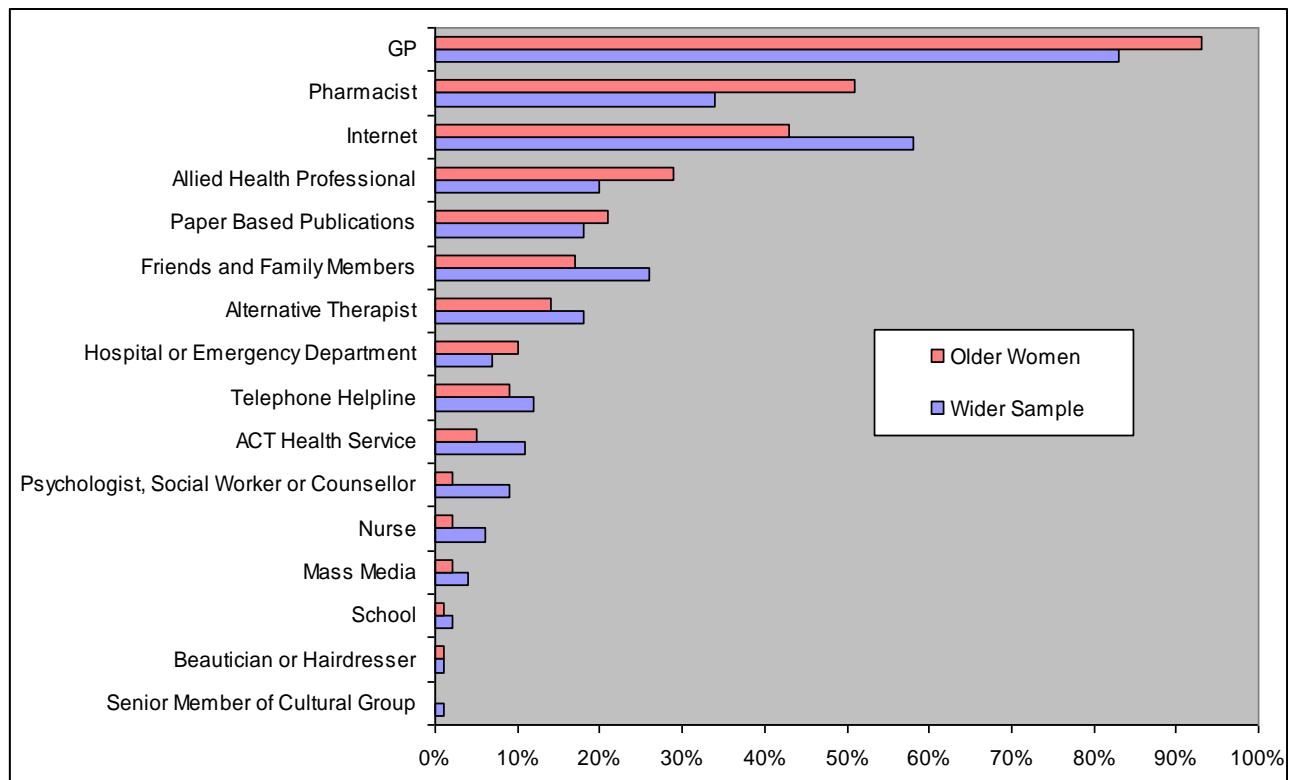
Ninety-seven percent (n=84) of respondents reported seeking health and wellbeing information for themselves, 6 percentage points higher than the wider survey sample; 43 percent (n=37) reported seeking information for their partner and 40 percent (n=35) for their children, both lower than the wider survey sample; 29 percent (n=25) reported seeking information for other family members; 23 percent (n=20) sought information for their friends; 15 percent (n=13) for other people in their community; 7 percent (n=6) for parents; and 6 percent (n=5) for another person.

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

Ninety-three percent (n=81) of respondents reported that they are most likely to obtain health and wellbeing information from their GP, ten percentage points higher than the wider survey sample; 51 percent (n=44) reported that they are most likely to obtain information from a pharmacist; and 43 percent (n=37) would most likely obtain information from the Internet.

Following these top three sources, 29 percent (n=25) of respondents would most likely obtain information from an allied health professional; 21 percent (n=18) from paper based publications; 17 percent (n=15) from friends or family members; and 14 percent (n=12) from an alternative therapist.

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



## **1.2.2 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.

### **1.2.2.1 General Wellbeing Information**

In the twelve months prior to completing the survey, the sources most commonly used by respondents for general wellbeing information were GPs, used by 60 percent (n=53) of respondents; pharmacists, used by 40 percent (n=28); and paper based publications, used by 30 percent (n=27) of survey respondents.

