

In the early stages of the Internet age, women lagged significantly behind men in almost all usage areas. Boys and men were far more likely to own a computer, use the Internet, surf the world-wide web on a regular basis, trust the Internet for commercial transactions, or otherwise capitalize on the new technologies. Beginning in the late 1990s, however, the gender-balance in terms of access to the Internet began to shift (There remains, however, a very sharp gender difference in utilization of computer technologies more broadly.) The rapid improvement in the Internet and, in particular, the proliferation of easy to use world-wide web sites and Internet processes transformed the public's use of the digital systems. The development of chat lines and messaging systems converted the Internet into an extension of the telephone; the proliferation of entertainment and teen-focused web-sites has drawn an increasing number of young people to the Internet and turned the Nintendo generation into the e-generations. Women in many countries have done caught up with males in terms of on-line capabilities and interests.

The Internet revolution, though broadly based and reasonably comprehensive, has not solved all of the problems associated with women's need for health information. A major digital "divide" exists between the wealthy and

the poor in the industrial world, a chasm addressed in part by the provision of public access terminals in libraries and other public spaces. An even greater digital "canyon" remains between the world's poorer nations and the industrial world. In the former, the vast majority of the population has little or no access to the Internet and is therefore cut off from digital information. In the industrial world, in contrast, Internet promoters have moved beyond personal computer-based delivery systems and are working on using mobile telephones, PDAs (personal data assistants) and other delivery systems to provide users with ready access to information. Governments and corporations have generally recognized that other forms of mass media (particularly the television, but with secondary commitments to newspapers and radio) provide more comprehensive coverage and offer somewhat assured access to a much broader range of consumers and members of the general public.

The greatest liberalization flowing from the development of the Internet is the information power that the technology places in the hands of individuals. Women seeking to learn more about specific symptoms, wishing to check up on a doctor's diagnosis, or uncertain about a prescription or treatment plan laid out for them by a physician can find hundreds of

potentially valuable web-sites within a matter of minutes. Many of these sites, in turn, offer access to thousands of page of supporting documentation, often in the form of research papers, statistics and reports. Only a few years ago, women had relatively few options when searching for additional information: they could seek a second medical or professional opinion, they could visit a local or university library (if one was available) and they could invest hundreds of hours in extensive and often imprecise bibliographic and library searches. The Internet transformed this pattern. An individual with a specific research question can, provided they have very basic world-wide web skills, very quickly identify numerous sites of potential value and utility.

The volume of information available, however, is not an assurance of quality reliability or suitability. The wrong kind of information or inaccurate information can easily cause difficulties and distress. The Internet is, after all, an open-ended and anarchistic system. There are virtually no controls, save for some relatively minimal financial constraints, on who can gain access to the Internet and who can make information available to people surfing the world-wide web. Internet users know that the billions of screens (pages) of information on the web contain a great deal of useful information, enormous

quantities of suspicious or highly questionable data, self-serving personal or corporate information, deliberately misleading or propagandistic sites, and a wide variety of postings that range from uncritical speculations to malicious and deceptive descriptions. While social scientists find the various contributions, musings, and other material to be illustrative of a complex, multi-faceted society, individuals concerned about health and medical information are extremely concerned about the proliferation and lack of regulation of health-related web-sites. In the medical field, after all, improper diagnosis, inaccurate assessments, or inappropriate treatments can cause fear, personal inconvenience, pain, acceleration of the illness or, in extreme cases, death.

The Internet, then, is simultaneously a vision of opportunity and a frightening nightmare for people, agencies and organizations wishing to promote women's health. Properly organized and carefully vetted health sites can provide women around the world with readily accessible, typically free and uncensored (and unmediated by male doctors) information about their bodies, their health and their treatments. For promoters of women's health, the Internet provides an unprecedented means of reaching women and offers consumers almost instant access to massive amounts of credible, usable and

female-specific information.

Simultaneously, however, the same technology permits medical manipulators an unexpected opportunity to reach thousands, if not millions, of needy and uncertain patients. Corporations have a new vehicle for promoting their wares, and health care charlatans can sell their untested and often unsuccessful treatments to the weak, the gullible, and the desperate. Women can gain access to information that may not suit their cultural situation or deal appropriately with their medical conditions. Just as the Internet holds the potential to save and improve the lives of women, it has the potential to confuse, mislead, and misinform those same women. Sadly, and importantly, the difference between useful information and unhelpful data is often difficult to discern; to make matters worse, the web sites containing these contrasting types of medical information rest only a "click" or two away from each other.

The purpose of this report is to provide a preliminary overview of the quality and nature of web-based medical and wellness information available for women in selected non-Asian countries. The research has been selective and is intended to illustrate the range and variety of material currently on the Internet. The web-sites listed and categorized at the end of the report represent but a tiny fraction of the total

number of Internet sites devoted to women's health. There is a bias in the selection; the sites included in this overview are generally those that have been vetted by a medical, academic or government authority and hence are bunched closer to the "high quality" end of the Internet spectrum. There are literally hundreds of thousands of web-sites related to women's health; most of them have little professional or medical merit and provide information that is either intensely personal. As a preliminary introduction to the key question of the utility of the Internet for educating women about wellness and health, it is useful to first consider a variety of issues concerning the use of the Internet/world-wide web as a means of gathering information on women's health.

