MARCH • 2009

HLA NEWS

NATIONAL NEWS BULLETIN OF **HEALTH LIBRARIES AUSTRALIA**, A GROUP OF THE AUSTRALIAN LIBRARY AND INFORMATION ASSOCIATION • ISSN 1448-0840

CONSUMER HEALTH
information services

Active participation by consumers in their own healthcare has been demonstrated to lead to improved health outcomes. Carol Bennett, Executive Director of The Consumers Health Forum of Australia, suggests libraries have a role to play in making health information more accessible to consumers and offers some advice on where the most reliable and useful consumer health information can be found.

The old adage that 'information is power' is particularly relevant in health care. When consumers have information, they can take part in decisions about their own health care and can contribute to the debate surrounding health policy and programs. Indeed, in 1978 the World Health Organisation stated: The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.

The assumption that personal health decisions are best left to the doctor has evolved into the current wisdom that people who are actively involved in their own health care have better health outcomes.

Likewise, it is now accepted that decisions about health policy and programs should involve health consumers as the users and beneficiaries of health care and, ultimately, those who pay for it. Consumers' unique and important perspectives provide an important balance to the views of health care professionals, service providers and industry.

This change to include consumers occurred over the last 20 years as our understanding about the delivery of health care changed and expanded with new information, research, experiences and understanding. Access to information through the internet contributed to the change.

Of course, a major stumbling block to consumers participating in health care decisions at the personal and national levels is access to the actual information that gives them the power to do so. Information must be readily accessible, easy to read and understand and from a trustworthy source. For example, medical articles and bureaucratic policy documents are not accessible to most consumers.

Information can be largely divided into two categories; information for consumer involvement in health policy at national and state levels; and information related to an illness/condition. This latter category can, of course, be broken down further into medical information for consumers, medical information for health professionals, information supporting consumers with the condition, research findings etc.

Consumer advocacy

While finding information on conditions is not very difficult, it is harder to find information on health consumer advocacy because it is driven by non-government organisations that often have few resources. These organisations

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INside

FROM YOUR

CONVENOR

Consumer Health Information • National Institutes of Health Revised Policy on Enhancing Public Access • HLA Executive

In the last column I talked about the important role of volunteers and this is yet again evident in this issue of HLA News when much of the content has been prepared by 'volunteers' to ensure HLA News remains a premier newsletter for all health librarians. Thanks to all the contributors.

As health librarians we often take consumer health information for granted. We know that whenever we need to find out information (for ourselves, family and friends and sometimes friends of friends) we can go to a range of sources – HealthInsite, MedlinePlus or even Mims if we want to know more about a particular drug. Last month I had reason to appreciate the importance of patient information that is packaged with drugs; my daughter was prescribed some medication but things didn't go as planned. Rather than rushing back to the doctor she read the consumer information and was quite content to see if her 'problem' resolved itself, which it did. Not only did this save a trip back to the doctor, it reinforced the concept of quality information.

Quality information is only as good as its source and the announcement in early March that President Obama signed into law the 2009 Consolidated Appropriations Act, which includes a provision making the National Institutes of Health (NIH) Public Access Policy permanent, was very welcome. The NIH Revised Policy on Enhancing Public Access requires eligible NIH-funded researchers to deposit electronic copies of their peer-reviewed manuscripts into the National Library of Medicine's online archive, PubMed Central (PMC). Full texts of the articles are made publicly available and searchable online in PMC no later than 12 months after publication in a journal.

The new provision reads:

> The Director of the National Institutes of Health shall require in the current fiscal year and thereafter that all investigators funded by the NIH submit or have submitted for them to the National Library of Medicine's PubMed Central an electronic version of their final, peer-reviewed manuscripts upon acceptance for publication to be made publicly available no later than 12 months after the official date of publication.

This will make a significant amount of information available to all health consumers.

Good consumer health information can come in a range of forms. Have you looked at any of the videos on the MedlinePlus website? You might be surprised at how much information is available. Another format is mp3 files. Both the ABC and NIH have audio files available for downloading. NIH Radio (http://www.nih.gov/news/radio/about.htm) is a 24-hour audio service designed to provide radio stations with the latest information about NIH research findings, highlights of press conferences, and health campaigns and is accessed by over 600 radio stations per week. The ABC has a very informative FACT BUSTER website (http://www.abc.net.au/health/talkinghealth/factbuster/)… from the site, "Do you know the difference between a health fact and an old wives' tale? Get to the bottom of common health beliefs…." Astound your colleagues with your knowledge!