The sources that the respondents most commonly used and the sources they preferred to use for general wellbeing information were slightly different. Forty-nine percent (n=44) of respondents would prefer to use a GP or medical doctor; 24 percent (n=21) would prefer to use the Internet; and 10 percent (n=9) would prefer to use mass media.

### **1.2.2.2 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 70 percent (n=62) of respondents; pharmacists, used by 53 percent (n=47) of respondents; and the Internet, used by 29 percent (n=26).

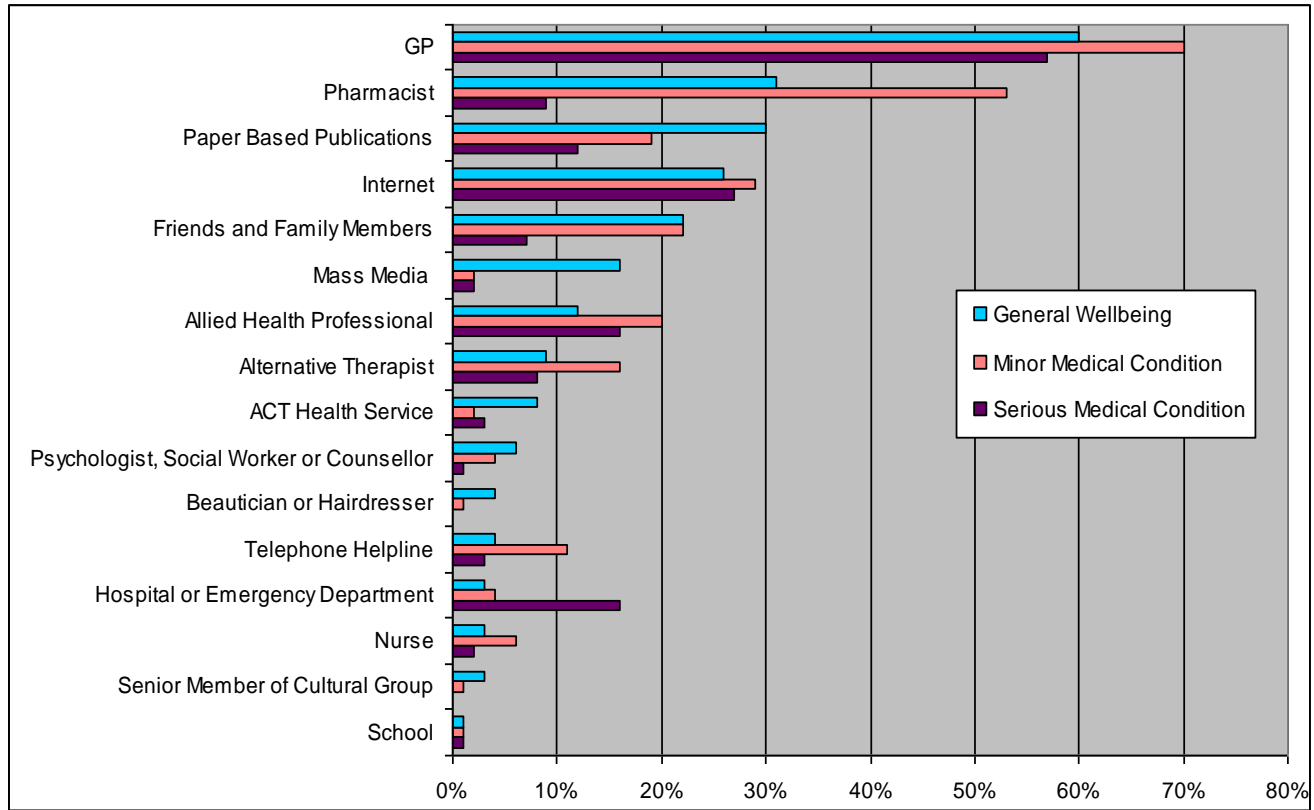
The sources that the respondents most commonly used and the sources they preferred to use to obtain information about minor medical conditions were the same. Sixty-four percent (n=57) of respondents would prefer to use a GP or medical doctor; 19 percent (n=17) would prefer to use a pharmacist; and 15 percent (n=13) would prefer to use the Internet.

### **1.2.2.3 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 57 percent (n=51) of respondents; the Internet, used by 27 percent (n=24) of respondents; and hospitals or emergency departments or allied health professionals, each used by 16 percent (n=14).

The sources that the respondents most commonly used and the sources they preferred to use to obtain information about serious medical conditions were slightly different. For information on serious medical conditions, 75 percent (n=67) of respondents would prefer to use a GP or medical doctor; 28 percent (n=25) would prefer to use a specialist; and 6 percent (n=5) would prefer to use either a hospital or emergency department or paper based publications.

