



Women's Health Victoria

"facilitating access to quality women's health information"

Access to Women's Health Information

Research Summary

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1. A literature review of women as information seekers
2. A survey of Victorian women as information seekers
3. A literature review of health professionals as information providers
4. Issues for opinion leaders and service providers
5. **Research summary**

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INTRODUCTION

Women's Health Victoria (WHV) is a state-wide women's health information service that aims to provide high quality, independent and up-to-date information to women, health service providers, and policy makers. To assist WHV in its' strategic development, Market Access, an independent market research company, was commissioned to undertake a study of the health information needs of women. The overall aim of the project was to identify how WHV can ensure better quality access to health information for women.

The study involved several components, including:

- A review of the literature regarding issues associated with women's access to health information.
- A review of the literature regarding issues related to service provider's access to and use of health information.
- A survey of Victorian women to quantify issues related to accessing health information.
- A study of opinion leaders and influencers in the field of women's health.

Each of these components of the project has been reported separately. This document provides a summary of the separate components of the project and outlines the key themes that arose during the research.

EMERGENT THEMES FROM ACROSS THE PROJECT

This project was undertaken to gather data about access to health information amongst the key target groups of policy makers, service providers and women in order to inform strategic development for WHV. In particular, the research was commissioned to find out more about the mechanisms that are used by each of these target groups for accessing health information, how satisfied people are with those mechanisms and what barriers are experienced in accessing health information. The purpose of the consultancy was to provide an understanding of the market place to assist WHV in determining how best to meet women's health information needs.

The consultancy has considered a broad range of issues related to the provision of and access to health information by and for women. It has taken into account current literature, from the perspective of both women as health consumers and their health care providers, collected survey data on the needs and experiences of Victorian women and consulted with key informants throughout the health field in Victoria.

While the range of issues addressed and methods of data collection used throughout the consultancy have been diverse, there are several important emergent themes from the project. Along with a snapshot of the current situation, these themes are documented below.

SOURCES OF HEALTH INFORMATION

From the perspective of women as health consumers it is useful to consider information sources in terms of the involvement required to access the information. From this model, health information sources have been classified as either active or passive. The active sources of health information used by the majority of Victorian women included doctors, followed by family and friends, pamphlets, pharmacists and books. By contrast, only a small

number of women used telephone helplines, however the literature suggested that this mechanism had particular value for women in certain crisis situations.

The passive sources of health information most commonly used include family and friends, followed by doctors and pamphlets. Some age and life stage differences were observed. For both passive and active approaches to information gathering, younger women were more likely to rely on family and friends, pamphlets, magazines and the internet, while older women were more reliant on doctors as a passive sources of health information.

As has been documented throughout the project, there are some groups of women for whom there are currently limitations in the provision of and access to appropriate health information. These groups tended to be women who are not as effectively entrenched within the health care system, including those from diverse cultural and linguistic backgrounds, those who do not have a regular doctor, Indigenous and elderly women.

For these groups, specifically targeted approaches to the provision of health information will continue to be required to meet their needs. A critical and consistent issue in this regard was with respect to the provision of health resources in an appropriate breadth of languages to meet the needs of the diverse language groups within the population.

SATISFACTION WITH HEALTH INFORMATION

The issue of quality of health information arose throughout the consultancy. The amount of health information available, especially when the mass media and the internet are taken into consideration, meant that questions of quality were paramount. Previous studies have documented the difficulties that both health professionals and health consumers experience in attempting to filter and evaluate the quality of health information available to them. It is for this reason that the association of WHV with quality should be considered as a key benefit and a potential opportunity for the organisation.

Overall, Victorian women rated the quality of health information they received quite highly, with information from doctors given the highest rating, followed by pharmacists, books and pamphlets. Women from diverse linguistic backgrounds and those who did not have a regular GP were less satisfied with the quality of health information they received, indicating that a particular focus on these groups may be required.

Service providers and those in government, the bureaucracy and other health agencies also raised questions about the quality of health information available for their purposes. In general, these people had developed mechanisms, preferences and relationships to ensure they had access to the quality of information they needed. However, it was apparent that there was a considerable gap specifically in relation to the availability of a credible gendered analysis of health data as an input into policy and program development. For service providers in community settings, the most obvious information gap was in relation to consumer information in an appropriate range of languages.

ROLE OF GPs IN HEALTH INFORMATION PROVISION

A strong and consistent finding throughout the research was that the role of GPs in the provision of health information is critical. As noted above, the survey of Victorian women showed that GPs were the most used and the most preferred channel for health information. The literature reviews highlighted that the role of GPs in health education and in promoting health related behaviour change was important to both the GPs and to the women they treated. Notably, the provision of written information has been consistently shown to be more effective in the context of the personalised advice and support offered during a consultation.