In the last HLA News we called for expressions of interest in becoming a member of the HLA Executive. Unfortunately we didn't receive any nominations so the existing executive has agreed to continue on for the time being. However, don't think this lets you off the hook; we will just have to be more proactive in getting you involved!

Hope to see you at ICML in Brisbane in September.

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Your 2009 HLA Executive

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OPPORTUNITIES FOR EXPANDING LIBRARY SERVICES IN THE DELIVERY OF PATIENT (PERSON) – CENTRED CARE:

THE HEALTH INFORMATION PRESCRIPTION

Nicky Hayward-Wright explores various health information prescription models used in the US and UK and suggests that the implementation of similar services by Australian health libraries could see them become integral to the ongoing development of the patient (person)-centred health care system.

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> Libraries can be instrumental in providing both access to relevant and appropriate consumer health information as well as appropriate tools to enable consumers to make informed health decisions.

Studies about health information seekers have found that there have been benefits derived from accessing relevant quality health information. Benefits include:

- an increased knowledge about health issues,
- gaining a better understanding of the health issues that their health care provider has discussed with them,
- improving the relationship with their health care provider,
- reducing their anxiety level about health issues,
- being better able to make health related decisions, and
- taking positive action to address health and care concerns.[1,2]

While there is an increase in the number of consumers who are actively seeking health information, approximately 60% of Australians aged between 15 and 74 do not have the relevant health literacy skills required to effectively undertake tasks across the five categories of health activities: health promotion, health protection, disease prevention, health care maintenance and system navigation.[3]

Professor Robert Bush, of the Health Communities Research Centre at the University of Queensland's Ipswich campus, in response to the poor health literacy results reported in the 2008 Australian Bureau of Statistics (ABS) Health Literacy report[3], commented that "the impact of such a high proportion of Australians without basic health literacy skills should be of major concern to anyone wanting to ensure people and communities are better able to promote their own health and prevent disease. … Achieving even a basic level of health literacy to join in ways to better health would seem a fundamental aspiration for Australia."[4]

Libraries can be instrumental in providing both access to relevant and appropriate consumer health information as well as appropriate tools to enable consumers to make informed health decisions.

Australian health libraries across the spectrum of the health continuum, support the 'consumer' health information seeker by providing:

- responses to health information requests,
- subject specific health collections, both physical and electronic,
- health information pathways, i.e., subject files, current topics of interest and reading lists,
- current awareness news services,
- health information portals, i.e., HealthInsite, and
- health information literacy training.

There are, however, further opportunities for libraries to partner within the health library sector, across the wider library sector and with the health care sector to expand the scope of service delivery to encompass additional elements of patient-centred or person-centred care.

By way of example, the following provides an overview of the Book Prescription Scheme, Medical Prescription Service, Information Therapy, Information Prescription and an Information Packet, all of which aim to provide evidence-based, reader-appropriate health information to patients, caregivers or consumers at the right time, to help them make informed health decisions.

The **Book Prescription Scheme** commenced in 2003 in Cardiff in

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the UK. The aim of this service is to provide access to a core list of high quality self help books for people with mild to moderate mental health problems such as depression, anxiety, stress, low self-esteem or eating disorders. The books selected usually offers a cognitive behaviour therapy (CBT) approach and include self assessments, diary sheets and treatment programs. General Practitioners (GPs) and primary health care workers, such as counsellors, are issued with 'Prescriber Packs' of book prescriptions. The local public libraries stock copies of the prescribed books and accept paper-based book prescriptions. The bibliotherapy (self help reading) approach has been taken up by other health areas and councils in the UK, with developments such as booklists to include other formats, new lists for other health conditions, and clinicians providing supported help working through books.[5, 6]

A modified version of the above is the **Medical Prescription Service** whereby a health professional prescribes further information that their client requires in order to achieve a better understanding of their health issues. This prescription, either print or electronic, is given to an information professional who researches the topic and provides an 'information pack'. The pack, which may be delivered via email, post or face-to-face contains relevant consumer health resources, or a list of other relevant resources. The recommended physical material is available to borrow from the local public library.[7] The information professional may be a health librarian or a public librarian who has health-based reference and research skills.

Information Therapy (Ix™) combines the bibliotherapy approach of the Book Prescription Scheme with computer and health information literacy, and information science. Broadly, information therapy "applies to a wide range of uses, situations and contexts, such as patient compliance, patient consent and general health literacy."[8] More specifically it is a prescription of evidence-based medical information that a person can use to make an informed health decision. An application of information therapy is the **Health Information Prescription**.