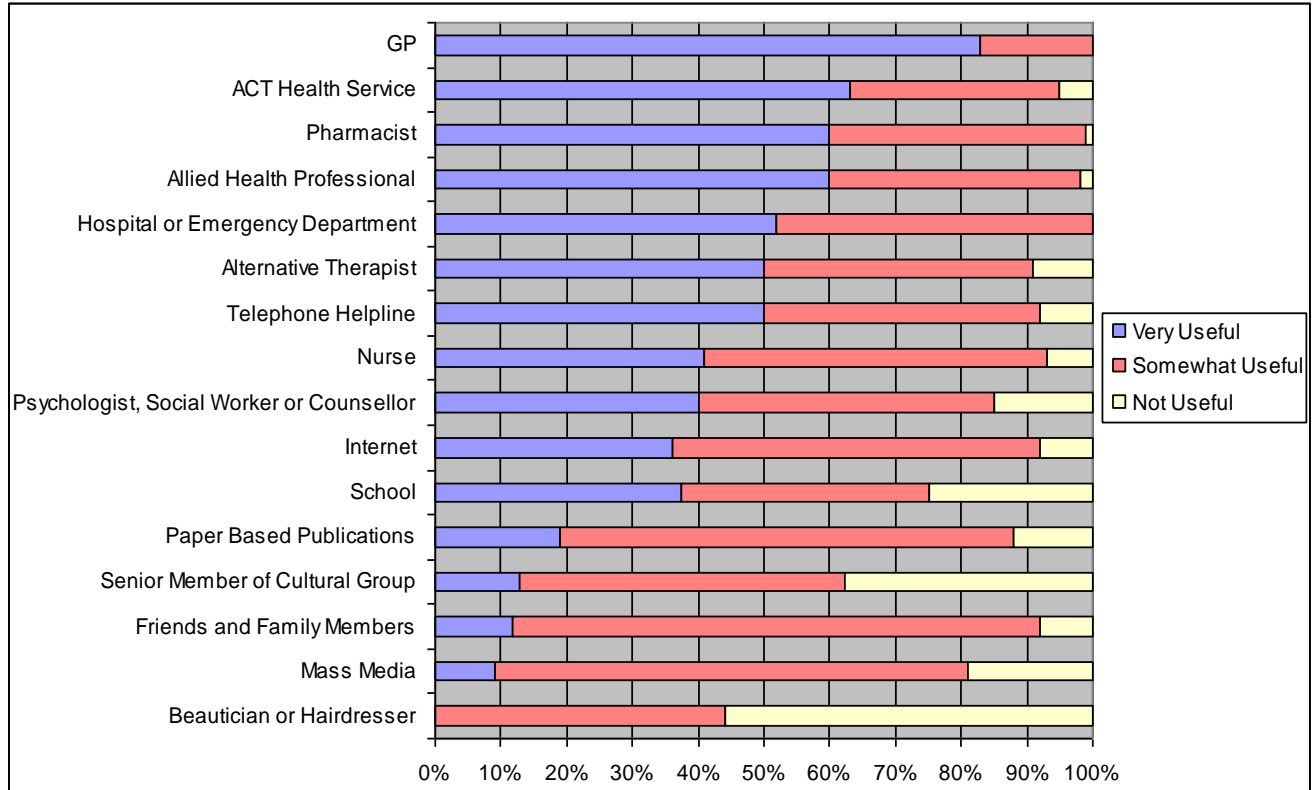
**Figure 2: Use of source for general wellbeing information in twelve months prior to survey completion**