That GPs have been identified as the most credible source of health information is important, especially in an environment where there are many concerns about the quality of health information available.

NEW TECHNOLOGIES IN HEALTH INFORMATION

The internet has been shown to be an emerging medium in the provision of health information. However, there are many issues that need to be acknowledged, and preferably addressed, with regard to its accessibility and utility. The literature reviews and the survey demonstrated that some groups of women are not using or do not have access to the internet. While it is apparent that the gap is not as large as it has been in the past, there is still some way to go before this medium can be considered to offer equal value and afford equal opportunity to all women.

In addition to issues of accessibility, a significant issue with the internet as a medium for health information is related to the sheer volume of information that is available, with related questions about the quality of much of that information. Hence, there is a need for appropriate filtering and quality control functions. While some such facilities are available, a clear opportunity exists for the provision of assistance to both health consumers and health care providers in using the internet and in assessing the information that is accessed through the internet.

While use of the internet is growing, it is not yet clear how this medium is substituting for other methods of information gathering. Further, use of the internet is changing rapidly, meaning that ongoing research will be needed to track use of this medium and to understand how best to maximise its potential in providing women with the health information they need.

Alongside the internet, there is development of other electronic media at the point of care, including desktop resources, Computerised Patient Information Systems, Patient Decision Aids and clinical practice guidelines. Given the increasingly wide spread use of these systems, their capacity to enhance and assist the role of health care providers and the opportunities they afford for ensuring that health consumers are provided with high quality information, there is both a need and an opportunity to work with the providers of such systems to optimise their value to consumers of health information.

CONCLUDING COMMENTS

In conclusion, the consultancy has demonstrated that while there is an enormous amount of health information available and a wide variety of channels for accessing that information, not all information needs are satisfactorily met. It is important to recognise the primacy of the role of GPs in providing information and to develop mechanisms to ensure that GPs have the appropriate information to pass on. Some specific groups of women are not adequately catered for and need to be specifically targeted. Those without a regular GP and without adequate English appear to experience the greatest difficulties. There is a need to provide policy makers and program developers with easy access to a credible gendered analysis of health data. Further, and partly because of the amount of information available, there is a need to assist women as health consumers, health care providers and opinion leaders in filtering and assessing the quality of the health information that is available.

SUMMARY OF EACH COMPONENT OF THE PROJECT

LITERATURE REVIEW: WOMEN'S HEALTH INFORMATION NEEDS

This review of literature was conducted as the preliminary element of the study of Victorian women's health information needs to provide a basis for subsequent components of the research.

The objectives of this literature review focussed on identifying the preferred channels and critical times for accessing health information, and on identifying the barriers experienced in accessing health information. A key aspect of the review was related to the emerging trends in access to health information.

CHANNELS FOR ACCESSING HEALTH INFORMATION

The review identified two conceptual models that are useful in the evaluation of health information channels. The first classifies health information sources in terms of the specificity and reach of the information. This can range from mass media, which delivers non-personalised information to the population, to health professionals, who deliver personalised information to the individual.

The second model classifies health information from the perspective of the consumer in terms of the involvement required of them in accessing health information. This model classifies health information sources as either passive (eg. mass media and popular press) or active (eg. consultation with a general practitioner (GP) or other health professional, telephone helplines, the internet and the like).

Mass media and the popular press, specifically TV, newspapers and magazines, are the most commonly cited sources of health information for women and for the population generally.

However, information from passive sources is unlikely to prompt women into health-related behaviour change, and is usually not sufficient when making specific decisions about investigations or treatments.

Information obtained via active seeking, most commonly from GPs and other health professionals, is more effective in promoting health-related behaviour change, and in enhancing women's choices about tests and treatments. Women regard information delivered by the GP as the most credible.

The internet is being used increasingly by women for obtaining health information. Importantly, once on line, women are more likely than men to use the internet to access health information.

The internet is surpassing other active sources of health information. It is used for a variety of reasons, including self-education prior to consultation with a health professional, verifying and adding to information obtained from health professionals and adding to women's overall health knowledge.

However, studies suggest that some groups are not utilising the internet as much as others. Specifically, women from lower socio-economic status, those in rural and remote areas, those with mental illness, those who are illiterate, people from Indigenous communities and the elderly use the internet less often.

Telephone helplines offer the advantage of being readily available, offering personalised service and being anonymous. These are especially important advantages for women in crisis situations.