#### **Technological Proficiency of Internet Users:**

Developments over the past decade have made the Internet extremely easy to use. The continual improvement of web browsers, improved speeds and connectivity, greater bandwidth (which determines the amount of data that can be delivered to the desktop) and growing levels of comfort with personal computers have produced millions of proficient web-surfers. This population is tilted toward the well-to-do and rich (substantially), the literate (almost

entirely), the urban (in most countries), males (the gap is narrowing), and the young (the age profile is gradually broadening). Most web-sites on health issues have relatively easy to follow architecture; it is not difficult to follow logical and well-laid out site maps that make it possible to navigate with ease through the various materials. Not all sites are intuitive, however, and the more technical sites are often harder to use. Even after a decade (but only a decade, it is important to remember), there are many people with Internet connections and personal computers who have only a preliminary understanding of how to use their computer and how to navigate the Internet. These same people tend to have only a rudimentary knowledge of search engines and research techniques, thus limiting further their ability to capitalize on the information on the Internet.

#### **Medical Literacy of Internet Users:**

The medical profession, particularly in western industrial nations, has long used technical language as a means of describing illnesses and treatment regimes. Patients have long complained that physicians present material in a fashion that is obscure, difficult to follow and subject to misinterpretation. Physicians, in turn, complain that patients and families want overly simplified explanations and prognoses for

complex, highly nuanced and often little understood medical challenges. The degree of medical literacy, therefore, has a significant impact on the utility of web-sites. A particular location might have technically superb information, properly vetted by health care professionals, and capable of providing superb data about a particular wellness issue or medical concern. If the language and level of technical detail on the site are too high, however, the information might well be of limited utility to the general public. The converse is also true. Health and medical information that has been stripped of its technical language might well surrender some accuracy and reliability in the interests of public accessibility. Increasingly, health-related web-sites are emphasizing plain language, with limited medical jargon (and explanations provided for technical terms) and a conscious effort at accessibility.

#### **Digital Pamphlets versus Multi-Media Web-Sites:**

Huge amounts of material on the Internet are little more than print material transferred to the Internet. Sites of this nature are best understood as digital pamphlets, for they differ very little from the polished and glossy printed materials that have long been around the health care field. Multi-media sites, in

contrast, provide multi-layered information, with hyperlinks (clickable links) to specific and related data, audio-visual material and interactive elements (questionnaires, surveys, self-assessment opportunities, and the like). Very few of the medical/health web-sites have begun to explore the technical potential of the Internet in this regard. (The multi-media material, incidentally, demands considerable band-width and a powerful computer). Individuals accessing the Internet with older machines – more than two years old is generally sufficient – often find that they cannot use the more complex sites or that the additional features slow the surfing process dramatically. The Internet holds a great deal more potential than is currently being utilized. At the same time, however, organizations and agencies which push the technological envelope have typically cut themselves off from a sizeable portion of their target audience. At present, only a small minority of health-related websites have progressed much beyond the stage of clickable digital pamphlets. This means, in turn, that the digital potential of the world-wide web has barely been scratched, particularly for an information-rich, highly visual, and intensely personal subject like health care.

#### **Digital Libraries: Access to the Medical**

#### **and Wellness Literature:**

One of the most promising aspects of the knowledge revolution – free access to the vast quantities of research material related to matters of human health – remains at a very preliminary stage. The vast majority of people seeking health and wellness information require very basic and preliminary data. For those with serious or advanced illnesses, however, gaining access to the most recent and cutting edge research could well have an impact on their acceptance of treatment regimes, their choice of medications, and ultimately the quality of their lives. The frontier research is available not in the open-ended world-wide web, except when news of major discoveries is released to the media, but rather through the vast and complicated medical research literature.

There are literally tens of thousands of academic and scientific periodicals related to health and wellness. Save for a handful of residents living near world-class research universities, the vast majority of this literature is not available in a quick and easy fashion. The Internet has provided a series of remarkable solutions, including on-line journal search engines (such as the Web of Science, Medline, Health Reference Centre) which provide ready and free bibliographic (ie. the citation and often the abstract of the articles) access to hundreds of scientific journals. There

are an increasing number of full-text services, providing either instant access to the complete contents of an article or a whole journal, or various forms of delivery of the articles to those willing to pay for the material. (The delivery systems vary from inter-library loan of the journal literature to rapid "fax back" systems which provide prompt access, usually for a premium price, to highly desired information.) There are, as well, a variety of commercial and free digital libraries, offering quick on-line access to hundreds of books, in their entirety. Although the availability of health and wellness information through digital libraries is at a very preliminary stage at present, there are signs that this situation is beginning to improve.

Having Internet access to the materials does not ensure ease of use or access to the actual research materials. The commercial site licenses which govern the use of the research material typically restrict access to on-site users (ie. Those able to actually visit the library and use in-house computers) or members of a specific community (ie. faculty, students and professional staff). Furthermore, the language and content of the more advanced journals is rarely easily accessible to the general public. The highly specialized and thereby exclusionary language of the medical professions can make it very difficult for the average person to read the material

or to make appropriate use of the information contained therein.