### 1.2.3 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**

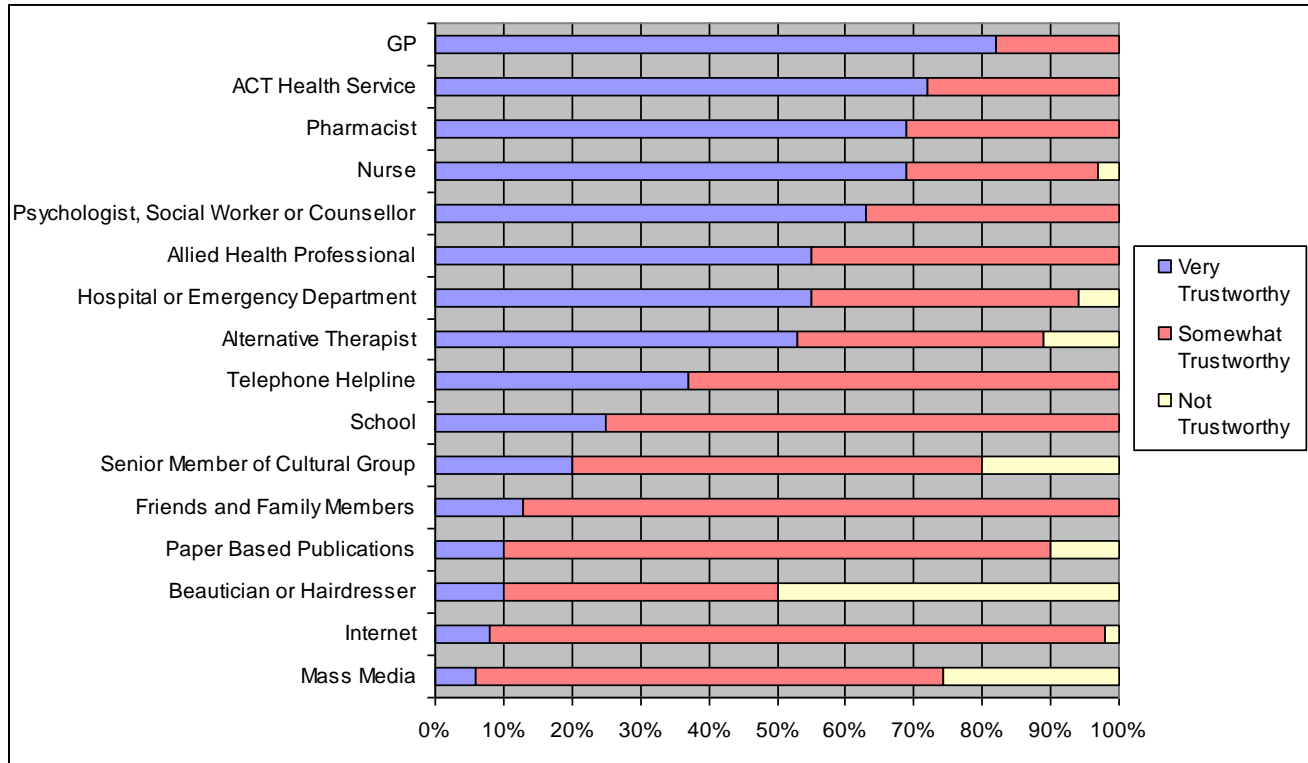


Unsure/don't use answers have been filtered out in order to present the level of usefulness of information from each source only for those respondents who used them. Many chose not to answer the question at all; therefore the figures in the graph represent 100% of those respondents who rated the information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

### 1.2.4 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.

### 1.2.5 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)	61 percent (n=52)
The source is easily accessible (suitable location)	59 percent (n=51)
I have already established a trusting relationship with the source	54 percent (n=46)
The information provided is of high quality	51 percent (n=44)
The information is understandable and I am supported to understand it	30 percent (n=26)

## 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, 70 percent (n=57) reported that they have considered obtaining health and wellbeing information from an alternative therapist. Of these, 26 percent (n=15) listed being unsure of the quality of information obtained from alternative therapists as the most significant barrier. The cost of using alternative therapists was a concern for 18 percent (n=10).

**Internet:** Of the respondents, 85 percent (n=70) reported that they have considered obtaining health and wellbeing information from the Internet. Of these, 60 percent (n=42) listed being unsure of the quality of the information obtained from the Internet as the most significant barrier. Thirty-three percent (n=23) of respondents reported no significant barriers to obtaining health and wellbeing information from the Internet.

**Paper Based Publications:** Of the respondents, 93 percent (n=79) 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 47 percent (n=37) of these respondents. Forty-nine percent (n=39) reported no barriers to obtaining health and wellbeing information from paper based publications.

**Psychologists, Social Workers and Counsellors:** Of the respondents, 63 percent (n=53) reported that they have considered obtaining health and wellbeing information from a psychologist, social worker or counsellor. Being unsure of the quality of the information obtained from psychologists, social workers or counsellors was identified as the most significant barrier by 13 percent (n=7) of these respondents. Seventy-nine percent (n=42) reported no barriers to obtaining health and wellbeing information from a psychologist, social worker or counsellor.

**Telephone Helplines:** Of the respondents, 51 percent (n=42) 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 24 percent (n=10). Seventy-four percent (n=31) reported no barriers to obtaining health and wellbeing information from telephone helplines.

### **1.3.2 Gaps in Health and Wellbeing Information**

Eight percent (n=7) of respondents reported there being health and wellbeing information that they were not able to obtain. The respondents said that they could not find information about: health and wellbeing issues associated with age; preventative health measures; chronic pain; explanations of medical tests and results; and general information on specific conditions.