Newsletters are an appropriate medium for isolated groups, especially women living in remote areas and those with a chronic health condition.

BARRIERS TO ACCESSING HEALTH INFORMATION

The major barriers for women in accessing health information relate to quality assurance (QA), concerns about confidentiality, and difficulties with comprehension. These barriers apply variously across the different information channels and the specific groups of women.

QA is most concerning in regard to internet-based health information and, to a lesser extent, popular magazines. QA on the internet is inhibited by the enormous quantity of information, and difficulties in verifying source, currency and accuracy. While many filtering mechanisms and accreditation systems have been developed to optimise the quality of internet-based health information, these are not fully utilised.

Confidentiality is most salient for young women dealing with sensitive health issues such as sexually transmitted infections (STIs), contraception, pregnancy and drug-related concerns. Hence, with young women, peer-education is a particularly common and effective health information mechanism.

Indigenous women and those from diverse linguistic and cultural backgrounds appear to have poorer access to health information, which is thought to account for their relatively low utilisation of screening and treatment services. While the internet is a relatively good channel for non-English speaking women, providing easy access to information in a range of languages, this is not the case for Indigenous women.

In relation to printed resources, and regardless of reading level and cultural background, there is evidence that pictorial and graphical representations in pamphlets are more effective than text.

Some specific groups of women, including lesbian women, sex workers and women in domestic violence situations, face many GP-related barriers that can inhibit disclosure of personal information. This either raises the reliance of these groups on other information sources or results in precluding their access to appropriate health information.

CONCLUDING COMMENTS

In conclusion, this review of the literature has highlighted some key areas that deserve attention in future research. Most obvious issues are in relation to the use of new technologies as a medium for accessing health information, and comparison of the internet with other channels of information access.

A range of questions also exists in relation to the access to and usefulness of the internet for health information for particular groups of women, including those from diverse linguistic and cultural backgrounds, indigenous women, those of lower socio-economic status, rural women, those with mental illness, those who are illiterate and the elderly.

LITERATURE REVIEW: SERVICE PROVIDER USE OF HEALTH INFORMATION

This literature review related to service providers, including GPs and other health professionals working in primary health care settings. The focus of the review was on how healthcare providers access information, both for their own education and in their role as an information channel for women.

This review was conducted with a primary focus on Australian literature and used overseas literature when no local studies could be sourced or to further the understandings of the Australian literature. While the review was designed to include a range of health care providers, the overwhelming majority of published data was in relation to general practitioners.

CURRENT PRACTICES

While most healthcare providers regard patient education as part of their role, patient studies suggested that there is some dissatisfaction with the amount and type of information provided in primary healthcare settings.

Similarly, studies suggested a lack of dissemination of printed resources to patients, often substantially below that recommended in clinical practice guidelines. Studies show that providers are more likely to give information to those clients who ask for it, which is of particular concern given that one of the greatest complaints from patients is that they do not have adequate opportunity to ask questions.

Many studies have demonstrated the efficacy to patients of providing printed educational resources in terms of increased knowledge, lifestyle change, screening behaviour and appropriate use of medicines. Importantly, these benefits are enhanced when information is provided within the consultation.

The literature clearly highlighted the internet and other computerised point-of-care systems as emerging trends in patient education as well as in health professionals' own self-education.

However, while GPs and other healthcare providers often turn to the internet for information about a specific patient problem, relatively few use the internet to access patient information at the point-of-care. The majority of GPs still rely on traditional information sources for patient information, such as text books and colleagues, rather than on new technologies.

Computerised patient information systems have positive benefits in terms of knowledge and behaviour change, in some cases over and above those offered by printed resources. They enable the provision of information that is tailored to the needs of each patient.

BARRIERS TO HEALTH INFORMATION PROVISION

A range of barriers was identified that relate to structural and relationship factors. These included time constraints, lack of remuneration for preventative healthcare, lack of skill and knowledge in specific areas and concerns about jeopardising the relationship with the patient.

A plethora of studies have demonstrated that printed materials are commonly pitched at reading levels higher than the general population. However, research has also suggested that in addressing comprehension issues content can be compromised, resulting in 'infantile' resources that do not adequately inform patients and clients.

Evaluations of printed resources suggest that testing resources with relevant target groups during their development is likely to optimise their usefulness.

Several studies amongst GPs and pharmacists have demonstrated that the patient requesting information is a key determinant of whether they receive information. Hence, it is important that patients know that information is available for them to access it and that they have the opportunity to do so.

