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# It goes with the Territory!

## The views of ACT Women with Disabilities 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**

February 2011



**whmi**  
women's centre for health matters ●

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# ACKNOWLEDGEMENTS

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Thanks to Sue Salthouse from Women With Disabilities ACT (WWDACT) for inviting and supporting women with disabilities to participate in the health and wellbeing information survey as well as the follow-up survey for women with disabilities. Thanks also to People with Disabilities ACT for promoting the research. Thanks especially to all the women who gave their time to contribute their insights, experiences and opinions to this research. We hope that through documenting your thoughts and experiences, your health and wellbeing information needs will be better met in the future.

Thanks to the Deafness Forum of Australia for allowing the use of the International Symbol for Deafness on the front cover of this report. The symbol is used to identify and promote venues that provide hearing augmentation or access, and to identify the existence of assistive listening systems (induction loops, FM and infrared) and other forms of hearing access.



## 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.

<b>EXECUTIVE SUMMARY .....</b>	<b>4</b>
<b>RECOMMENDATIONS .....</b>	<b>6</b>
<b>INTRODUCTION .....</b>	<b>8</b>
<b>METHODOLOGY .....</b>	<b>10</b>
<b>LITERATURE REVIEW .....</b>	<b>12</b>
1.1 DEMOGRAPHIC CHARACTERISTICS OF THE SURVEY RESPONDENTS .....	14
1.2 SOURCES OF HEALTH AND WELLBEING INFORMATION .....	16
1.2.1 Who Respondents Seek Information For .....	16
1.2.2 Where Respondents are Most Likely to Obtain Health and Wellbeing Information .....	16
1.2.3 Actual and Preferred Use of Information Source .....	17
1.2.3.1 General Wellbeing Information .....	17
1.2.3.2 Minor Medical Conditions .....	17
1.2.3.3 Serious or Chronic Medical Conditions .....	17
1.2.4 Usefulness of Health and Wellbeing Information from Sources .....	19
1.2.5 Trustworthiness of Health and Wellbeing Information from Sources .....	20
1.2.6 Contributing Factors for Deciding Where to Seek Information .....	21
1.3 BARRIERS TO OBTAINING HEALTH AND WELLBEING INFORMATION .....	22
1.3.1 Barriers to Obtaining Health and Wellbeing Information from Particular Sources .....	22
1.3.2 Gaps in Health and Wellbeing Information .....	23
1.3.3 Barriers to Obtaining Health and Wellbeing Information .....	24
1.4 BARRIERS TO ACCESSING GENERAL PRACTITIONERS .....	25
1.4.1 Respondents Who Do See a General Practitioner .....	25
1.4.2 Respondents Who Do Not See a General Practitioner .....	25
<b>FOLLOW-UP SURVEY FINDINGS .....</b>	<b>26</b>
2.1 INFORMATION SOURCES .....	27
2.1.1 General Practitioners .....	27
2.1.2 Internet .....	28
2.1.3 Telephone Helplines .....	29
2.1.4 Paper Based Publications .....	30
<b>DISCUSSION.....</b>	<b>31</b>
<b>CONCLUSION.....</b>	<b>36</b>
<b>REFERENCES .....</b>	<b>38</b>

# EXECUTIVE SUMMARY

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

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

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

It is for these reasons 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 ACT women with disabilities, who comprised 30 percent of the total respondents to the original health and wellbeing information survey.

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 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 women with disabilities face.

It is WCHM's hope that this companion report will improve the understanding of the needs of women with disabilities 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 for each about:
  - Their scope of practice;
  - confirmation of their qualifications and skills; and,
  - when to use them or access them.
- WCHM to work with ACT Health in relation to the GP Taskforce recommendation on the development of a GP Register and to ensure the incorporation of the feedback from ACT women.
- WCHM to work with ACT Health to consider the issues raised by women about the ACT Health website and white pages entries, and the need for better navigation about the range and scope of available services for women in the ACT.
- WCHM to advocate with ACT Government about the need to continue to explore, pilot and evaluate new community based primary care that is supplementary to both GP practices and 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 as health consumers in using the Internet and in navigating and assessing the information that is accessed through the Internet, particularly through:
  - The provision of tools to support ACT women to understand how to assess and identify trusted sites—by enabling women to access trusted information they will be able to make more rational and informed health decisions without needing to access GPs 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 women with disabilities 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 with disabilities.
- Advocate with ACT Health and the ACT Department of Disabilities, Housing and Community Services (DHCS) about the need to develop pathways to *available, affordable, accessible and appropriate* information for women with disabilities, which addresses:
  - The availability of health and wellbeing information in different formats;
  - the need to provide health promotion and illness prevention messages in a way that will reach women with disabilities; and,
  - the responsiveness of ACT health services to the needs of women with disabilities.
- Work with partners such as Women With Disabilities ACT (WWDACT) to develop links on the WCHM website to ACT specific information and services that is relevant to women with disabilities.

# INTRODUCTION

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Women with disabilities, 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. It is well established, that women benefit by receiving information from a range of sources,<sup>2 3</sup> as it affords them great autonomy and control over the health and wellbeing information they engage with.

The vital difference for women with disabilities is that they need to be able to access information in a format and style that is appropriate to their needs, which can limit the information sources available to them. Not being able to access a diverse spectrum of information in a variety of formats can limit the extent to which a woman with a disability can make informed decision about her health. Considering that women are often the primary information seekers and decision makers for their families health as well, not being able to access the information they need in the most appropriate format can have ever further reaching consequences.

This report presents the views of the 199 women who responded to the health and wellbeing information survey and reported having a disability or long-term or chronic health issue, and of the respondents to the follow-up qualitative survey.

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 30 percent of women in the overall survey sample who reported having a disability or long-term or chronic condition.

Section two is a presentation of the follow-up survey findings. It covers the five major areas surveyed: the specific health and wellbeing needs of women with disabilities; general practitioners; the Internet; telephone helplines; paper based publications; and the gaps in information for women with disabilities.

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

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<sup>2</sup> 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.

<sup>3</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. 6.

The report begins with a brief review of the literature on how and where women with disabilities seek health and wellbeing information. The review was undertaken to place the study in the context of similar national and international research as well as to examine the growing body of academic research on how adults, particularly women, access health information.

# 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 30 percent (n=199) reported that they have a disability or a long-term or chronic health condition.

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

The online survey was available via a link on the WCHM website and was distributed throughout email networks and personal contacts. A link to the survey was also available on the websites of 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>4 5</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

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<sup>4</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>5</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.

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.

A small number of studies relating specifically to women with disabilities were resourced for the literature review. These studies were added to by the published work of Women With Disabilities ACT (WWDACT) and Women with Disabilities Australia (WWDA) for this companion report.