The creation and gradual sharing of digital data-bases is providing an unprecedented level of access to cutting edge research information. (It should be noted that many newspapers and magazines provide ready access to all but the most recent editions, thus offering a huge data base of general content on matters related to health and wellness.) The on-line collections of journalistic, academic and scientific material continue to grow in leaps and bounds and promises, in the coming years, to displace the more common print issues and volumes. Having access through well-developed and easy to use search devices ensures that even relatively unsophisticated Internet users can locate large quantities of relevant and potentially important information.

#### **Quality Control and the Provision of Web-Sites:**

Setting up a web-site is a remarkably easy process, requiring little more than basic word-processing skills and a connection to the Internet. The development of sophisticated and inexpensive web-design tools (like Dreamweaver) makes it easy for a fairly junior web developer to produce a first-rate website. (There are even a variety of locations where a person can post a website for free.) Cost, as well as

competence, are no longer barriers to intervening in the medical discourse. As a consequence, it has become increasingly difficult to differentiate between a website produced at great expenses and vetted carefully by medical and health professionals from a hastily assembled, unsophisticated package put on the web by a self-appointed “doctor,” who espouses weird and potentially dangerous health care solutions. For the non-professional web-surfer, similarities in design can mask the fact that the two systems are of vastly different levels of quality and reliability.

Put differently, it is crucial to note that there is no quality control on the Internet. In most areas – opinions about movie stars, commentaries on sporting figures, political opinions about sitting governments, suggestions for how to make a quick million dollars – the fact that junk sites outnumber professional, high-quality sites is generally a mild irritant or a useful sociological insight. Within the health and wellness field, the fact that charlatans can masquerade as physicians, that self-promoters can pass themselves off as sophisticated scientists, and that dangerous medical practices can be offered as cures is a matter of enormous concern. Users can abide by the standard web-rules when determining the value and legitimacy of a web-site: the status of the host (ie. a major hospital or university), the

reputations of the people associated with the site, links (and reverse links) to other high quality sites, endorsement by major medical or professional associations, and the like.

The world-wide web has not yet developed suitable protocols, structures or procedures to protect against the wide variations in quality, particularly in the medical field. As a consequence, medical practitioners tend to be very wary of information posted on the Internet and are reluctant to recommend to their patients that they use the web to identify suitable sources of information. Until this problem is addressed systematically, through standard tests and accreditation of sites by professional bodies, this challenge will linger and the Internet will fail to live up to its potential as a platform for the dissemination of high quality health and wellness information.

#### Language and Language Conversion Systems:

Language is one of the most important barriers to global use of the Internet. Ten years ago, observers assumed that the Internet would establish the hegemony of English language. Recent estimates suggest that Mandarin Chinese will dominate the Internet before the end of this decade. There are several countries, Japan foremost among them, that have nation-specific

world-wide webs. Few people outside the country examine their material and few in the country make regular use of websites in a different language. In most European countries, the majority of Internet users have advanced facility in other languages. In North America, in contrast, few non-immigrants have more than a rudimentary familiarity with other languages and are therefore constrained to work in English. The world-wide web, in other words, carries a very large qualification: language facility plays a major role in determining access and the ability to use relevant information placed on the web.

There is help in the offing, although the current state of the technology leaves a fair bit to be desired. There are currently Internet-based translation devices available, which will translate a section of text or entire web-sites. (See, for example, altavista.com, particularly the babelfish translation device. The translation tool – there are several systems available – will translate portions of text or entire websites.) The translations are rough and unreliable at present, particularly when moving information between an Asian site and a European-based site. It is possible, even with the current technology, to get a rudimentary sense of the coverage of issues in countries operating with a different language base.

### **Finding Relevant Sites: Yahoo!, Goggle and Other Search Engines:**

Given the size and complexity of the Internet, it is very difficult for the casual user to find appropriate web-sites.

There are a variety of easy to use strategies that have proven extremely successful in identifying the most useful sites. These include:

1. Get advice from a medical professional on which site(s) to use. For most specific medical and health issues there are one or two sites which are superior to all others.
2. Begin with the web-sites of major and credible medical and health care organizations. Almost every one of these sites has links to other, more specialized web-sites.
3. For specific and major ailments or diseases, find the web-site(s) of the principal non-profit organization with an interest in this area. These associations monitor web-sites regularly and are typically very cautious about recommending sites.
4. Learn how to make effective and efficient use of one of the many search engines available on the market. The most popular search engines at present are Google (google.com, with

national variants) and Yahoo! (Yahoo.com, also with versions in other languages). Google is extremely fast and lists based on the number of other links and references to a site. The search engine uses connections as a surrogate for importance. Yahoo!, in contrast, is a menu-driven and selective web-site. Yahoo! agents review websites and determine their suitability for inclusion on their lists. The selection is relatively careful, but the screening focuses more on the sustainability and technical quality of the web-site than on considerations of content.

5. Recognize that there is no substitute for trial and error. Identifying appropriate sites can take a fair bit of time and require careful assessment by users. The blistering speed of the Internet has made most users very time-conscious. Results are expected quickly and many people demonstrate little patience in completing their research. On matters related to medical care and wellness, the time is extremely well-spent, but many thousands of users are unprepared for the time and effort required.