Several barriers and limitations were identified in the use of internet information for patient education in primary care settings. The internet is perceived as being too slow for point-of-care searching for patient information, particularly given the time-constraints of the consultation, and GPs have concerns about the potential for negative impact on the doctor-patient relationship.

The literature suggested that GPs and other health professionals are increasingly being called upon to act as 'gatekeepers' to ensure patients and clients access quality health information. However, it was apparent that the medium does not provide them with as much assistance in this regard as they require.

Similar barriers were identified in relation to the use of other computerised systems at the point-of-care. Some systems are too slow or not sufficiently user-friendly and some clinicians have concerns about lack of patient receptivity.

ASSESSING QUALITY OF HEALTH INFORMATION

Relatively few studies have explored how healthcare professionals access printed patient resources. However, some evidence suggests an over-reliance on drug-company leaflets due to their widespread availability and affordability and noted that this could result in biases in information provided.

Likewise, few studies have investigated how healthcare providers appraise the quality of patient information resources. While guidelines are available for assessing these resources, there is no clear evidence to show that GPs and other healthcare professionals are using these guidelines.

Some studies have proposed that a key benefit of patient education via computerised systems, such as desktop resources, Computerised Patient Information Systems, and Patient Decision Aids, is that they optimise QA in regard to the information given to patients. Because computerised systems are based on research evidence and clinical practice guidelines, their use helps to promote evidence-based medicine.

INFORMATION SOURCES USED BY HEALTH CARE PROVIDERS

In terms of their own continuing education, GPs and other healthcare professionals have a preference for traditional methods of learning, including text-books and consultation with colleagues. In the context of CME programs, in-person conferences and print-based journal articles are the most commonly used and preferred media. Again, most studies in this area have focussed on GPs.

While relatively few GPs currently use electronic methods such as the internet and CD-ROM for their continuing education, there were some indications that these media are gaining increasing appeal.

As for patient education, issues of QA also pose a considerable barrier to the use of the internet for professional education. For some health professionals, lack of training and lack of skill also inhibit use.

Computerised decision support systems are gaining increasing acceptance by GPs. These systems, which present clinical practice guidelines, have been shown to be more effective than written guidelines in changing GP behaviour. They also appear to have high learning efficiency.

CONCLUDING COMMENTS

The provision of quality information has considerable advantages to patients, notably in relation to their knowledge, but also in terms of adopting lifestyle changes, screening behaviours and in the appropriate use of medicines. However, there is a lack of research that considers how health professionals determine the quality of information resources. This is of particular concern given the reliance on commercial organisations for some of this information and the biases that have been observed in this information.

The literature review highlighted the use of internet and other computerised point-of-care systems as emerging trends in both patient education and health professionals' self education. While there are some concerns about and barriers to using these technologies, the review suggests that the advantages of these mechanisms can also be regarded as overcoming some of the limitations experienced in using other resources for health information.

This review of the literature has highlighted that the bulk of knowledge in this field is related to general practitioners, with a relative paucity of literature existing in relation to other health care providers.

SURVEY OF VICTORIAN WOMEN

The survey aimed to identify women's active and passive sources of health information, identify their preferred channels for accessing health information, explore perceptions of the quality of health information and identify the difficulties women experienced accessing health information.

A total of 500 Victorian adult women were surveyed, with the sample being selected to reflect metropolitan and rural population breakdowns. The results showed some age group differences in experiences of health information, with three somewhat distinct age categories being identified: younger (18-34 year old), mid-aged (35-54) and older (55+) women.

SOURCES OF HEALTH INFORMATION

The most common active sources of health information were doctors (96%), followed by family and friends (76%), pamphlets (69%), pharmacists (65%) and books (61%). The main passive sources of health information were family and friends (59%), followed by doctors (57%) and pamphlets (50%). Books, magazines, television, newspapers and pharmacists were all mentioned by between 40% and 50% of the sample as passive sources.

For both passive and active approaches to information gathering, younger women were more likely to rely on family and friends, pamphlets, magazines and the internet, while older women were more likely to rely on doctors as a passive source of health information.

Doctors were by far the preferred source of health information, being rated as such by three-quarters of women. The only other preferred sources mentioned by more than 5% of women were the internet and family and friends.

Internet usage figures suggest that access to the medium is increasing in comparison with previously reported studies, and that it is becoming more widely used specifically for accessing health information. A total of 63% of women reported having internet access and 50% of these women had used the internet for health information. Consistent with previous Australian research, those who currently use the internet for health information tend to be younger, university educated, have a higher income and have dependent children.