A comment from the survey:

*It seems that not all Health Professionals are of the opinion that an individual has a right to all the information about themselves and the impact upon them. Too often it is left to the individual to find out what questions they need to ask to get the information.*

### **1.3.3 Barriers to Obtaining Health and Wellbeing Information**

Seventeen percent (n=15) of respondents reported experiencing significant barriers in obtaining the health and wellbeing information they require. The barriers reported were: cost; waiting times for appointments with health professionals and for elective surgery; access to public dental services; availability of health professionals; access to personal medical records; not being listened to or having personal views respected; short consultation times; and not having questions answered.

Some comments from the survey included:

*Obtaining my medical records when my GP moves from one practice to another within ACT. I would like to see this changed so my records are accessible to any GP or Hospital I may have to attend across Australia.*

*The amount of time allowed for each individual person for an appointment and whether the medical professional is familiar with the individual file or notes. Some patients do not like to ask too many questions as it results in the fee being doubled.*

*Time and willingness of specialists to answer all questions can sometimes be a problem.*

*Inability to access my doctor as often, or for as long, as I would like.*

## 1.4 BARRIERS TO ACCESSING GENERAL PRACTITIONERS

### 1.4.1 Respondents Who Do See a General Practitioner

Of the survey respondents, 100 percent (n=89) 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	42 percent (n=34)
High cost	17 percent (n=14)
Not being able to find a GP who bulk bills	12 percent (n=10)

Fifty-seven percent (n=46) of respondents reported that they had not experienced any significant barriers in accessing a GP.

In terms of the gender preferences of GPs, 4 percent (n=3) of respondents always insist on seeing a female GP; 41 percent (n=34) prefer a female GP but will see whoever is available; 52 percent (n=43) don't care if the GP is male or female; 2 percent (n=2) prefer a male GP but will take whoever is available; and one respondent insists on seeing a male GP.

In terms of the cultural background of GPs, 2 percent (n=2) of respondents insist on seeing a GP of their own cultural background; 39 percent (n=33) prefer to see a GP from their own cultural background but will see whoever is available; 58 percent (n=49) 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, 40 percent (n=33) of respondents always insist on using their local GP; 17 percent (n=14) prefer to use their local GP but will go wherever they can get an appointment; and 43 percent (n=36) don't mind travelling if they find a GP that they like.



# FOCUS GROUP FINDINGS

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The older women who participated in the focus group were eager to identify solutions to the difficulties they currently experience in accessing the health and wellbeing information they need. While they agreed, like the respondents of the survey, that they would prefer to receive information from one regular GP, they were pragmatic about the barriers to realising this in the ACT and were eager to demonstrate a commitment to taking responsibility for their own information needs through engaging with a range of information sources. They did, however, make several innovative suggestions that would synthesise their information needs with their seeking preferences.

## 2.1 GOOD QUALITY HEALTH AND WELLBEING INFORMATION

The focus group began with a discussion about the definition of good quality health and wellbeing information. The participants felt that good quality health and wellbeing information is information upon which a person can make informed decisions about their health and lifestyle. Generally, the participants felt that information that instructs individuals to make lifestyle changes is not as effective as information that presents an argument for taking particular health and wellbeing measures and respects an individual's ability to make informed decisions.

They also acknowledged, however, that making decisions about one's health—particularly the decision to enact change—requires more than information; it requires role modelling and constant support from peers and health professionals. Following this line, one participant reflected that there is ample health and wellbeing information that individuals can access, but they do not always have the skills required to turn that information into knowledge or action. She felt that education, or health literacy, is the crucial element in assisting individuals to know why they should adopt the information in their own lives or how they could go about doing so, especially how and where they could take action and access relevant services. She said that...

*there are some people who have a confidence level or an education level to then go and pursue those things. But there are always going to be people who don't have that confidence, or the access to be able to then take the next step.*

She concluded that women in the ACT have the advantage of a good education coupled with good access to services, which allows them to take information and understand how and why they could apply it to their own lives.

Another participant disagreed with this sentiment, saying that while preventative health information is a fantastic ideal, most women only absorb information when they need it. She agreed with some other participants that preventative health and wellbeing information would best be incorporated into the basic education structure, but furthered that for public education campaigns to pre-empt the community's health information needs and present information in such a way as to influence individuals is too big an ask because individuals "filter out what you need right now".

Overall, most of the participants agreed—unlike the participants in any other focus group—that each individual is responsible for their own health and wellbeing, and for seeking the information they require. “It gets back to you as an individual. You’ve got to be responsible for yourself. You can’t expect everything to come knocking on your door.”

## **2.2 INFORMATION FOR OLDER WOMEN**

While the participants acknowledged that they have to be active in seeking the information they need, they also agreed that there are particular challenges or needs for older women accessing health and wellbeing information.