## **FOCUS GROUPS**

The overall survey data was complemented by focus groups held with different populations, which WCHM considered might be vulnerable to having their needs unmet. The focus group discussions were conducted to ensure an understanding of the needs of different groups of women.

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

Participants for the follow-up survey were recruited through individuals, peak community sector networks or community organisations working with the specific groups of women.

# LITERATURE REVIEW

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There is significant research indicating that although individuals with a disability have greater needs in accessing health care and health information, they face greater disadvantage and significant barriers in attempting to do so.<sup>6</sup> For example, many women with visual impairment express frustration “that most educational materials about health issues that concern them were written materials, rendering them useless.”<sup>7</sup>

In a submission to inform the development of the framework for the *National Women’s Health Policy*, Women with Disabilities Australia (WWDA) argued that:

Promoting the right to health requires the Government to undertake actions that create, maintain and restore the health of women with disabilities. Health promotion is an important component of the measures necessary to fulfill the right to health. In order to enjoy the right to health, women with disabilities must have adequate and appropriate health-related information.<sup>8</sup>

WWDA supported this claim with evidence from the United Nations Committee on Economic, Social and Cultural Rights. In May 2000, the Committee adopted a General Comment on the right to health, which recognised that the right to health is closely related to the right to, among other things, access to information and health-related education. The Committee also argued that it is vital for the population to participate in all health-related decision making at the community, national and international levels.<sup>9</sup>

Further research conducted by WWDA found that women with disabilities are less likely to know about preventative health procedures. One example of this is that many states and territories in Australia send out routine written reminders to women who are due for a pap screen, however, because data on disability is not collected, the agency cannot know when women need reminders written in plain English or delivered via an alternative format.<sup>10</sup> This means that women with disabilities can experience limited access to screening programs, such as breast and cervical screening, which can be compounded by a lack of accessible information detailing why screening programs are so important to long term health and wellbeing. A study by Di Temby, on behalf of the

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<sup>6</sup> McColl, M., Forster, D., Hunter, D., Dorland, J., Goodwin, M. & Rosser, W., “Physician Experience Providing Primary Care to People with Disabilities”, *Health Care Policy*, 4(1), 2008, e129-147.

<sup>7</sup> Smeltzer, S., Sharts-Hopko, N., Ott, B., Zimmerman, V., & Duffin, J., “Perspectives of Women with Disabilities on Reaching Those Who Are Hard to Reach”, *Journal of Neuroscience Nursing*, 39 (3), 2007, 167.

<sup>8</sup> Frohmader, C. & Swift, K., *Submission to Inform the Development of the Framework for the National Women’s Health Policy*, Women With Disabilities Australia; Tasmania, 2009.

<sup>9</sup> Frohmader, C. & Swift, K., *Submission to Inform the Development of the Framework for the National Women’s Health Policy*, Women With Disabilities Australia; Tasmania, 2009.

<sup>10</sup> Howe, K. & Salthouse, S., *Lack of Data Means Lack of Action: A clinical examination of access to health services for women with disabilities*, Women with Disabilities Australia; Tasmania, 2004.

Victorian Women with Disabilities Network, reported that health providers focus more on a woman's disability than on ensuring she receives health promotion advice and screening to safeguard her overall health.<sup>11</sup>

Women with disabilities also identify negative stereotyping from health care providers and short consultation times as areas of concern; reporting that they often feel depersonalised and burdensome to health care providers, especially when doctors are unable to provide facilities or advice to meet their needs.<sup>12</sup>

Because of difficulties in accessing health professionals, women with disabilities often source information from other health and wellbeing information sources.<sup>13</sup> However, health and wellbeing information is often not provided in alternative formats that are suitable for women with disabilities—such as plain English, simple pictorial styles, audio tape, Braille and video—and is often not located where women with disabilities can access it.<sup>14</sup>

Women's Health West, located in Melbourne, has developed health information videos and a peer outreach model for women with disabilities that provide a good example of accessible health information.<sup>15</sup> But it is vitally important that innovative methods for communicating health information to women with disabilities are used by a greater number of health and community services.

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<sup>11</sup> Frohmader, C. & Howe, K., *Going Inclusive: Access to Health Care for Women with Disabilities*, Women with Disabilities Australia; Tasmania, 2001.

<sup>12</sup> Smeltzer, S., Sharts-Hopko, N., Ott, B., Zimmerman, V., & Duffin, J., "Perspectives of Women with Disabilities on Reaching Those Who Are Hard to Reach", *Journal of Neuroscience Nursing*, 39 (3), 2007, p. 167.

<sup>13</sup> Murphy, M., Murphy, B. & Kantos, D., *Access to Women's Health information: A literature review of women as health information seekers*, Women's Health Victoria, Melbourne, 2003, p. 49.

<sup>14</sup> Frohmader, C. & Howe, K., *Going Inclusive: Access to Health Care for Women with Disabilities*, Women with Disabilities Australia; Tasmania, 2001.

<sup>15</sup> Frohmader, C. & Howe, K., *Going Inclusive: Access to Health Care for Women with Disabilities*, Women with Disabilities Australia; Tasmania, 2001.

# SURVEY FINDINGS

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## 1.1 DEMOGRAPHIC CHARACTERISTICS OF THE SURVEY RESPONDENTS

There were 199 completed survey responses from women with a disability or long-term or chronic health condition, making up 30 percent of the total survey sample. In the ACT, women who require assistance due to a disability or a long-term or chronic health condition make up 4 percent (n=5,373) of the female population 15 years and older.<sup>16</sup>

**Age:** Fifteen percent (n=30) of respondents were 15-29 years; 17 percent (n=34) were 30-39 years; 27 percent (n=53) were 40-49 years; 24 percent (n=48) were 50-59 years; 17 percent (n=33) 60 years or older.

**Educational Attainment:** Nineteen percent (n=38) of respondents had completed a high school qualification; 79 percent (n=157) had completed some post high school study (Certificate I-IV, Diploma or Certificate, Advanced Diploma, Bachelor's Degree, Postgraduate Degree).

**Household Composition:** Twenty-five percent (n=50) of respondents were single (including separated or widowed) with no dependent children; 31 percent (n=61) were partnered with no dependent children; 12 percent (n=23) were single (including separated or widowed) with dependent children; 26 percent (n=52) were partnered with dependent children; 6 percent (n=12) listed their household composition as other.

**Household Income:** Twenty-four percent (n=44) of respondents reported a total household income of \$41,599 or less; 36 percent (n=65) reported a total household income between \$41,600 and \$88,399; 36 percent (n=71) reported a total household income of \$88,400 or more; 10 percent (n=19) preferred not to answer.