#### **Finding Relevant Users:**

##### **Permission-Based Technological Systems:**

The current structure of the Internet is based on search and assess systems. An individual seeking information about a specific topic is required to identify an appropriate search engine or linked web-site and to surf through hundreds if not thousands of relevant web-sites.

Initial searches can be time-consuming, frustrating and disappointing, if only because the large number of marginally valuable sites overwhelms the truly useful sources of information.

Furthermore, a web-user who wishes to remain on top of recent developments is required to reproduce the same or similar search process at a later date in order to ascertain if additional information has come available.

The technology exists for an easier, user friendly means of keeping abreast of recent developments. On a variety of web-sites, including those operated by news organizations, financial companies, entertainment retailers, bookstores and the like, web visitors are able to register in order to receive regular or as-required updates. These systems, which are used primarily by commercial interests, are called permission-based. An individual registers on the site, and provides detailed information about the kind of data that is being sought. Whenever relevant updates come

available, an email is sent to all registered users. This structure can permit an individual to identify all subjects of interest within the range of material included on the web-site or the information service. It also permits the organization, company, agency or web-site producer to maintain an active connection with the site visitors, thus ensuring the widespread and systematic dissemination of the collected material. Over time, permission-based information sharing is likely to assume a greater role in the use of the Internet to provide up-to-date medical and wellness information, targeted specifically at the individuals who need and who have indicated an interest in receiving information.

#### **Reviewing the Web-Sites (By Category):**

There are literally hundreds of thousands of web-sites devoted to issues related to wellness and health care. A smaller sub-set, still numbering in the thousands, provides access to more specialized information related to women's health concerns. A list of selected sites relevant to women's health issues is appended to the end of this report; it provides a preliminary indication of the breadth and complexity of the Internet-based material of relevant to women. There are, however, several general categories of information which must be considered. A brief summary of these is provided

below.

#### **Government and**

##### **Government-Sanctioned Web-Sites:**

Governments have a long-standing interest in public and preventative health. In countries with a strong commitment to state-funded health care – Canada, Australia, New Zealand and the United Kingdom – governments also play a crucial role in medical intervention and health care services. These same authorities, consequently, have a commitment to public education and to the dissemination of carefully collected and presented information.

Government-sponsored sites place a strong emphasis on preventative measures, and generally direct visitors to make use of physician or nurse services as required. They often provide very general information on health and wellness, but shy away from detailed or analytical content related to specific illnesses or treatments. Befitting their origins within the state bureaucracy, government websites tend to be cautious and deliberate, capitalizing primarily on the opportunity to inform patients about general health care concerns.

Government websites are best understood, in the main, as library-like efforts to provide information without leaving visitors with the belief that they can self-diagnose. In most jurisdictions, there are sites prepared by national

governments, regional authorities (state, provinces, prefectures, etc) and local councils.

#### **Medical Association and Physicians**

**Web-Sites:** In some countries, and particularly in the United States, physicians and other organizations have moved quickly to capitalize on the opportunities presented by the Internet. Medical organizations share with government an interest in public education and a desire to ensure that visitors to websites understand the limitations of the web-based material. There is, again especially in the litigious United States of America, a considerable caution evidenced on these websites. Care is taken to provide general information, and to make it clear that diagnoses and treatment regimes for individuals are not included. Several of the better sites provide two (or more) levels of information. The first, presented in easy to follow, lay-person's terms, is designed to provide a measure of public information. The second, heavily laden with scientific and medical vocabulary and concepts, is targeted specifically at practicing physicians. This second set of materials is difficult for non-specialists to follow, but can provide extremely useful updates and insights for medical and health care professionals. Some of these websites, like WebMD (from the United States) provide very

useful advisory sections, rather like making available a larger, regularly updated encyclopedia on medical matters. The careful vetting of these sites by medical professionals adds a considerable level of comfort for users.

**Women's Organizations Web-Sites:** One of the hallmarks of the women's movement has been the drive to regain control of women's bodies and to assert greater control over wellness and medical care. Women's organizations, consequently, have been at the forefront in providing women-centred information, designed to empower women in their conversations with health care professionals and to provide women with detailed preventative advice. Larger women's organizations have clearly had their material vetted by professionals and have made available extremely valuable sets of reports, suggestions around nutrition, lifestyle, reproductive health choices, and excellent commentaries on health care. Advice sections often include information on how to work with doctors and hospitals, ensuring that women have the background necessary to maintain a strong measure of autonomy and independence. Some of the women's organizations sites press very specific, and sometimes radical, approaches to health care, with emphases on alternative medicines, holistic medical

care, and less interventionist approaches to wellness and healing.

**Disease-Centred Web-Sites:** Perhaps the most information rich sites on the Internet are those maintained by societies associated with specific diseases or sets of diseases. These organizations, particularly in North America, are well-funded and devoted a great deal of effort to public education (preventative care) and advice (for those who find themselves diagnosed with the specific disease). Although the quality and complexity of the websites vary considerably, they nonetheless provide an enormous amount of detailed information. Even more helpfully, most of the websites provide a step-by-step description of the progress of the disease and the healing/remediation processes. Introductory sections typically describe common symptoms and early warning signs (and medical procedures) related to the illness. They then take visitors through the various stages of the disease, describing impacts on lifestyle, steps that can be taken to ameliorate the disease, common therapies or interventions, and statistics and information related to survival rates. The best sites provide links to current research results, suggestions on how and where to find medical care, advice on psychological aspects of the disease, and related matters. Most major countries have a

full or substantial set of these disease-centred websites, which clearly represent a growing component in public education, outreach and patient care for the organizations. Many of these sites have specific sections, as appropriate, associated with women and the disease in question; on occasion, these portions of the website are extremely useful for women coping with the illness.