The fact that women over 70 are no longer required to have regular pap smears was particularly controversial among the participants. One participant reported that when she turned 70, her GP informed her that she no longer needed regular pap smear tests and therefore would no longer receive reminders. The participant was ambivalent about this information and shared with the other participants that her children felt that she should continue to have pap smears irrespective of her age, even though it suited her to not have them anymore. The other participants encouraged her to continue with regular pap testing in order to guard against cervical cancer, irrespective of the fact that the incidence rate drops after the age of 70. “You’ve still got the same bits and you can still get cancer” one participant advised, to which another added “they’re saying that you don’t have to but it’s still a choice to go.”

Following on from this, a couple of participants felt very strongly about the negative focus of health information for ageing women. “All the passive information that’s out there is fear tactics. Do you see any information out there that says: ‘Great you’re 60 start a new sex life’?” They felt that general health and wellbeing information and preventative health campaigns should inform women about the possibilities for them at particular ages and life stages, not the risks and health conditions associated with being a particular age.

However, it is not always information about health and wellbeing that older women need, but information on managing major life events such as putting a loved one into care. One participant shared her experience of having her husband assessed and admitted into an aged care facility, which she found highly distressing.

*I was just so confused. I didn't really know who to turn to. And in the end I went to Alzheimer's and they helped me a lot. But I had to do a whole lot of forms for Vet Affairs and a whole lot of forms for Centrelink, I had to do another lot for Vet Affairs again, which I've just got the reply back now. But it's just all so confusing and I mean, I managed to work my way through it...but I don't know how people get on when they don't really understand. You need help with those things...you're confronted with a book of about fifty pages that you have to fill in...It was a very difficult time in my life... [others] weren't forthcoming with help and I was too proud.*

At this point another participant added...

*At that stage you're very, very emotional, so all your faculties aren't with you...it's just awful. You really have to be there to know how horrible it is.*

Another participant strongly agreed with this...

*It makes me worry...when my husband and I have to do this kind of paperwork, even tax forms or something, and I think 'now look, I'm an educated woman, he's an educated man, we're struggling with this. What on earth is that poor single woman, with five children, in a government home, what hope has she got to understand this?'*

## **2.3 INFORMATION SOURCES**

The participants then moved on to discussing which information sources they currently use and the issues they associate with each.

### **2.3.1 GPs**

One participant, who is currently caring for her very elderly mother, said that her mother implicitly trusts the information she obtains from her GP, which the participant felt was at the expense of seeking other opinions and treatments that may be beneficial. This anecdote supports research conducted by Women's Health Victoria (WHV) into Victorian women's health and wellbeing information seeking trends and preferences, which found that older women are less likely to be active in seeking health information, relying almost exclusively upon their GP.<sup>23</sup> WHV found that older women are far less likely to report receiving health information passively from any source other than their GP, which may indicate that many GPs are proactive with pre-empting the information needs of older women.<sup>24</sup> The participant caring for her mother agreed with this stating that her mother "is not going to try and find anything, or get any new knowledge" outside of the knowledge provided to her by her GP.

Most participants agreed, like participants across the study, that they would insist upon a female health professional for sexual and mental health matters but would be happy to see a male health professional for everything else.

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

Not all participants agreed with this sentiment. One participant said, "that's not to say that every female doctor has a good bedside manner and is supportive, they're not. I had one for five years who...came across as very uncaring." Overall the participants were also pragmatic about their

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<sup>23</sup> 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. 27.

<sup>24</sup> *Ibid.*

choices of GP in the current ACT climate, with one saying that “it boils down to who you can see as quickly as possible”.

GP sensitivity was perhaps more of a concern for the participants than whether the GP is male or female, with some participants feeling completely unable to find a GP who could respond sensitively to their needs. One participant said that she is “so disenchanted with what GPs have to offer” that she does not prefer to have a GP as part of her sources of health and wellbeing information. However, she qualified that this preference, or lack thereof, is...

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

The quality of relationship between the participants and the information source was vitally important, and it was no less so for the participants in their relationship to their GP. In fact, several of the participants stated that despite the difficulties they sometimes experience in accessing and using GPs, they still prefer to have one with whom they have explained their history and built a relationship. In part this preference is due to the perception that “you do need to have that history with a GP to get onto further things in the medical system”, such as scripts for medication and referrals to specialists. But it is also due to the value placed on maintaining a constant and caring relationship with a health care provider. Not having this relationship can prove stressful for women, as demonstrated in the following exchange between participants...