**Location:** Twenty percent (n=39) of respondents were living in Canberra's Inner North; 7 percent (n=13) were living in Canberra's Inner South; 14 percent (n=28) were living in Belconnen; 12 percent (n=24) were living in Gungahlin or Hall; 18 percent (n=36) were living in Woden Valley or Weston Creek; 24 percent (n=47) were living in Tuggeranong; 6 percent (n=12) were living in Queanbeyan, Jerrabomberra or Other NSW.

**Work Status:** Forty-eight percent (n=95) of survey respondents were working full-time; 25 percent (n=49) were working part-time or casual; 16 percent (n=32) were not working (studying full-time, not currently in paid employment, or full-time mother or carer); 12 percent (n=23) were retired.

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<sup>16</sup> Australian Bureau of Statistics, *Census Population and Housing: Core Activity Need for Assistance by Age and Sex – Australian Capital Territory*, ABS Cat. No. 2068.0, Australian Bureau of Statistics; Canberra, 2006.

**Aboriginal or Torres Strait Islander:** Of the survey respondents, 7 percent (n=13) also identified as a woman of Aboriginal or Torres Strait Islander descent.

**Carer Responsibilities:** Of the survey respondents, 16 percent (n=31) also reported having carer responsibilities for someone other than a dependent child.

**Culturally and Linguistically Diverse:** Of the survey respondents, 16 percent (n=32) also identified as a women from a culturally and linguistically diverse background.

## 1.2 SOURCES OF HEALTH AND WELLBEING INFORMATION

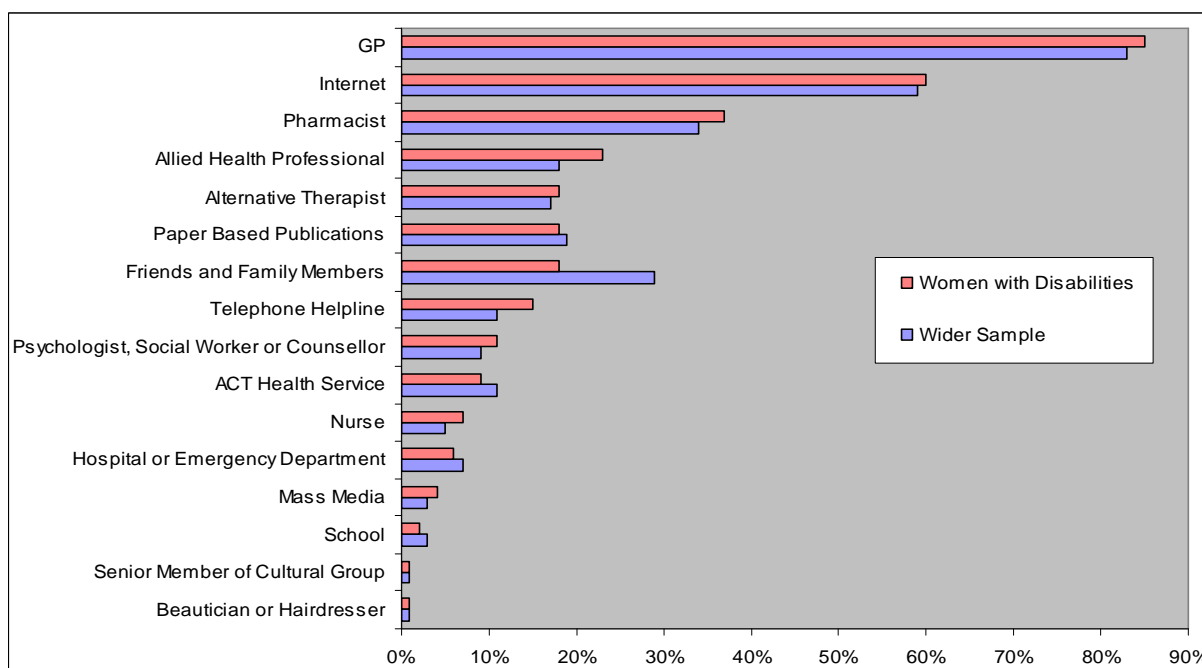
### 1.2.1 Who Respondents Seek Information For

Ninety-one percent (n=180) of respondents reported seeking health and wellbeing information for themselves, and 49 percent (n=96) reported seeking information for their children. Both figures were consistent with the wider survey sample. Forty-six percent (n=91) reported seeking information for their partner, which was ten percentage points lower than the wider sample. Thirty-one percent (n=61) sought information for their friends (compared to 29 percent in the wider sample); 29 percent (n=57) for other family members (compared to 25 percent); 24 percent (n=47) for their parents (compared to 32 percent); 18 percent (n=36) for other people in their community (compared to 16 percent); and 10 percent (n=20) for another person (compared to 5 percent).

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

Eighty-five percent (n=153) of respondents reported that they are most likely to obtain health and wellbeing information from their GP and 60 percent (n=114) reported that they are most likely to obtain information from the Internet. Both figures were consistent with the wider survey sample. Thirty-seven percent (n=70), three percentage points higher than the wider sample, would most likely obtain information from a pharmacist. Following these top three sources, 23 percent (n=44) of respondents would most likely obtain information from an allied health professional; 18 percent (n=35) from an alternative therapist, paper-based publication or family members or friends respectively; and 15 percent (n=29) from a telephone helpline.

**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 women with disabilities or long-term or chronic health conditions for general wellbeing information were GPs, used by 54 percent (n=107) of survey respondents, the Internet, used by 48 percent (n=96) of respondents, and friends and family members, used by 41 percent (n=81).

The sources that the respondents most commonly used, and the sources they preferred to use to obtain general wellbeing information were the same. However, the order in which they were most commonly used—GP, the Internet and then friends and family members—was different to their order of preference, which was the Internet, preferred by 38 percent (n=75) of respondents, followed by GPs, preferred by 31 percent (n=62) of respondents and then friends and family members, preferred by 13 percent (n=25). This differed to the wider survey results where paper based publications were third most preferred source after the Internet and GPs.

#### **1.2.3.2 Minor Medical Conditions**

In the twelve months prior to completing the survey, the sources most commonly used for information about minor medical conditions were GPs at 74 percent (n=147) of respondents, followed by pharmacists at 57 percent (n=114) of respondents, and the Internet at 48 percent (n=103).

The sources that the respondents most commonly used, and the sources they preferred to use to obtain minor medical condition information were the same. However, the order in which they were most commonly used—GP, pharmacist and then the Internet—was different to their order of preference, which was GPs, preferred by 58 percent (n=115) of respondents, the Internet, preferred by 27 percent (n=53) and pharmacists, preferred by 17 percent (n=34). This was consistent with the findings from the wider survey.