In 2003 the National Library of Medicine (NLM) launched the Health Information Prescription program (Information Rx) which provided doctors with prescription pads that they could customise to point clients to quality online health information in NLM's MedlinePlus database.[9] A key focus of the Information Prescription model is access to evidence-based, health subject specific, online information. In this model librarians play a key role, though, there is variation across libraries in the application of this program, most notably the documentation of the information request process into a computerised patient record system.[10]

The Patient Information Consult Service (PICS) developed by Vanderbilt Medical Centre

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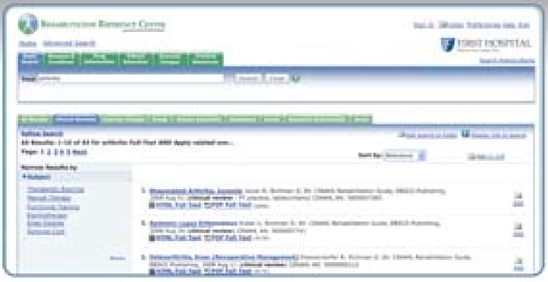

THE HEALTH INFORMATION PRESCRIPTION

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in conjunction with Eskind Biomedical Library combines access to the library's health collection with the expertise of the PICS information specialist. The information specialist, taking into consideration a client's education and literacy level, develops an 'information packet' based on the 'Prescription for Information', which is completed by a patient's (or caregiver's) doctor. The packet usually contains a summary of the condition, a bibliography of relevant resources and the most relevant articles full-text. To complete the information loop, a copy of the packet is sent to the health care provider.[11, 12]

The UK Information Prescription Scheme has been established in the UK under the auspices of the National Health Service (NHS).[13, 14] A pilot of 20 sites was undertaken in 2007, with a national roll out commencing in 2008. The focus of the UK Information Prescription (IP) is on links to online resources that are available through NHS Choices, such as general information and treatment options. A key extension of this model is the inclusion of local services, benefits advice and support groups. Additionally, a template, which can be customised, has been designed for organisations. An individual's IP can be created in consultation with a health or social care professional, or individually via the web.

In Australia, the only reference to an information prescription model that the author could locate is one being developed by the Asthma Foundation.[15] This model requires a GP to complete an information prescription, indicating topics that the patient/carer requires further information about. The information provided is Asthma Foundation topic brochures. As this model is under development, further investigation is required.

While librarians already provide quality assured 'information packets' to clients, the above models of information delivery provide additional opportunities for libraries and librarians to be integral to the ongoing development of a patient (person)-centred health care system.

Before embarking on implementing an information prescription model a thorough analysis of each model is required, as is the partnership opportunities for libraries both within the health care sector and within the library sector. Some elements of the above models, however, may be easily deployed in your library to further facilitate existing programs which aim to improve health information literacy and 'foster informed patient decision-making and participatory healthcare'.[16]

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THE CHILD HEALTH LIBRARY at Princess Margaret Hospital, WA

The Child Health Library (CHL) is located within Western Australia's only tertiary level children's hospital, Princess Margaret Hospital (PMH). It is part of the Child and Adolescent Health Service (CAHS), comprised of PMH and Child and Adolescent Community Health (CACH), which includes School Nurses, Child Health Nurses and Child Development Centres throughout the State.

The CHL was officially opened on 26 April 2005 after 8 years of lobbying and planning and was established with start-up funding of $25 000. Its initial stock was 900 items, which grew to approximately 1300 items by the end of December. Due to space restrictions and the need to ensure that only current information is kept, the collection is rigorously weeded and now numbers approximately 2350 items. It occupies 40m2 of space, adjacent to both the hospital's main entry and the Emergency Department, and near both booked admissions and the outpatient clinics.

The library is staffed by the hospital's Medical Library, and is open from 9:00-12:00 and 1:00-3:00 each weekday. Two librarians share staffing the library, rotating between it and the medical library, but one has responsibility for selection, acquisition and cataloguing of stock, marketing, and maintaining the database and web site. Management of the CHL, including allocating the budget and determining its resourcing level, is under the direction of the manager of the Medical Library.

Our clientele are the caregivers of Western Australian children. This includes not only their parents and guardians, but also hospital staff and the staff of Child and Adolescent Community Health through their state-wide service points. Many of our clients seek information following a new diagnosis of a child's medical condition, while others return again and again to obtain as much information as possible or to research new health issues as they arise. Some walk in while waiting for appointments, or while taking a break from their child's bedside, others are referred to us from the community-based staff.