*Participant One: I'm 55 and I don't remember ever, ever having a GP who I felt close to or who I could trust and I've had both male and female...and yet that next level down, or even further down—in places like the Women's Health Centre, Women's Information and Referral Centre, Women's Domestic Violence Refuges and even allied health professionals like massage therapists and even physiotherapists—[are] particularly caring and thoughtful. Even my vet looks after my pets with more care and attention...Therefore I've built up this barrier towards my doctor and [when] she moved...she's been my doctor for about six years, I breathed a sigh of relief.*

*Participant Two: But you had a choice to change her. I mean, you don't have to go to her.*

*Participant One: Yeah, but I've been quite sick over the past five years and sometimes those choices are too hard.*

*Participant Three: You don't want to start another relationship.*

Participant one, along with other participants felt that while they definitely want to be able to obtain health and wellbeing information from a person with health knowledge, they do not necessarily require that person to be a GP. For example, one participant wants “someone that can suggest different avenues. It certainly needs to be a person...Someone with a bit of credibility, not to know

everything, but to suggest different avenues”. Another participant agreed that this person would be better if not a GP because they would be able to recommend “‘left field stuff’ like alternative therapists and would not necessarily say ‘you need to go and see this specialist or that specialist’ when you know that all you really need is a good massage or a bit of acupuncture.” Another participant described this person as a “clearinghouse of health issues”; a person who looks at the client holistically and provides broad information. The participants said they want a person with whom they can canvas their concerns and receive information or referral that is specific to their needs. The participants agreed that the benefits of this would be numerous, and would greatly reduce the current burden on GPs.

*If you’re going to a health centre and you’re getting that relationship and you’re treated as an individual and you feel like you’ve been heard, then maybe the GP does become more mechanical, and you don’t need the relationship out of that, you need the service.*

It cannot be underestimated just how beneficial for health and wellbeing the participants considered a caring and ongoing relationship with a health professional. “We take a lot of responsibility for [our health] ourselves, as we should. But isn’t it nice to have someone to say ‘how are you going on this? Don’t forget about so and so and such and such’.”

### **2.3.2 Internet**

Although most of the participants do use the Internet for health and wellbeing information, they were rather nonchalant about their use of the Internet for health and wellbeing information. Consistent with the survey findings, the participants who do use the Internet agreed that common sense and scepticism were important tools for navigating the health and wellbeing information available from it.

The participants were interested in knowing about trusted and reliable health and wellbeing information websites because this would allow them to access information from the Internet without worry. They felt that endorsements from women with public notoriety and credibility would make them more inclined to go directly to particular sites when seeking health and wellbeing information. The participants agreed that the public figure, like a radio or television presenter, would be better than a politician.

### **2.3.3 Friends and Family Members**

The participants agreed that while family members and friends may not provide the most accurate or current information, they are not only a good starting place but *the* starting place for most women. “Women talk, that’s the best thing we do.” This participant explained that she is caring for her mother who has Alzheimer’s and when she obtains any new information about the illness she tells absolutely everyone, including the people that serve her in the supermarket, in the knowledge that they may need that information one day.

Another participant said that she thinks that involvement in a community activity can often fulfil the gap left by not having one’s family in the ACT, and that being a part of such activities usually opens women up to the opportunity to receive information from peers that she may not have otherwise

obtained; particularly if she is isolated or marginalized. This participant would like to see more funding go into making community activities more available to women.

## **2.4 GAPS, BARRIERS AND SOLUTIONS**

The participants felt—like many in other focus groups—that more preventative health information is needed as it is often when an individual has reached crisis point that they obtain information. One participant said that she would like there to be more preventative information available to the general public that informs people of what they may need to know about at sometime in their lives. She gave the example “coming into your 60s? There’s a chance you might need this.” She would like there to be simple thoughts, ideas or pieces of information that people can draw on when they are presented with a particular health issue.

At this point, some of the participants devised the idea of ‘health action plans’ which would help women, in this case older women, to know in which order they need to do things when dealing with particular issues, such as putting a loved one into care or arranging a funeral. These action plans could be pre-emptive and simple sources of information that can be kept on hand for when or if a particular health issue arises. One participant said that they could be drawn up by the relevant department and then pulled together by an organisation such as WCHM. They would then be made available online, in health centres, hospitals, community centres, education centres, shopping centres, pharmacists, or even feature as part of a ten minute radio or television segment on ‘what to do if...’ The action plan would be in simplified language and would be dot pointed. The participants considered them primary sources of information; something that can be obtained before a person actually needs the information and without the guidance of a person, health professional or otherwise.

Some of the other participants preferred the idea of going to a ‘health resource centre’ and seeing a ‘health agent’ who could help to devise specific action plans. Your health agent would say “these are the things you need to think about, these are the things you need to do and these are the forms that you need to start filling out.” These participants felt that it is important to be able to sit down with a person and talk about options that are relevant to them and their circumstances, and to be able to go back to that person when in need of assistance with forms and applications; someone that can take them through the administrative side of a health issue, which is often the know-how that people lack. One participant likened it to the services available at the library and thought perhaps the two could be fused.