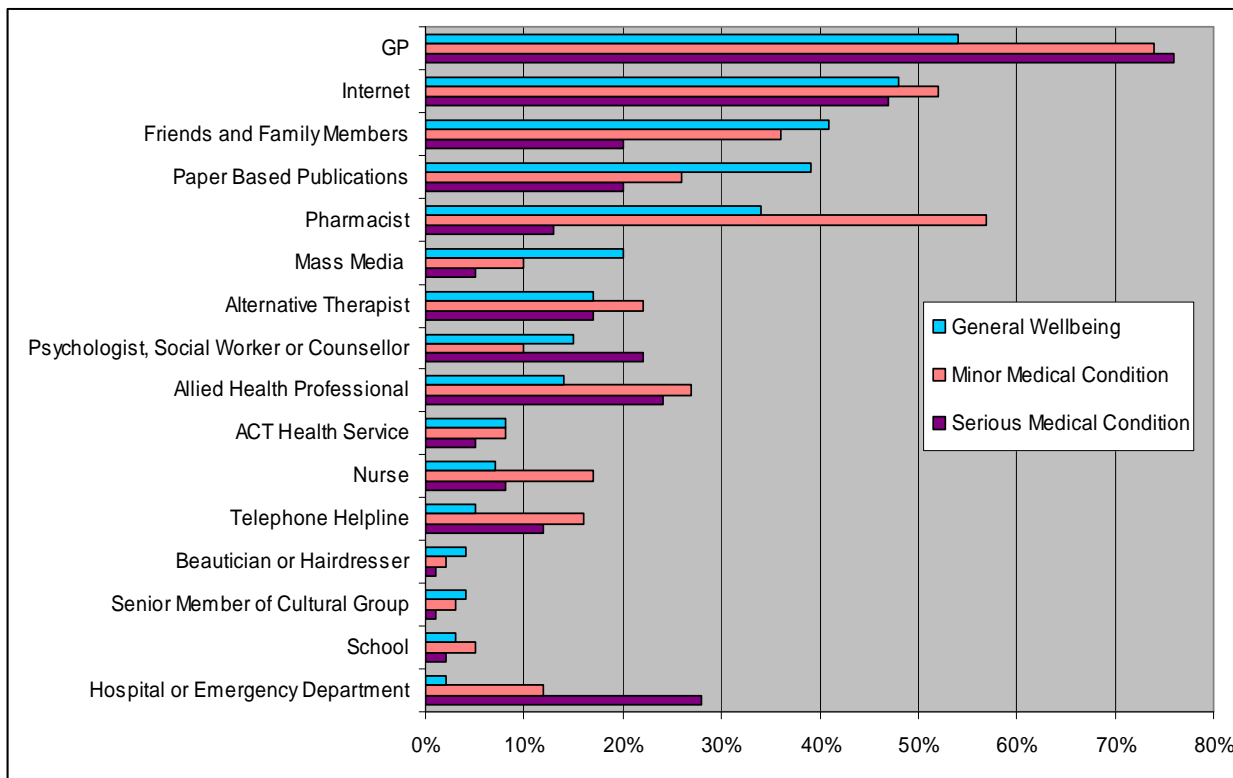
#### **1.2.3.3 Serious or Chronic Medical Conditions**

In the twelve months prior to completing the survey, the sources most commonly used for information about serious or chronic medical conditions were GPs at 76 percent (n=152) of respondents (compared to 48 percent in the wider sample), followed by the Internet at 47 percent

(n=94) of respondents (compared to 32 percent in the wider sample), and hospitals or emergency departments at 28 percent (n=56) (compared to 23 percent).

While respondents most commonly used GPs, the Internet and hospitals and emergency departments for information on serious or chronic medical conditions, their preferred sources differed slightly. Seventy-four percent (n=147) of respondents preferred to obtain information about serious or chronic medical conditions from GPs (compared to 77 percent in the wider survey), 25 percent (n=49) from medical specialists (compared to 23 percent), and 19 percent (n=38) from the Internet (compared to 14 percent).

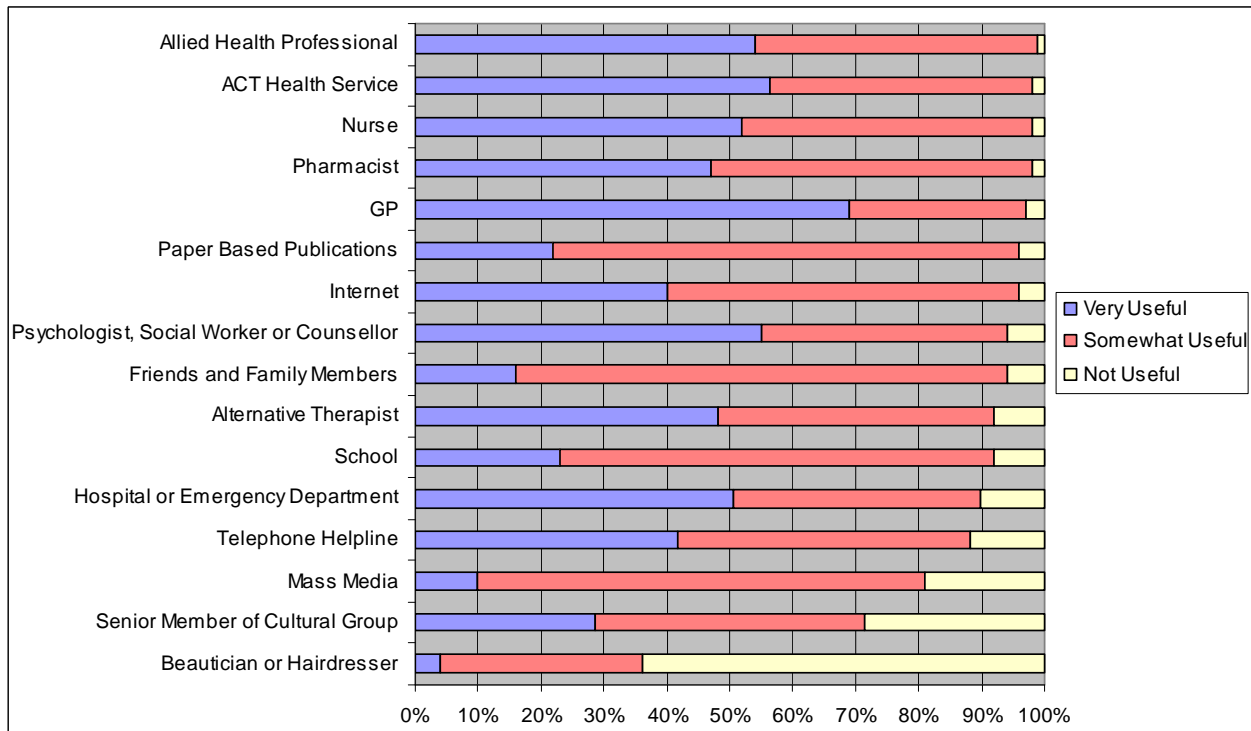
**Figure 2: Use of source for general wellbeing, minor medical condition and serious medical condition information in twelve months prior to survey completion**