The resources available in the CHL include the book collection, a wide range of pamphlets which are offered free of charge to caregivers, a range of databases (NORD Rare Diseases Database - funded by the PMH foundation, Healia, Medline Plus, PubMed and Cochrane) and web-based resources, including health fact sheets and health information web sites, and a range of online publications which are linked to from the library's web-based catalogue. You are welcome to visit the CHL website, which is at: http://pmh.health.wa.gov.au/services/chl/

The difficulty of providing consumer health information from a service such as the CHL is that public awareness of it will never be high. It is therefore important to raise awareness of the service among health professionals. This is being done by improving links to the Hospital's departments and CACH staff, and by promoting the service to other groups such as the Disability Services Commission and through membership of the WA Disabilities Information Network. The service is also being promoted to the State Library of Western Australia and to public librarians. In this way more people seeking information on child health will be directed to a service they need – even if they didn't know it existed!

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EBSCO leads the way in Health Consortia Management

Part of EBSCO's most recent success is being proactive when it comes to health consortia management.

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SOUTHERN SHOWCASING OF PATIENT INFORMATION SERVICES: REPORT ON VISITS TO exemplary HEALTH SCIENCES LIBRARIES in the United States of America

As recipient of the MLA's Cunningham Fellowship, Lisa Kruesi traveled to the USA in 2008 to meet with both Patty Lee, Assistant Director at the Annette and Irwin Eskind Biomedical Library, Vanderbilt University Medical Center, and Christie Silbajoris, Director of NC Health Info at the Health Sciences Library, University of North Carolina, to learn about the patient information services operating at their respective institutions. This article describes these services, reviews wider trends, and concludes that it is important for disparate bodies, including library services, to come together to develop consumer health information services for the Australian public.

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In June 2008 I had the good fortune to visit and learn about 'patient information services' at the **Annette and Irwin Eskind Biomedical Library, Vanderbilt University Medical Center** and the **Health Sciences Library, University of North Carolina**. Patient health information services at these libraries have been underway over the past decade.

These libraries were prompted to establish patient information services:

- to support their local communities, which was a priority for their organizations;
- as evidence indicated health information is of high importance for patients, as eight out of ten users search the Internet for medical information[1];
- due to concern about the quality of the information found by patients;
- to encourage patient involvement with the healthcare process;
- as librarians have the expertise to find the best sources; and
- because of the growth in electronic records management systems.

In the USA 47 million people (16% of the population)[2] don't have medical insurance; this is a major reason for the Internet playing such a significant role in provision of health information.

Patient Information Services

The Eskind Biomedical Library offers a Patient Informatics Consult Service (PICS) that includes a patient education collection, a consumer health book and video collection for in-library use, and a website for consumer health information. Details about this service are available at http://www.mc.vanderbilt.edu/biolib/services/pics/index.html as is a paper by Williams et al[3] describing the service.

Patient access to health information and personal health records is becoming increasingly important in today's healthcare environment. In the USA, the National Library of Medicine has consumer health initiatives, such as MedlinePlus, NIH Senior Health, and ClinicalTrials.gov, which are services designed to get medical information directly into the hands of patients[4]. In Australia we have HealthInsite provided by the Federal Department of Health and Ageing. These services provide avenues for patient access to information, but do not address directly the communication between patient and provider. Information technology systems such as electronic health records and patient-focused web portals present another means for increased patient-provider communication and information sharing. The growth of these portals presents information professionals opportunities to extend support for evidence-based medicine, consumer health and health literacy efforts directly to patients via processes that are driven by patient-specific data[4].

Studies report the loss of as much as 68% of information

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following a visit with a clinician. Patient recall is aided when an information request sent by the nurse or physician transmits medical terms directly to the librarian, facilitating the retrieval of appropriate information[3].

The literature suggests that knowledge-empowered patients are able to partake in health care decisions and in their own treatment, consequently helping to improve their state of health. This is particularly the case with diabetic patients who are involved in decisions regarding their treatment who have demonstrated improved management of their condition[3].

At Eskind Biomedical Library (EBL), collaboration is undertaken with informatics and clinical teams to foster informed patient decision-making and participatory healthcare through an online patient portal[4].

The MyHealthatVanderbilt (MHAV) portal encourages patients to become active partners in the management of their care and provides open communication with healthcare practitioners. Interactive features such as appointment scheduling, online bill payment, and secure electronic messaging to providers engage patients in various steps of the healthcare process[4]. Patient data is extracted from StarPanel, at the Vanderbilt Medical Center's electronic health record system[4] and disclosed to the patient within the MHAV portal. From the beginning of the portal's extensive re-development process in 2005 (which added numerous enhancements), the Library has played a key role in the provision of health information and evidence to foster increased patient health literacy. This effort uses several means: health topics; inclusion of journalist-written news stories; and patient-oriented information about laboratory tests.