**Other Non-Governmental Web-Sites:**

The world-wide web is a diverse and complex universe, offering a wide and sometimes baffling array of information. There is no shortage of unique and unusual web sites associated with women's health and wellness issues. There are, for example, sites related to phases of life (menopause), parts of the body (including the clitoris), human sexuality, nutrition, lifestyle questions, pain and pain amelioration, eating disorders, smoking (and how to quit smoking), ethnic/cultural issues related to women's health, and a variety of other such topics. The quality of the information and the balance between provision of data and promotion/polemic varies widely on these sites.

**Corporate Web-Sites:**

Health care generally and women's health in particular represent multi-billion dollar industries world-wide. The enormous corporate investment in

research and development of pharmaceuticals, surgical procedures, detection and treatment equipment, and thousands of highly specialized medical supplies is intended to produce profits for companies in this sector. Companies vie vigorously for the attention of health care professionals and, increasingly, patients. While the vast majority of the sector's advertising money is devoted to television and print promotions, some companies have sponsored health information web-sites (obviously, typically those associated with the disease that their medicine or technology is intended to address). The corporate websites differ qualitatively from most health-related web materials. They are often quite expensively made, with significant audio-visual or high-technology elements. Also, while the sites generally promote wellness, encourage visitors to see physicians with their concerns, and often provide general information on the specific illness or set of diseases, the primary purpose of the site is to promote a specific product or service.

#### **Personal Web-Sites:**

One of the fastest growing areas of the world-wide web relate to the posting of personal material on the web. This is also true of women's health and wellness. There are countless sites recounting women's experience with the health care

industry, typically relating to surviving a severe illness. Other personal sites promote the use of a specific therapy, approach to nutrition and wellness, or another sub-field in health and wellness. These sites are rarely, if ever, vetted and can contain a great deal of inaccurate or unsubstantiated information. They may also have been placed on the web to attract visitors, through web links, to other organizational or corporate sites. These sites are not particularly useful for the most part and may, in fact, be dangerous. In one very important and often overlooked aspect, however, the personal web-sites are very important. Most of the medical information on the world wide web is clinical and impersonal. There are numerous charts, diagrams, lists of symptoms, discussions of treatment regimes, and advice on a wide range of issues and practices related to wellness and health care. Except for these personal sites, however, there is very little testimony and very few personal accounts of the experiences of living through a major illness of coping with symptoms, the medical system, and the treatments. For individuals coping, often in a lonely and isolating way, with a disease or ailment, the discovery of a personal account from another individual is often critical. Whatever shortcomings these personal websites have in medical terms – and they can be considerable – these materials can be emotionally and

psychologically very valuable.

#### **Assessing the Quality of Internet-Based Health and Medical Information for Women:**

As noted earlier, the quality and reliability of health and wellness information posted on the world-wide web varies greatly. There are a large number of superb and useful sites, principally those maintained by the disease-associations, major health professional organizations and government agencies (the latter, particularly in the area of preventative care and public health). The sites are not, as a group, very technologically advanced. Most are in the category of digital pamphlets rather than sophisticated, interactive and multi-media Internet sites. This is unfortunate, as the multi-media capabilities of the web provide an opportunity to make available highly interactive and instructive documentation and to empower patients and visitors by allowing them to "navigate" through their disease or medical concern.

Most reviews of health care and medical information on the Internet have indicated that more careful scrutiny and monitoring of the websites is in order. The review of this material is still at a very early stage. Consider, for example, the conclusions of the most extensive

study to date of the nature and quality of health information on the world wide web.

The epidemiology of consumer health information on the Web is an emerging research discipline at the intersection of medical informatics and public health. Many descriptive, cross-sectional studies have attempted to draw attention to perceived "outbreaks" of misinformation on the Web by estimating the proportion or prevalence of inadequate health information. However, the individual's risk (R) of encountering an inadequate site on the Web is a function of both the proportion of inadequate information on the Web (P) and the inability (I) of the individual (or his tools) to filter the inadequate sites. Since studies usually report R, but not I, we cannot infer P, or adjust study results to make them comparable across domains or time. Even if we could know P, we would still not know how this measurement of "true" misinformation on the Web translates into health outcomes or critical incidents in a population. On an individual level, R can be reduced by improving the ability of the user to locate trustworthy sites or to filter the inadequate ones.

Public e-health interventions such as MedCERTAIN (121) therefore strive to reduce P and I by increasing, for example, the proportion of health information providers making disclosure

statements (119) and by empowering consumers to identify trusted sites through educational and technological innovations, including the possibilities of the semantic Web. (G. Eysenbach, J. Powell, Ol. Kuss and E-R Sa, "Empirical Studies Assessing the Quality of Health Information on the World Wide Web: A Systematic Review," JAMA, The Journal of the American Medical Association, May 22, 2002, vol. 287, issue 20, page 2691.)