### 1.2.4 Usefulness of Health and Wellbeing Information from Sources

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

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

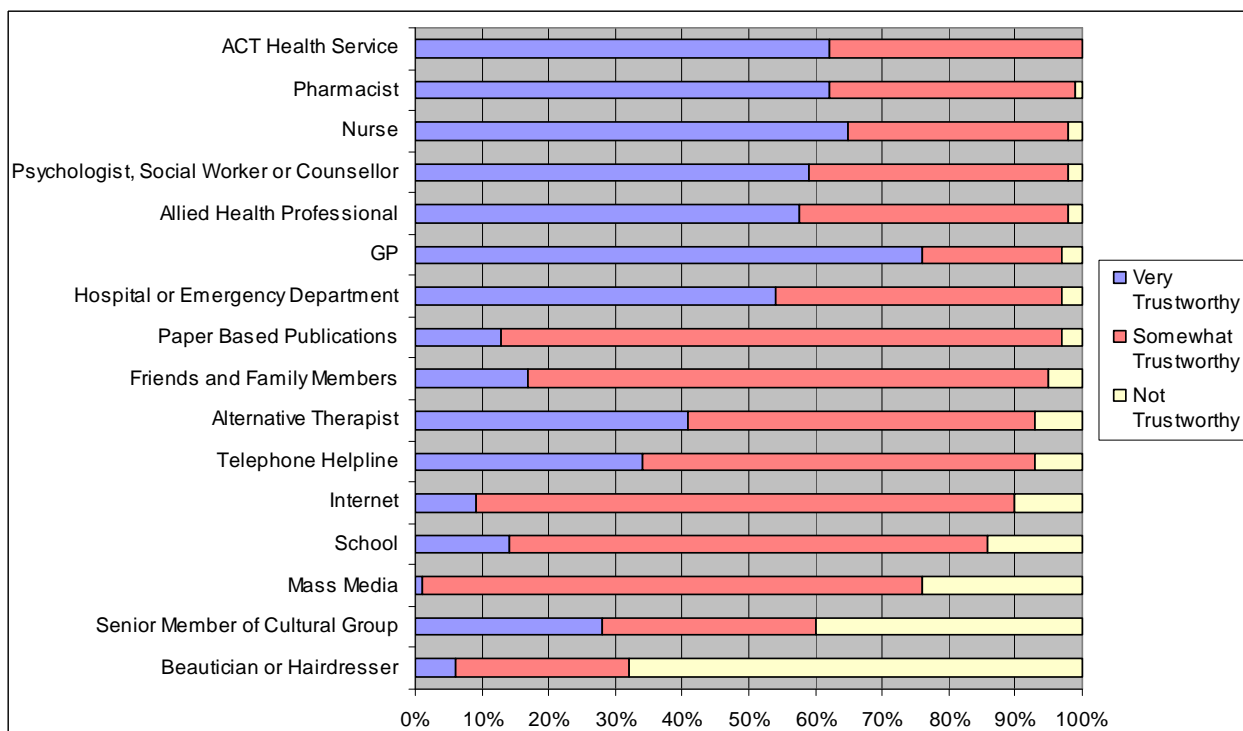


Unsure/don't use answers have been filtered out in order to present the level of usefulness of information from each source only for those respondents who used them. Many chose not to answer the question at all, therefore the figures in the graph represent 100% of those respondents who rated the information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

### 1.2.5 Trustworthiness of Health and Wellbeing Information from Sources

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

**Figure 4: Level of trustworthiness attributed to the health and wellbeing information obtained from sources**



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

### 1.2.6 Contributing Factors for Deciding Where to Seek Information

The five most important factors that the respondents with a disability or long-term or chronic health condition consider before deciding where to seek health and wellbeing information were:

The information provided is of high quality	58 percent (n=113)
The source is easily available (suitable waiting times)	57 percent (n=111)
The source is easily accessible (suitable location)	49 percent (n=95)
I have already established a trusting relationship with the source	45 percent (n=88)
The cost is affordable	42 percent (n=82)

The order differed slightly to the wider sample where “the source is easily available” and “the information provided is of high quality” were rated first and second.

## 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, 76 percent (n=151) reported that they have considered obtaining health and wellbeing information from an alternative therapist. The cost of using alternative therapists was identified as the most significant barrier, identified by 31 percent (n=47) of the respondents. Being unsure of the quality of information obtained from alternative therapists was the second most significant barrier, identified by 30 percent (n=45). Not trusting the information obtained from alternative therapists was the third most significant barrier for 7 percent (n=10). These results differed to the results from the wider survey where cost was the second most common barrier identified by 21 percent of respondents and being unsure of quality of information obtained was the most significant barrier at 28 percent.

**Internet:** Of the respondents, 97 percent (n=189) reported that they have considered obtaining health and wellbeing information from the Internet. Being unsure of the quality of the information obtained from the Internet was the most significant barrier, identified by 60 percent (n=113) of respondents and not feeling that the information provided to the Internet is treated as confidential was the second most significant barrier, identified by 14 percent (n=27). Thirty-three percent (n=62) of respondents do not experience any significant barriers to obtaining information from the Internet. These results are consistent with the wider survey sample.

**Paper Based Publications:** Of the respondents, 96 percent (n=187) reported that they have considered obtaining health and wellbeing information from paper based publications, compared to 92 percent from the wider survey sample. Being unsure of the quality of the information obtained from paper based publications was the most significant barrier, identified by 37 percent (n=70) of respondents. The cost of buying paper based publications was the second most significant barrier, identified by 12 percent (n=22). Fifty-seven percent (n=106) of respondents do not experience any significant barriers in obtaining information from paper based publications. These results are consistent with the wider survey sample.

**Psychologists, Social Workers and Counsellors:** Of the respondents, 87 percent (n=166) reported that they have considered obtaining health and wellbeing information from a psychologist, social worker or counsellor, compared to 72 percent of the wider survey sample. The cost of using psychologists, social workers or counsellors was identified as the most significant barrier, identified by 25 percent (n=41) of the respondents. Being unsure of the quality of information obtained from psychologists, social workers or counsellors was the second most significant barrier, identified by 12 percent (n=20). Sixty-five percent (n=107) do not experience any barriers in obtaining information from psychologists, social workers or counsellors. These results are consistent with the wider survey sample.

**Telephone Helplines:** Of the respondents, 63 percent (n=121) reported that they have considered obtaining health and wellbeing information from a telephone helpline, compared with 55 percent of the wider survey sample. Being unsure of the quality of the information obtained from telephone helplines was the most significant barrier, identified by 31 percent (n=38) of respondents. Not feeling that the information provided to telephone helplines is treated as confidential was the second most significant barrier, identified by 5 percent (n=6). Sixty-five percent (n=78) do not experience any barriers in obtaining information from telephone helplines. These results are consistent with the wider survey sample.