MyHealthatVanderbilt was set up in 2005 and by 2008 over 59,000 accounts for patients have been set up. The PICS information service has had over 66,000 hits (searches) since established. Most of the information provided by the Library has been on laboratory tests (78%) and disease/prevention topics (22%).

In May 2008 Google began offering online personal health records to the world. A range of companies all hope to capitalise eventually on the trend of consumers increasingly seeking health information online, and the potential of Internet tools to help consumers manage their own health care and medical spending[5].

Go Local

The Go Local links on MedlinePlus, the consumer health site maintained by the National Library of Medicine and the National Institutes of Health, take you to information about health services in local geographic areas, including hospitals, physicians, nursing homes, support groups, health screening providers and many others. You can link directly from each MedlinePlus health topic to

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services related to that particular topic. For example, if you choose Go Local from the MedlinePlus Breast Cancer page, you will find links to local services such as cancer clinics, oncologists and support groups in the area you select.

By way of history, in 1999 Ms. Carol Jenkins (Director University of North Carolina (UNC) Health Sciences Libraries) proposed to the National Library of Medicine that MedlinePlus combine health information with local health services information. A feasibility study was undertaken at UNC and the Go Local initiative was created. A developer and two librarians were hired and after two years of development NC Health Info (http://www.nchealthinfo.org) was launched to the public in 2001. This database of local links was the first resource of its kind to link local health services with corresponding information from MedlinePlus. Currently there are thirty-two Go Local participants with many more to be released in the future. The National Library of Medicine is partnering with libraries and library consortia for national coverage of health services. The National Library of Medicine hosts Go Local data, but does not claim ownership or copyright of the data.

In 2005, the State Library of North Carolina asked the UNC health libraries to ascertain how the provision of consumer health information in public libraries might be improved. NC public libraries were receiving a significant number of health queries and staff often lacked the confidence and expertise to respond to them effectively. A Steering Committee made up of academic health sciences, AHEC and public librarians was formed to study the problem. The group recommended the development of an easy-to-use web site focused on the health issues of North Carolina. To reduce confusion and avoid marketing and outreach efforts for two separate sites, this new content was wrapped around the existing NC Health Info site.

NC Health Info is an online guide to web sites of quality health and medical information and local health services throughout North Carolina. Designed to meet the needs and interests of North Carolinians, NC Health Info leads users to resources that are reliable and easy to understand. Links on NC Health Info are selected and maintained by North Carolina librarians.

International trends

The National Institute of Medicine's Crossing the Quality Chasm report highlights the critical need for patient involvement in the healthcare process. One of six proposed aims for improving quality of care, the "patient-centered" approach of providing care that respects and incorporates patient preferences in clinical decision making, requires adequate information, communication and education.[6,7]

> "In health, the impact of an online information search is more likely to be helpful, not harmful. Thirty-one percent of e-patients say they or someone they know has been significantly helped by following medical advice or health information found on the internet. Only 3% of health seekers say they or someone they know has been seriously harmed by following the advice or information they found online."
>
> The Engaged ePatient Polulation
> by Susannah Fox
> http://www.pewinternet.org/pdfs/PIP_Health_Aug08.pdf

A review from the Journal of Health Services Research and Policy reports that better educated populations make greater use of information and are more likely to exercise choice in health care. Patients do, however, want to be more involved in individual decisions about their own treatment, and generally participate much less in these decisions than they would wish[8].

Muir Gray's writings, in particular, The resourceful patient, are all about empowering patients so they can participate in their healthcare[9].

Healthcare trends in Australia

"The Forster Review", an independent review of the Healthcare system in Queensland undertaken by Peter Forster in 2005, recommended a Patient Centred approach to healthcare[10].

In Australia the high level of government involvement has led to care of patients being organised around funding arrangements rather than the funding arrangements supporting a planned consumer centered approach to health.

This has been followed by the National Health and Hospitals Reform Commission report, Beyond the blame game: accountability and performance benchmarks for the next Australian Health Care Agreements, released in 2008[11].