Work has begun, through an organization called MedCIRCLE.org, which is devoted to "Internet rating, certification, labeling and evaluation of health information" and which has the following objectives: "The overarching aim of MedCIRCLE is to develop and promote technologies able to guide consumers to trustworthy information on the Internet." Such an organization is clearly needed if individuals interested in using the Internet to find relevant and useful medical information are to have an assured, well-vetted set of properly assessed medical and health care websites, perhaps through some form of accreditation and/or "branding" of top information sites.

Put simply, Internet-based health care materials aimed at women are of uneven quality and utility. Some are superb and provide excellent guidance; others have misleading and potentially dangerous recommendations

or information. Identifying the most useful sites, particularly outside one's regional and national context, is a major challenge. Women have particular needs – for private access to sensitive information and for material specifically aimed at women's medical and health care requirements – that go beyond generic, population-wide information sources. This is particularly the case for women in countries which restrict women's access to health care or impose limited of women's freedom to make personal medical choices.

#### **The Future of Internet-Based Health and Medical Information for Women:**

In the aftermath of the dot.com boom and subsequent meltdown, it is impossible to ascertain precisely where the future of Internet-based medical information for women might lie. Several key considerations can be identified; these are preliminary and speculative thoughts, of course, but they provide some indication of how health information systems might change in the coming years.:

1. There will be more information, from a wider variety of sources, and it will therefore be harder than ever to identify the most relevant and urgently needed material;
2. There will be continued difficulty with widely divergent quality of the

- web-sites and with the inaccuracies of specific sites;
3. Search engines and linked sites will make a more concerted effort to remove or to isolate questionable websites;
  4. A system of accreditation (like MediCIRCLE, but not necessarily this organization) will establish national and international standards for health-related web-sites.
  5. Key search engines will likely use accreditation by an organization like MediCircle as a means of identifying suitable and high quality sites.
  6. There will be growing interest in working with health professionals and organizations in other countries. This will result in extensive cross-linking of web-sites, sharing of key data, and other accommodations.
  7. Language will emerge as a major, ongoing stumbling block to international understanding for and support for women's health issues. There will be greater collaboration and interaction between nationally-bounded organizations. Technological innovations will be key to supporting this transition, for nation-specific world-wide webs will continue into the future.
  8. Women and women's organizations are likely to be very successful in drawing attention to the need for more women's specific health and wellness information. This will result in both the proliferation of websites devoted to women and the greater inclusion of women's themes and concerns within existing and new websites.
  9. Access to digital libraries and, through permission-based systems, the provision of direct research results and service reviews to patients will greatly empower women and enable them to make informed health care decisions.
  10. Companies and organizations will pay greater attention to the best ways of delivering appropriate and timely information to specific patients (as through, for example, permission-based systems),
  11. The improvement in computer literacy, through both training and practice, will transform the health and wellness professions over the next thirty years.
  12. Developments in tele-medicine, including remote testing and monitoring, will enhance the status of Internet-based medical knowledge.
  13. Companies, governments and health care providers will explore alternate means (particularly the wireless telephone systems) of sharing health care information. Increasingly, this information and, in fact, medical care generally, will

- be tied to individual health histories and needs. Generic information will likely, over a very long period of time, become less important.
14. As the speed of health care research accelerates, so will the intensity of information sharing on Internet-based websites. There will be growing demand for greater access to health care information and for remote access to health assessments, provide through Internet connections.
  15. The aging population in many industrial nations will be both older and more computer-aware (if not computer-literate in an advanced sense). The extension of tele-health implementations to this same group will spur and interest in treatments, monitoring systems and the activities of health

organizations.

16. Perhaps most ominously, the digital divide in the area of health care information will grow dramatically. This will, in turn, likely result in improved health care results in wealthier nations and dramatically lower results in the poorest countries in the world.

Despite impressive improvements over the past ten years, the provision of health and wellness information for women via the Internet remains in its infancy. There is abundant evidence, however, that the vast untapped potential of this relatively new technology continues to revolutionize the sharing of research and medical information. This, in all likelihood, will result in the greater empowerment of women in their relationships with the medical and increased demands for a truly women's centre health care system

#### Appendix I: Selected Web-Sites Related to Aboriginal Women's Health for New Zealand, Australia, Great Britain, Canada and the United States of America

##### **New Zealand**

Health Research Council <http://www.hrc.govt.nz/>

Ministry of Health <http://www.moh.govt.nz/moh.nsf>

New Zealand Health Network <http://www.nzhealth.net.nz/index.html>

NZ Health Online <http://www.everybody.co.nz/>

Division of Health Science (UofO) <http://healthsci.otago.ac.nz/division/home.htm>

Department of Community Health (UofA)