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

Of the respondents, 19 percent (n=37) reported there being health and wellbeing information that they were not able to obtain compared with 12 percent of the wider survey sample.

The most commonly cited gap was information on specific illnesses or conditions including new research findings for those illnesses or conditions. Other gaps identified were: tailored advice that is not too expensive; accurate diagnoses; and access to personal records, including from parent countries.

Qualitative comments from the survey included :

*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.*

*Sometimes, a full explanation of medical tests and their results. GP does not have enough time to give complete explanation of details. I usually amplify info from Internet and can assess their worth without problem and see how up to date they are.*

*I was recently diagnosed with Endometriosis and there appears to be no support groups in the ACT or access to people who are sufferers. Sometimes it is nice to talk to people who understand the emotional burden of this condition and how they cope with it. The professionals seem to have little time to discuss anything other than the treatment they can provide as a possible aid. Waiting three months for a specialist appointment and going through sometimes unbearable pain made me sometimes want to scream. In desperation I contacted an endometriosis group in Queensland, who confirmed that there are no support groups for this condition in the ACT. I find this astounding as surely I am not the only female who has this condition in the whole of Canberra!*

### 1.3.3 Barriers to Obtaining Health and Wellbeing Information

Of the respondents, 42 percent (n=84) reported experiencing significant barriers in obtaining the health and wellbeing information they require.

The most commonly reported barriers were: the high cost associated with some information sources; waiting times; health professional availability; personal time constraints; and accessibility of health professionals. While all of these barriers apply to seeking information from a health professional, three respondents did say that having to rely upon a GP because they did not know where else to get reliable information was also a significant barrier. It is possible that other respondents also rely upon health professionals more heavily because they are unsure about the quality and reliability of information obtained from other sources. This was reinforced by comments like “finding accurate information on the Internet”, “information can be contradictory from different sources so am not sure who to believe” and “lack of truly reliable sources”.

Other comments from the survey included:

*Some of the questions I have don't seem enough to make a special trip to the doctor but I can't find the answer elsewhere*

*Having to sort out good information from bad i.e. commercial interests masquerading as advice.*

*Information can be contradictory from different sources so am not sure who to believe. Different sources also don't work very well together, ie GPs are sceptical of alternative therapies*

*Doctors don't have enough time to look at your health holistically some doctors lack the ability to explain things in plain English. Also specialists and GPs don't talk to each other.*

*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.*

*Information overload, quality of it, and the amount of new information is exponential so keeping up with it can be an issue.*

*Experts/specialists being willing to explain a topic in enough detail or to refer to a reputable source.*

## 1.4 BARRIERS TO ACCESSING GENERAL PRACTITIONERS

### 1.4.1 Respondents Who Do See a General Practitioner

Of the survey respondents, 99 percent (n=197) reported seeing a GP compared to 96 percent of the wider sample.

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

Difficulties getting in to see a GP due to waiting times	55 percent (n=104)
High cost	40 percent (n=76)
Not being able to find a GP who bulk bills	22 percent (n=41)

These were the same as the barriers identified by the wider survey sample.

In terms of the gender preferences of GPs, 12 percent (n=22) of respondents always insist on seeing a female GP; 39 percent (n=74) prefer a female GP but will see whoever is available; 49 percent (n=94) don't care if the GP is male or female; and 1 percent (n=2) prefer a male GP but will take whoever is available. No respondents insisted on seeing a male GP.

In terms of travelling to see a GP, 49 percent (n=95) of respondents don't mind travelling if they find a GP that they like, compared to 42 percent in the wider survey. Twenty-five percent (n=48) of the respondents always insist on using their local GP, compared to 29 percent of the wider sample. And a further 26 percent (n=50) prefer to use a local GP but will go wherever they can get an appointment, compared to 29 percent of the wider survey sample.

### 1.4.2 Respondents Who Do Not See a General Practitioner

Only 1 percent (n=2) of respondents reported that they do not see a GP. Their reasons included not being able to find a GP who is taking new patients, not being able to trust the information they obtain from a GP, and the high cost of seeing a GP.

# FOLLOW-UP SURVEY FINDINGS

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The respondents of the follow-up survey for women with disabilities highlighted that they have complex and diverse health and wellbeing information needs that often go unmet.

Several of the respondents felt that women with disabilities do have specific health and wellbeing information needs. One respondent said that women with disabilities are more likely to have complex health information needs because they have both health and disability issues, that sometimes are and sometimes are not connected.

*The information we need is not readily available from any source because within the medical profession, general practitioners do not have the expertise sometimes for complex problems or to look at how one treatment might affect another. Specialists also may not have the right information because their area of expertise is too narrow.*

She explained that specific information is rarely available from any one source because of the lack of expertise in the complex interrelation of health and disability issues. This participant felt that different issues, whether health or disability related, are dealt with best by different health professionals.

Another respondent felt that women with disabilities need information about how prescribed medication will interfere with medication they routinely take for their disability. She thought that it is not so much a matter of this information not being provided to women by GPs, but that little in general is known about the way different drugs interact.

One respondent said that she does not “have any specific needs relating to being both a woman and having a disability.” She said that she does have a need for information on disability aids that can assist her with her particular impairment, but that it is the same information that a man with the same impairment would require.

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

The need for information to be available in a range of formats was raised by three of the respondents. The first respondent felt that those who create brochures often do not “make allowances for the information to be provided in alternate formats.” The second respondent commented on the risks posed to women with disabilities when information about medications—the purpose, dosage, allergic reactions and side effects—is not available in alternate formats.

The third, speaking specifically about hearing impaired women, pointed out that many miss out on vital health information, especially those who require interpreters. She felt that support should continue for interpreters for hospital admissions and consultations with allied health professionals. This would ensure women get the health information they require in a way they understand, thereby not “endangering their health and wellbeing through missing vital information.” She felt that the needs of hearing impaired women in obtaining health information from health professionals could be aided by the health professionals understanding lip-reading as a method of receiving verbal information and the need to support this with face-to-face viewing and good lighting. Health professionals also need to know how to use an interpreter and understand why this could be important to some of their clients. “Deaf women often lack understanding about many health issues as they have not heard it or have low literacy levels and so cannot read about it.”

Another respondent summed it up as:

*As long as I can access the Internet, make telephone calls to a 24 hour information base and have regular access to my GP, my information needs can be met. However, there are occasions when I need to have the recorded information via a CD, for example brochures on pharmaceutical information...I find that many well meaning project officers who develop these brochures do not make allowance for the information to be provided in alternate formats.*

## **2.1 INFORMATION SOURCES**

The follow-up survey focussed on health and wellbeing information sources that were highlighted as significant to women with disabilities through the health and wellbeing information survey. As a result, a limited number of sources are discussed below.