The Commission has developed a set of draft design principles for the Australian health system that will shape the Commission's work to develop a long-term health plan for a modern Australia. Some of the Commission's proposed principles to guide reform and future directions of the Australian health care system are:

- People and family centred (on the top of the list)
- Shared responsibility,
- Strengthening prevention and wellness,
- Safety and quality

Conclusion

It is important for disparate groups to work together on health

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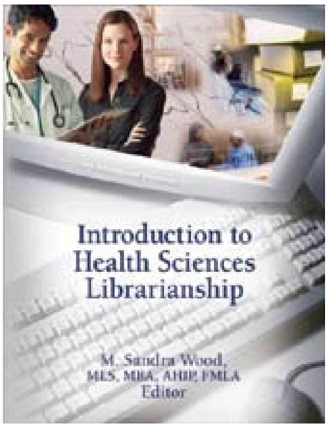

BOOK REVIEW

Catherine Brady from the Australian Government Department of Health and Ageing reviewed *Introduction to Health Sciences Librarianship*, edited by M Sandra Wood and published by The Haworth Press (New York, 2008, 493p).

ISBN 978-0-7890-3596-7

M Sandra Wood, a retired US medical librarian of some 35 years standing, has filled a niche with the publication of this textbook introducing library students and librarians to the field of health sciences librarianship. Health sciences librarianship (more commonly called 'health librarianship' in Australia) is a sub-speciality of librarianship which includes medical, hospital, health and academic librarians.

The book covers a broad range of subjects from the perspective of a health sciences librarian. Similar publications have usually covered one particular aspect of health sciences librarianship or are introductory textbooks intended for a more general library audience. I especially liked the perspective given by the 'day in the life of a health sciences librarian' anecdotes that appear boxed throughout the main text. They really give you a taste of what it is like to work in the sector.

The editor's intention was to fast-track the publication process and this has delivered content that is highly relevant and up-to-date. Far from being an historical treatise, the book aims to cover the current issues for the profession, plus a snapshot of where health sciences librarians are heading into the future. A particular focus on how technology and the information revolution is transforming practice makes the content pertinent and thought-provoking. The chapters were written by different authors chosen for their knowledge or expertise in that particular subject. Given this multiple authorship, the book is remarkably cohesive. The chapters are arranged by topic and cover everything from collection development, information access, information retrieval and information literacy to marketing, management and library space planning. While many of these subjects are common to all libraries, the authors bring a uniquely health sciences perspective to their discussion. In addition, the book covers some areas on the fringe of health sciences librarianship including health informatics (e-health) and consumer health information. Comprehensive references are included at the end of each chapter and a glossary is also provided.

All of the contributors are US-based and this gives the book a North-Americancentric view. This is not a major problem because much of it translates fairly well to the experience of health sciences librarians in other countries. Nonetheless, it would have been useful to have some of the book's discussion placed within an international context.

As an introductory text, Introduction to Health Sciences Librarianship provides breadth of subject coverage without being overwhelming in its depth. It is a comprehensive, current and accessible publication, introducing concepts that translate easily into the reality of today's health sciences library. As a single resource for health sciences librarianship, this will serve new and experienced librarians very well.

Catherine Brady

Note: Review reprinted with permission from AARL v39 n4, December 2008.

EXEMPLARY HEALTH SCIENCES LIBRARIES
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information services for patients in Australia – from government bodies, public and state libraries, university and hospital libraries. There is an opportunity for health librarians to combine their skills with the expertise of health professionals and patient educators to enhance patient information services. Our USA health library colleagues are leading the way having proven their success with patient information services.

NOTE: This paper is based on a talk delivered by Lisa Kruesi at the Health Libraries Inc Conference in November 2008.)

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The Sexual and Reproductive Health and Blood Borne Virus Resources CD project.

It may come as a surprise to some that not all healthcare workers can access the Internet. Jill Griffin, the Information Resource Centre Co-ordinator at Family Planning Queensland, describes the Sexual and Reproductive Health and Blood Borne Virus (BBV) Resources CD project which involves producing and distributing a CD-ROM containing up-to-date, consumer-level health information that practitioners can provide their clients.

ABOUT THE AUTHOR

Jill Griffin is the Information resource centre co-ordinator at FPQ, a position she has held for almost 2 years. She has worked for most of her career in health libraries, mostly in OPAL situations. Originally from Melbourne where she gained her library qualifications in 1991, she has lived in Brisbane since 1994.

In October 2007 Family Planning Queensland (FPQ) was approached by Queensland Health to take over production of a compact disk (CD) that is distributed to health service providers and sexual health workers around Queensland. The CD distributes consumer-level information to practitioners for their clients without the need to search and access this information themselves on the internet. The project acknowledges that internet access is often problematic in regional, rural and remote Queensland and that everyone has a right to up-to-date and accurate sexual and reproductive health information. The CD is produced bi-annually to ensure the most current information is always available.