# DISCUSSION

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The older women survey respondents were more likely to seek health and wellbeing information from a GP than any other group of women. Further, the rate at which they would likely use any other information source dropped significantly to 50 percent for pharmacists and even lower for all other sources. A trend toward obtaining health and wellbeing information from GPs was strengthened as older women respondents listed GPs as the main source used—and preferred—for general wellbeing information, information about minor medical conditions and information about serious or chronic medical conditions. And yet despite this, women aged 60 years and older were more generous with their ratings of “very useful” and “somewhat useful” and “very trustworthy” and “somewhat trustworthy” in their ratings of all information sources than any other age group; reserving “not useful” for very few sources and judging fewer sources overall as “not trustworthy” than any other age group.

Women aged 60 years and older were the only group of respondents to not regard cost as one of the five most important factors in deciding where to seek health and wellbeing information. Rather, they were the only age group to consider it important that the information is understandable and that they are supported to understand it. This may provide some explanation for older women’s preference for obtaining information from health professionals, particularly GPs, as they are more likely to ensure that the information provided can be understood and can provide women with the support to understand information in a way that the Internet or family and friends perhaps cannot.

The fact that older women do rely upon health professionals for the majority of their information may also explain why fewer older women respondents reported there being information about their health and wellbeing that they are unable to obtain than any other age group.

There were also fewer older women who reported there being significant barriers to obtaining the health and wellbeing information they need. Only 17 percent (n=15) reported that there were significant barriers, while the average for the other age groups was 48 percent. Of the barriers listed by those fifteen respondents, almost all of them related exclusively to health professionals as information sources. This suggests either that the respondents use these sources more frequently than any other group, or that they do not experience any significant barriers accessing information from other sources. Recent research, coupled with our findings, suggest that older women simply rely upon health professionals for most of their health and wellbeing information needs.

But the participants of the focus group demonstrated that they are happy to use a multitude of sources apart from a GP provided they know which sources are useful and trustworthy. While the participants felt that ample health and wellbeing information was available, they were not clear on where to access it and doubted their ability to navigate the ACT health system, and then manage and apply information effectively in their lives.

The way health messages are communicated was an important point for the focus group participants. They want information that is life and health affirming, not fear and illness based. They don't want to be threatened into taking particular action in regard to their health and wellbeing for fear of illness, disease and death. Rather, they want to be shown all the wonderful things there are to be gained and enjoyed by taking certain health and wellbeing measures. The exchange that the participants had about the need for regular pap smear testing after the age of 70 was an important example of how women share information and encourage one another to be proactive about their own health and wellbeing. But it was also an example of how public health messages need to be communicated in a way that will encourage those they are aimed at to understand and remember them.

Finally, older woman want information that prepares them for transitions in later life; information they don't know that they don't know but may need as they age. It is difficult to provide this kind of information in the personalised, one-stop shop format that the older women respondents and participants said they prefer. Therefore, the challenge is to utilise passive information sources, such as mass media or written publications in a way that appeals to older women. In a way that is personal, affirming, endorsed by a credible individual or organisation and which can demonstrate an authority on health and wellbeing.



# CONCLUSION

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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.<sup>25</sup> 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 89 women aged 60 years and over who participated in WCHM's Health and Wellbeing Information Survey 2009, and the findings of the focus group conducted with a further nine older women.

As has been demonstrated throughout the survey and focus group findings, older women rely upon health professionals—particularly GPs—for the majority of their health and wellbeing information. They are also, however, pragmatic about the reality of GP shortages in the ACT and eager to see alternative sources of information for older women in the ACT that can provide them with personalised information that is tailored to their history, circumstances and preferences in the way that information provided by a GP would be.

The preference for a people-based one-stop shop was echoed by participants throughout the research who feel that the problem is not so much a lack of information, but that having to wade through information in order to find trustworthy and credible information is challenging in our increasingly information soaked social environment. Older women need the tools to sort through the health and wellbeing information already available and the skills or health literacy to understand it.

Ensuring that older women can access trustworthy and understandable information on a wide range of topics not only ensures that they can fully engage with health decision-making and cope well with the transitions of later life, but also ensures that they can access sources that offer broader ranging information about general wellbeing and reduces the burden and reliance on GPs.

All aspects of health knowledge and care are affected by an individual's health literacy, which should be developed in coordination with the creation and dissemination of health and wellbeing information. Health literacy assists individuals to engage with and understand health and wellbeing information. It enables them to navigate health systems, access care, and understand their own

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<sup>25</sup> 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.

health risks and needs.<sup>26 27</sup> 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 older women.

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<sup>26</sup> Torres, R. & Marks, R., *op cit.*

<sup>27</sup> von Wagner, C., Knight, K., Steptoe, A. & Wardle, J., *op cit.*

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