<http://www2.auckland.ac.nz/mch//chhome.htm>

NZ National Health Committee <http://www.nhc.govt.nz/>

Women's Health Action Trust <http://www.womens-health.org.nz/>

Mental Health Commission <http://www.mhc.govt.nz/>  
 Health Sponsorship Council <http://www.healthsponsorship.co.nz/>  
 Health Network <http://www.health.net.nz/>  
 Nelson Marlborough Health Services <http://www.nmhs.co.nz/>  
 Ngati Awa Social & Health Services <http://www.nash.org.nz/>  
 Canterbury District Health Board <http://www.cdhb.govt.nz/>  
 Breast Health New Zealand <http://www.breast.co.nz/>  
 Health Chemist <http://www.healthchemist.co.nz>  
 Department of Molecular Medicine and Pathology (UofA)  
<http://www.health.auckland.ac.nz/molmedpath/>  
 Wellington Cancer Society <http://www.cancersoc.org.nz/>  
 Fertility NZ <http://www.fertilitynz.org.nz/>  
 Auckland Institute for Cognitive Behaviour Therapy <http://www.aicbt.co.nz/>  
 Health Site <http://www.healthsite.co.nz/>  
 Kiwi Kiss Diet <http://www.kiwikiss.co.nz/>  
 Midcentral District Health Board <http://www.midcentral.co.nz/>  
 New Zealand Institute of Environmental Health <http://www.nzieh.org.nz/>  
 Department of Obstetrics & Gynaecology (UofA) <http://www.obsgynae.auckland.ac.nz/>  
 Injury Prevention Research Centre <http://www2.auckland.ac.nz/ipc/>  
 Fitness Corporation <http://www.fitcorp.co.nz/>  
 EMFacts Information Service <http://www.tassie.net.au/emfacts/>  
 New Zealand Sports Medicine <http://www.sportsmedicine.co.nz/>  
 Tui Ora <http://www.tuiora.co.nz/>  
 Women's Balance LTD <http://www.womensbalance.co.nz/>  
 Safeguard \* (women's) <http://www.safeguard.co.nz/default.htm>  
 Healtheries <http://www.healtheries.co.nz/>  
 Parkinson's New Zealand <http://parkinsons.org.nz/>  
 New Zealand Online Pharmacy <http://www.newzealandpharmacy.co.nz/>  
 Menz Medical Centre <http://www.menzmedical.co.nz/>  
 Everybody's Sexfiles <http://www.sexfiles.co.nz/>  
 Wright Health Care <http://www.wrighthealth.co.nz/>  
 Female Life New Zealand <http://www.femalelife.co.nz/>  
 Urge <http://www.urge.org.nz/index2.html>  
 New Zealand Food Safety Authority <http://www.nzfsa.govt.nz/>  
 YMCA <http://www.ymca.org.nz/>  
 North Shore Women's Centre <http://www.womyn-ctr.co.nz/>  
 New Zealand Breast Cancer Foundation <http://www.nzbcf.org.nz/>  
 Natural Family Planning Association of New Zealand <http://www.natfamplan.co.nz/>  
 Baby Times <http://www.babytimes.co.nz/>  
 New Zealand College of Midwives <http://www.midwife.org.nz/>  
 Fertility Associates <http://www.fertilityassociates.co.nz/>  
 Well Being <http://www.wellbeing.com.au/>  
 NZ Society of Naturopaths <http://www.naturopath.org.nz/>  
 Rebirthing Network of NZ <http://www.rebirthing.co.nz/>  
 Alcohol Advisory Council of New Zealand <http://www.alcohol.org.nz/>  
 Motor Neurone Disease Association of New Zealand <http://www.mndanz.org.nz/>

Arachnoiditis Suffers Action and Monitoring Society <http://www.aboutarachnoiditis.org/>  
 ADHD NZ <http://www.adhd.org.nz/>  
 Diabetes Research New Zealand <http://www.diabetesresearch.org.nz/>  
 Diabetes New Zealand <http://www.diabetes.org.nz/>  
 Rotorua & District Multiple Sclerosis Society <http://www.cole.gen.nz/MS/>  
 Living With <http://www.livingwith.co.nz/>  
 Borderline Personality Disorder In NZ <http://www.bpd.net.nz/>  
 Head Injury Society of NZ <http://www.head-injury.org.nz/>  
 Cancer Society of New Zealand <http://www.cancernz.org.nz/>  
 Depression Reality <http://www.bestsitez.com/depression/>  
 New Zealand Haemochromatosis Support Group <http://www.ironz.org.nz/>  
 Heart Support Wellington <http://www.heartsupport.org.nz/>  
 Heart Children New Zealand <http://www.heartchildren.org.nz/>  
 New Zealand Herpes Foundation <http://www.herpes.org.nz/>  
 Schizophrenia Fellowship of New Zealand <http://www.sfnat.org.nz/>  
 Web-OOS Online Network <http://www.creators.co.nz/OOSinjuries.html>  
 Immunisation Awareness Society <http://www.ias.org.nz/>  
 NZ Society of Otolaryngology and Neck Surgery <http://www.orl.org.nz/>  
 5 + A Day <http://www.5aday.co.nz/>  
 Medical Laboratory Wellington <http://www.welpath.co.nz/>  
 Weight Watchers NZ <http://www3.weightwatchers.com/international/nz/>  
 Australia/NZ Food Authority <http://www.foodstandards.gov.au/>  
 New Zealand Health Information Service <http://www.nzhis.govt.nz/>  
 Health Informatics NZ <http://www.hinz.org.nz/>  
 Public Health Association <http://www.hinz.org.nz/>  
 New Zealand AIDS Foundation <http://www.nzaf.org.nz/default.html>  
 Body Positive <http://www.bodypositive.org.nz/>  
 Eating Disorders <http://www.nzhealth.net.nz/diet/eating.dis.html>  
 Crohn's and Colitis Support Group <http://home.clear.net.nz/pages/ccsg/>  
 Canteen <http://www.canteen.org.nz/>  
 The Asthma and Respiratory Foundation of New Zealand <http://www.asthmanz.co.nz/>  
 New Zealand Endometriosis Foundation <http://www.nzendo.co.nz/>  
 Multiple Sclerosis <http://www.malaghan.org.nz/research/ms.htm>  
 Multiple Sclerosis Society of New Zealand <http://www.mssocietynz.co.nz>  
 Multiple Sclerosis Society of Auckland, New Zealand <http://www.msakl.org.nz/>  
 Home Birth <http://www.homebirth.org.uk/>  
 Fertility NZ <http://www.nzinfertility.org.nz>  
 Marcé Society Australasian Branch <http://www.wairua.co.nz/marce/>  
 Miscarriage Support Groups in NZ <http://www.miscarriage.org.nz/>  
 XtraMSN:Health Library: Women <http://www.xtramsn.co.nz/health/0,,8289,00.html>  
 Vulvodynia Support Network <http://www.geocities.com/wellingtonbvs/>  
 Vivace Health <http://www.vivacehealth.co.nz/>  
 Healthy Women <http://healthywomen.org.nz/>  
 NZWomen.Com <http://www.nzwomen.com/content/index.php>  
 Mothers Network NZ <http://www.mothersnetwork.co.nz/>  
 Maternity Services Consumer Council (MSCC) <http://www.maternity.org.nz/>