The project

Co-ordinated by FPQ on behalf of Queensland Health, the resource is distributed to promote the use of high-standard, up-to-date fact sheets and resources across the HIV/AIDS, BBV, and sexual and reproductive health program areas. It combines FPQ and Queensland Health fact sheets with those of other funded or evidence-based service providers and allows clinicians and other service providers to produce fact sheets directly from their desktops.

The need for the CD

Many people working in Queensland do not have internet access because of unreliable connections, no connections or because of restrictions by their employers. The typical users of the resource are school-based youth health nurses, clinicians and workers in sexual health clinics, general practitioners, youth workers, mobile women's health nurses and community health centre workers. It is hoped that by avoiding possible delays in accessing these resources via the internet that the practice of pre-photocopying and filing fact sheets away in bulk is avoided and that information provided to clients is always up-to-date.

Funding for the project

Funding for the CD Rom is by the Communicable Diseases Unit of Queensland Health. FPQ was approached to produce version 3 of this resource, Queensland Health having produced the previous two editions internally. As a non-government organisation, and leading provider of sexual and reproductive health services, FPQ is well-positioned to provide and source comprehensive information on all of the relevant sexual health topics.

Responsibility for the project

The Information Resource Centre Co-ordinator at FPQ was identified as the most appropriate person to co-ordinate this project. The role requires sourcing the information and liaising with the various organisations that have produced the original material and obtaining permission to use the information on the CD. Following this, the material is reviewed by a clinical committee within FPQ for suitability for inclusion on the CD. The Senior Director of the Communicable Diseases Branch of Queensland Health gives final approval for inclusion of resources on the CD. Production of the CD also includes liaising with

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Sexual & Reproductive Health CD Project
continues from p11 ...

the FPQ Information Technology Department, so that it reflects FPQ guidelines and identity, as well as liaising with the outside production company who produces the CD.

How is the project managed?

The process for the production of the CD and the twice-yearly updates includes reviewing the current CD contents, consulting with the agencies providing the information and checking for updates as well as identifying any new or appropriate information for inclusion. It also involves the production and distribution of the CD. Version 3 of the CD had a print run of 600 copies. Approximately 270 of these were distributed in the first instance. Because FPQ retains ownership of the CD and the contents, it is able to distribute any of the remaining CDs either by selling them or by distributing them to participants of FPQ courses.

The final product

Version 3 of the CD contained 992 files in 135 folders and had multicultural resources on 14 different topics.

The information was sourced from 20 organisations that work in the areas of sexual and reproductive health and blood-borne diseases.

The organizations contributing to the CD included:

- Queensland Health
- Family Planning Queensland (FPQ)
- Hepatitis Council of Queensland
- Spiritus Positive Directions
- The Cancer Council of Queensland
- Australian Government, Department of Health and Ageing
- Queensland Association of Healthy Communities (QAHC)
- Shine SA
- Women’s Health Queensland Wide (WHQW)
- Australian Federation of AIDS organizations (AFAO)
- Andrology Australia
- Australasian Society for HIV medicine (ASHM)
- The Cancer Council Victoria
- Children by Choice
- The Ethnic Communities Council of Queensland (ECCQ)
- Fertility UK
- Gastroenterological Society of Australia
- The Jean Hailes Foundation for Women's Health
- Marie Stopes International
- National Breast and Ovarian Cancer Centre

The 270 CDs that were initially distributed went to 195 separate addresses in September 2008. The CDs were sent to people on the distribution list as supplied by the Acting Principal Program Adviser - Sexual Health, Communicable Diseases Branch of Queensland Health. One copy was also distributed to each of the agencies that contributed to the project.

Feedback / evaluations

All recipients received a cover letter, but no actual form, in which they were encouraged to provide feedback via the project co-ordinator on the resource, identify any gaps in the list of resources included and communicate any concerns about any of the content provided.

The general feedback on the CD was positive. Feedback received indicated the users were happy with the easy access to information. One negative comment received was that the photos on the CD of STIs should not be viewed immediately before lunch! As there was such little feedback initially a follow-up email was sent to recipients, for whom we had email addresses, seeking feedback and suggestions for the improvement of the next version. Of course, the main rationale for the project is the lack of internet access so there has been a minimal response rate to this method of seeking feedback.

Internal evaluation of the production of the CD noted that there were missed deadlines in the development and delivery of this resource. The IT component, including the re-branding to FPQ guidelines, took the longest time. Seeking and gaining permission from the contributing agencies also took a long time, often requiring several follow-up emails and phone calls.