Interestingly, use of the internet to access health information was not associated with geographic location, language spoken at home or current health status.

QUALITY OF HEALTH INFORMATION

Overall, the survey suggested that women rated the quality of health information that is available quite highly. However, while only a small proportion rated the overall quality as poor, one-quarter of the sample gave it a neutral rating, indicating that some are not satisfied with the health information they obtain.

Doctors were rated highest in terms of quality of information they provided, followed by the pharmacists, books and pamphlets.

Those who spoke a language other than English at home and those without a regular GP were more likely to rate the information they received as being of lower quality. Possible explanations could be related continuity of care afforded to those who have a regular GP and the difficulties experienced accessing language specific information for those from non-English speaking backgrounds.

Almost one in ten women reported experiencing some difficulty accessing health information. This experience was more common amongst those with no dependent children, who tended to be older, not partnered, less in touch with electronic media, have lower incomes and have long-term health problems: factors that might conceivably contribute to difficulties accessing information.

Of those who reported specific concerns accessing health information, there were two distinct groups of people: on the one hand were the well-educated mid-age women, with partner, children and internet access, who most likely have high expectations for the quality of information they require. On the other hand were the older, unwell, single, separated or widowed women, who were less well-educated and not linked to the internet, who most likely have specific condition-related needs and who are perhaps relatively out-of-touch with current information sources.

CONCLUDING COMMENTS

In summary, this study provides an up-to-date snapshot of Victorian women's use and perceptions of various sources of health information. The results of this survey generally support previously documented findings regarding women's access to health information, highlighting the importance of the role of GPs and identifying some groups of women for whom access to health information is somewhat problematic.

ANALYSIS OF NEEDS OF OPINION LEADERS AND SERVICE PROVIDERS

This study involved an analysis of the needs that opinion leaders, policy influencers and service providers have of a women's health organisation. It incorporated a series of interviews with people from across the health sector, including those from State Government departments, the media, service providers, professional organisations, academic organisations, non-government organisations and national and Statewide agencies.

The main areas of inquiry during the consultations included assessing perceptions of the process of influencing health policy, gathering data about individuals' and organisations' means of collecting, analysing and utilising health information, and discussing awareness and perceptions of WHV.

A key finding of the study was the limited awareness that key people in the development of policy and the delivery of health services had of WHV and the limited understanding of the breadth of WHV's activities and of its role within the field of women's health. As a

consequence it was apparent that the potential sphere of influence of the organisation was restricted. There is a need to clearly communicate WHV's purpose and expertise.

The consultation also raised a question with regard to the potentially conflicting roles of advocacy and information provision. Within an environment where credibility is critical, this potential conflict needs to be acknowledged.

There is a lack of understanding of WHV's relationships with other women's health organisations and of the role of Women's Health Association of Victoria as the peak body in the field. For the purposes of clarity and credibility, this needs to be addressed.

Several suggestions were documented where opportunities exist for WHV to enhance its profile and increase its influence amongst different segments of the health field. In undertaking many of these opportunities, it is apparent that the most efficient approach to the delivery of services for health consumers is through the development of partnerships that match relevant expertise of organisations.

The analysis identified that general practitioners are a primary source of health information for women. Hence, there is an opportunity for WHV to influence the provision of health information and services to a large number of Victorian women through enhancing its influence with GPs. This would be achieved most effectively in partnership with those organisations who provide training and information products for GPs.

There is currently an unmet need for the provision of gendered analysis of health data. Such information would be valuable to government, the bureaucracy, the media, other agencies and health service providers. However, the utility of this analysis for some will depend on communication of the value of a gendered approach.

There is potential for WHV to enhance its position and influence in the general community through a more pro-active approach to the provision of information, comment and advice regarding gendered health issues to the media. It is likely that such a strategy would provide indirect benefits associated with enhancing the profile of the organisation throughout the health community and improving the capacity of WHV to influence policy and program development.

It is important to recognise the political sphere as a critical element of influence in establishing the funding environment and the health policy agenda. Influence within this sphere is as much in the context of informal relationships as formal ones. In this regard, there is a need for WHV to seek to establish informal relationships with individuals identified as key influencers within political organisations, including Ministers, their Ministerial Advisers and media personnel, and with all women Members of Parliament.

The positive regard with which key WHV personnel are regarded should be used as a beginning point for increasing awareness of the range of roles and activities of the organisation.

A limitation of this analysis needs to be recognised: these observations and conclusions have been based on external perceptions of WHV and did not include an analysis of the organisation from within. To be complete, the analysis ultimately needs to be considered within the context of the philosophical approach and charter of WHV.