Nutrition Society of New Zealand <http://www.nutritionociety.ac.nz/>  
New Zealand Medical Association <http://www.nzma.org.nz/>  
Occupational Health and Safety <http://www.osh.dol.govt.nz/>  
Health and Disability Commissioner <http://www.hdc.org.nz>  
HealthEd <http://www.healthed.govt.nz/index.html>  
Māori Health NZ <http://www.maorihealth.govt.nz>  
Hauora Maori [http://www.healthsite.co.nz/hauora\\_maori/](http://www.healthsite.co.nz/hauora_maori/)

## **Australia**

Aboriginal Drug and Alcohol Council <http://www.adac.org.au/>  
Australian Indigenous Health Info <http://www.healthinonet.ecu.edu.au/>  
Kimberly Aboriginal Medical Services <http://www.kamsc.org.au/>  
Australian Natural Therapists Association <http://www.anta.com.au/>  
Natural Health Society of Australia <http://www.naturalhealth.org.au/>  
The Health Nut <http://www.thehealthnut.com.au/>  
Women's Health Advisory Service <http://www.whas.com.au/>  
Victorian Obesity Surgery Centre <http://www.vosc.com.au/>  
Diet Advice International <http://members.ozemail.com.au/~dietinfo/>  
National Conception Control <http://www.usmev.com.au/cji.htm>  
Planned Parenthood of Australia <http://websites.golden-orb.com/plannedparenthood/>  
Australian Roaccutane Survivors Group <http://www.roaccutanesurvivors.com/>  
Acoustic Neuroma Association <http://www.acousticneuroma.com.au/>  
Alcohol Related Brain Injury <http://home.vicnet.net.au/~arbias/>  
Australian Addison's Disease Web Site <http://www.addisons.org.au/>  
HIV Positive Women Victoria <http://www.positivewomen.org.au/>  
National Centre In HIV Social Research <http://www.arts.unsw.edu.au/nchsr/index2.htm>  
AIDS Trust of Australia <http://www.aidstrust.com.au/www/Site/Home/index.cfm>  
Australian AIDS Fund <http://www.aids.net.au/>  
Australian Federation of AIDS Organisations <http://www.afao.org.au/index.asp>  
Ancahrd <http://www.ancahrd.org/>  
SHARPS <http://home.vicnet.net.au/~fitshop/>  
Alzheimer's Association <http://www.alzheimers.org.au/>  
ALS/MND <http://home.goulburn.net.au/~shack/>  
Motor Neurone Disease Association of Western Australia <http://www.mndawa.iinet.net.au/>  
FACTS <http://www.allergyfacts.org.au/>  
AIS Support Group Australia <http://home.vicnet.net.au/~aissg/>  
New Castle Aneurysm & AVM Support <http://www.naavm.org/site/index.cfm>  
Bodycage <http://www.bodycage.com/>  
Anxiety Disorders Foundation of Australia <http://www.geocities.com/adfanswinc/>  
Panic and Anxiety Hub <http://www.panicattacks.com.au/>  
Arthritis Foundation of Australia <http://www.arthritisfoundation.com.au/html/index.php>  
Asperger Syndrome <http://members.ozemail.com.au/~rbmitch/Asperger.htm>  
National Asthma Campaign <http://www.nationalasthma.org.au/>  
Active INC <http://home.vicnet.net.au/~active/>  
Victorian Lupus Association <http://www.lupusvic.org.au/>  
MS Australia <http://www.msaustralia.org.au/>