### **2.1.1 General Practitioners**

Many respondents throughout the study indicated that, despite the difficulties they sometimes experience in accessing GPs, they prefer and trust them for health and wellbeing information. The respondents of the follow-up survey were also asked for their thoughts on this, to which one respondent replied: “I think it is understandable that women with disabilities would trust their GPs for BASIC health and well-being information.” Although this respondent explained that the GP shortage, a lack of bulk-billing GPs, lack of female GPs overall and the lack of accessible surgeries are all factors to be taken into account when accessing this information source.

Another respondent said:

*Yes, in most cases GPs are properly trained, have access to up to date information, and are able to answer my questions, and give me a measure of confidence [that] I have been seen by a properly trained physician, I just wish there were more of them that bulk billed!*

A third respondent said that GPs are a good first option when seeking information and that she expects them, because of their training, to have most of the answers she requires or the ability to refer her on to the appropriate source for further information, such as a specialist.

Not all respondents felt that the relationship to their GP was vital. One participant said that she “found it difficult to find a GP that I truly trust and like.” She said, “fortunately, I rarely visit my GP.” This participant preferred to use alternative therapists to GPs. When asked if she thought that nurse practitioners would be able to fulfil some of the functions that GPs currently do she replied, “no, they are not as qualified.”

However, not all respondents agreed that nurse practitioners are unqualified to fulfil some of the functions of the GP. One respondent gave the following advice:

*With all information obtained, you have to be analytical, and use the right person at the right time. E.g. the nurse could give me better information about pressure sores and continence supplies, but the GP would give me better information about my kidney failure.*

Another respondent felt that in some basic cases, such as for medical certificate, nurse practitioners would be beneficial. She also felt that they could relieve the difficulty of being able to get an appointment on the actual day it is needed. She added, however, that nurse practitioners would “never be a substitute for sufficient numbers of properly trained physicians.” A fourth respondent thought that information could be provided by nurse practitioners in place of GPs, but only provided they are qualified and accessible.

### **2.1.2 Internet**

The Internet was an important source of information for all respondents.

One respondent said that while she does not use the Internet very often, she does use it to investigate disability diagnoses that she knows little about by “Google[ing] the term and see[ing] what happens.” When asked if the information she obtained from the Internet is trustworthy she replied:

*I don't know if it is trustworthy, but double checking on a number of sites helps, if it was something that I really, really wanted information on, and was not sure of what I read on the Internet, or found conflicting information, or non specific information, I would go to the library and get a book.*

This respondent thought that the best way for good quality government health websites to be promoted would be through Google Adwords so that the site would come up at the top of the page in the web search. She thought it would also be useful to advertise them on local television and radio and in local newspapers.

Another participant said that she uses the Internet to find local services and for general information on topics such as bullying and stress. Her preference is for government funded sites or those of reputable and certified practitioners, by which she meant accredited with relevant professional bodies.

Government funded websites were also the preference of one respondent who commended the Victorian Health website. This respondent reported using the Internet after a consultation with a health professional to locate information about the purpose, dosage, allergic affects and possible side effects of prescribed medication. She said that she learns of government operated websites through her membership with the Consumer Health Forum.

A fourth respondent reported using Google to search for information, and accessing a range of websites depending on what the Google search suggested. She reported using the Internet to investigate medications, to learn about healthy eating and obtain recipes as well as a range of other issues, and said that she does not assess the information for trustworthiness.

Using the Google search engine proved popular among participants of the wider WCHM study, and was no less so for respondents with a disability. While the respondents used the Internet in different ways and to different degrees, they all recognised accessibility of information as its primary value: "I think all information about everything is obtainable if you have access to the Internet, or have contact with someone who has such access."

### **2.1.3 Telephone Helplines**

In the overall survey sample, women with a disability or long-term or chronic health condition reported higher rates of usage of telephone helplines than any other group. The follow-up survey respondents were asked about this trend, and invited to talk about their own use of telephone helplines for health and wellbeing information.

One respondent felt that many women are comforted by having a real person on the other end of the line, which she thought makes many feel that they are getting accurate and trustworthy information. She added, however, that while telephone helplines are a good starting point for gathering information, the quality of that information will depend upon the level of expertise of the person taking the call.

Another respondent said that the benefit of telephone helplines is that the response is fast and relevant. She has used telephone helplines to obtain information about medications and vaccinations.

A third respondent with a hearing impairment disliked telephone helplines or any information source that requires people to use a telephone. She said that she wastes a lots of time having to physically visit services in order to be able to lip-read and make an appointment. Another respondent with a hearing impairment agreed that telephone helplines are difficult for deaf women as they need to go through the relay service, which is a slow and lengthy process. To add to the difficulty, she said that many people do not know how to use a relay service, which limits the number of information sources available and accessible to hearing impaired women.

#### **2.1.4 Paper Based Publications**

In the overall survey sample, women with a disability or long-term or chronic health condition reported higher rates of usage of paper based publications than any other group. The follow-up survey respondents were asked about this trend, and invited to talk about their own use of paper based publications for health and wellbeing information.

One of the respondents felt that paper based publications remain an important health and wellbeing information source because the “editing process is a slightly greater safeguard for accuracy.” She pointed out that medical journals contain peer reviewed research, which can also be an easy way to ensure the credibility of the information.

One respondent explained that she uses paper based publications as a “second or third line of enquiry” only. When asked about the usefulness of receiving written information during a consultation she replied:

*Information from textbooks, read together with the health professional, with opportunity to ask questions at the same time is the most useful. This needs to be coupled with reflective questions from the health professional to check on your understanding of the information under discussion. Some GPs and specialists are extremely good at this and some are extremely poor at it, or ignore it altogether.*

Receiving paper based information during a consultation with a health professional was also preferred by another respondent who felt that it makes the information more trustworthy as it can be assumed to be relevant and important information.

In regard to the information available in waiting rooms, such as pamphlets, this respondent said:

*This is of marginal use, it is generalist, and transient. There are too many distractions in a waiting room, so that if you really wanted to find something out it would be nigh on impossible. You may pick up useful information by some sort of casual osmosis.*

One participant did not use paper-based publications due to vision impairment.

# DISCUSSION

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

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

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

The responses from women with disabilities for both the initial health and wellbeing information survey and the follow-up survey demonstrated a willingness to use a variety of health and wellbeing information sources in order to obtain the information they require. Like all other survey respondents, they engage with these sources with a degree of scepticism and seek out the source that they feel will be most appropriate for the health or disability issue they require information on.

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

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

## **Promotion and Awareness of Alternatives**

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

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

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

## **Navigation**

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

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

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

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

### **Tools and Support for Internet Literacy**

The Internet is the fastest growing source of health and wellbeing information. It is the most likely used health information source for 60 percent of women with disabilities—second only to GPs—and one of the most likely used sources of information for general health and wellbeing, minor health issues and serious or chronic health issues.

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

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

*Re Internet information—I am careful in my use of this information and am aware there is a lot of inaccurate information on the Internet. I limit my use to 'trusted' sites.*

*The Internet is an excellent source of reliable information — it is also the source of a lot of utter rubbish. Its usefulness depends on how it's used. It's very useful if used in a discriminating way and for general information only. No information about serious or chronic conditions obtained over the Internet should be relied on without the advice of a doctor.*

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

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

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

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

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

## **Barriers**

### Accessibility

As discussed earlier not being able to access a range of information in an appropriate format is a significant barrier for women with disabilities. Not being able to access a diverse spectrum of information in a variety of formats can limit the extent to which a woman with a disability can make informed decision about her health and wellbeing. Considering that women are often the primary information seekers and decision makers for their families health as well, not being able to access the information they need in the most appropriate format can have far reaching consequences.

One respondent, speaking about the issues for women with hearing impairment, said that solutions to this may be sought through working with peak groups like Deafness Forum and ACT Deaf Society to promote the need for accessible consumer information, and to ensure that public health messages are available to all in a variety of ways. Public health campaigns, for example, need to be promoted through various channels and in a range of mediums and multimedia formats in order to be effective for women with disabilities.

### Time Constraints

Personal time constraints were also a barrier for women with disabilities in the ACT seeking health and wellbeing information.

*Time is limited with the busy-ness of life particularly if you work fulltime as I do. This usually means that information is not accessed unless there is a personal issue affecting myself.*

There is an emerging field of literature on women's lack of time and how it impacts upon their health and wellbeing and health literacy. What is known is that many women lack sufficient time to make their health and wellbeing a priority, and lack the choice to organise their time differently, which has been proved to be true for many of the research participants.

The time constraint on health professionals was also highlighted as a barrier. For example, consultation time constraints often mean that information is a one-way factual transfer from health

professionals to women, which is less effective than a dialogue where women can develop their understanding of the information and engage with it in a meaningful way.<sup>17</sup> The respondents overall felt that paper based publications were more meaningful, useful and trustworthy when provided in the context of a consultation with a health professional. Providing paper based information during a consultation is one way that health professionals can ensure that their clients have a way of recalling and interacting with the information provided to them during a short consultation.

It cannot be assumed, however, that one policy surrounding information provision will work for all women with a disability. Women with vision impairment, for example, express frustration that many educational health materials are written, rendering them useless.<sup>18</sup>

What is possible, and vitally important, is that health and wellbeing information be made available from a number of sources in a variety of formats. For example, sources of information that are frequented in person should have wheelchair accessibility and waiting and consulting rooms that are manoeuvrable; sources that provide information over the telephone should offer and promote the use of the relay service; and printed brochures should be available in audio format.

### Transport

Transport was identified by many women who participated in the research as a barrier to accessing good health care for many women, which relates to closure of local services and the lack of available options in close proximity.

### Cost

The overall research showed that out of pocket expenses are greatly impacting on many women's access to health care in the ACT. Many women are forgoing basic services and provisions to cover their health costs or missing recommended follow up visits, not having treatment or deciding not to visit their doctor, buy their medicine or visit their dentist. This is exacerbating health problems and the costs to themselves and the health system.

*Money. Often I can't afford to go to the GP or other practitioners to get help.*

*General questions and answers/discussion to maintain my health is no longer affordable or accessible in Canberra ..... If you don't have a specific complaint that needs to be addressed, you can't afford the time or money to have a general checkup.*

*Scarcity of bulk-billing practices and especially the high cost of appointments means that I'm less willing to go to the Dr even when I'm ill (let alone for information); I'd rather wait it out or see the pharmacist/chemist instead, which is less ideal*

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<sup>17</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>18</sup> Smeltzer, S., Sharts-Hopko, N., Ott, B., Zimmerman, V. & Duffin, J., "Perspectives of Women with Disabilities on Reaching Those Who Are Hard to Reach", *Journal of Neuroscience Nursing*, 39(3), 2007, pp.167.

# 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>19</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 199 women with a disability or long-term or chronic health issue who participated in WCHM's Health and Wellbeing Information Survey 2009, and the findings of the follow-up survey completed by four women with a disability.

As explored throughout the report, the greatest barrier for women with disabilities in accessing the health and wellbeing information they need is not being able to access a range of information in an appropriate format. Not being able to access a diverse spectrum of information in a variety of formats can limit the extent to which a woman with a disability can make informed decisions about her health. More than this, however, it entrenches disadvantage by enabling some women access to health and wellbeing information and not others. Considering that women are often the primary information seekers and decision makers for their families health as well, not being able to access the information they need in the most appropriate format can have far reaching consequences

Ensuring that all women can access the health and wellbeing information they require in the format that is most suitable empowers women and enables them to fully engage with health decision-making. It extends the right to women with disabilities to be their own best guide on matters of health and wellbeing.

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

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<sup>19</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.

their own health risks and needs.<sup>20 21</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 all women with disabilities.

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<sup>20</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>21</sup> von Wagner, C., Knight, K., Steptoe, A. & Wardle, J., "Functional health literacy and health promoting behaviour in a national sample of British adults", *Journal of Epidemiology and Community Health*, 61(12), 2007, pp.1086–1090.

# REFERENCES

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

Australian Bureau of Statistics, *Census Population and Housing: Core Activity Need for Assistance by Age and Sex – Australian Capital Territory*, ABS Cat. No. 2068.0, Australian Bureau of Statistics; Canberra, 2006.

Frohman, C. & Howe, K., *Going Inclusive: Access to Health Care for Women with Disabilities*, Women with Disabilities Australia; Tasmania, 2001.

Frohman, C. & Swift, K., *Submission to Inform the Development of the Framework for the National Women's Health Policy*, Women With Disabilities Australia; Tasmania, 2009.

Howe, K. & Salthouse, S., *Lack of Data Means Lack of Action: A clinical examination of access to health services for women with disabilities*, Women with Disabilities Australia; Tasmania, 2004.

McColl, M., Forster, D., Hunter, D., Dorland, J., Goodwin, M. & Rosser, W., "Physician Experience Providing Primary Care to People with Disabilities", *Health Care Policy*, 4(1), 2008.

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

Renkert, S. and Nutbeam, D., "Opportunities to improve maternal health literacy through antenatal education: an exploratory study", *Health Promotion International*, 16(4), 2001.

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

Smeltzer, S., Sharts-Hopko, N., Ott, B., Zimmerman, V. and Duffin, J., "Perspectives of Women with Disabilities on Reaching Those Who Are Hard to Reach", *Journal of Neuroscience Nursing*, 39(3), 2007.

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

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