The future

FPQ has been funded to produce version 4 of this resource, which is currently in the information gathering stage. The CD will be ready for distribution by May 2009. FPQ is hopeful that this will be an on-going project for the organisation and is confident that version 4 will be less time-intensive to produce and that all timelines will be met.

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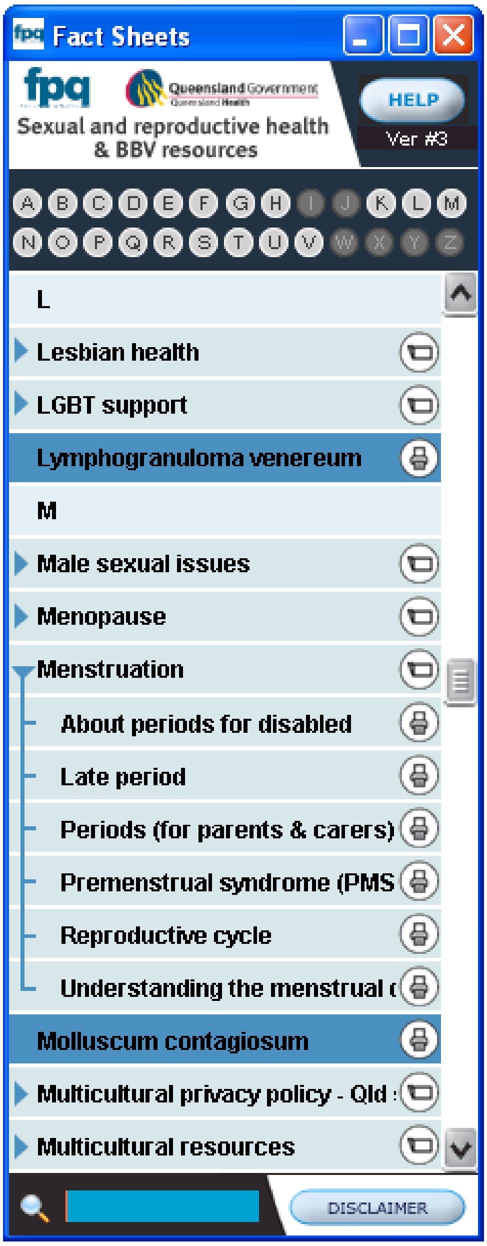

Fig 1. A screen shot of the index. There are drop-downs inside subject headings if there are several fact sheets on the same topics.

Consumer Health information services
continues from p1 ...

network with each other, and with peak organisations and government, but are not so well known by other health stakeholders such as libraries.

The Consumers Health Forum of Australia (CHF) is the national organisation representing health consumer organisations; similar peak organisations exist in most states and territories. They research consumer perspectives and facilitate the appointment of consumer representatives to health-related committees. Their websites are the best source of information on consumers' perspectives on health policy as they publish information papers, submissions and research. They also provide links to their member organisations, which do a similar thing for their area of interest.

The Health Issues Centre in Victoria has an extensive library of information on consumer involvement in health care.

Consumer information

For consumers themselves, access to information does not just relate to being able to find the information easily. It means the information is written and presented in a way they can understand and use. This is no mean task given that each consumer starts at a different place in terms of background, prior knowledge, literacy level etc.

When a person is first diagnosed with a condition, they do not usually know very much about it. Apart from the information given by the doctor, they will usually want to do basic research. A simple encyclopaedia or Google search is a good start, particularly where that search sends them to illness-based health consumer organisations. As their knowledge of the condition deepens from their reading – and first hand experience – they will usually be able to understand more complex information. This can be accessed through the health consumer organisations or books and websites that are targeted more at health professionals.

CHF has worked with consumers and health consumer organisations to find what kind of information people want and where they can find it. While the internet has become a primary source, there is still a role for more traditional written documents – and, of course, libraries. A major advantage of online health information, including online support groups, is their ability to help consumers overcome isolation, including isolation due to a condition or living in a rural and remote area.

It is important for health professionals to provide information to their patients about their condition. Consumers do not see the internet (and books) as an alternative – or competitor – to their doctor, but as a supplement that gives them a better understanding and empowers them to participate in decisions about their health care to get the best outcome for their situation.

CHF therefore encourages health professionals to research consumer health websites and other literature and recommend relevant sites to patients, or print the information for them. It is important the information is easy for the patient to read and understand.

Consumers have warned, however, that health professionals must not assume information is accessible if it is on the internet. Many people, particularly older people and those from poorer socio-economic backgrounds, do not have internet access and/or the skills to use the internet. Access in rural and remote areas is further hampered by the lack of broadband.

This is where libraries can take on an important role. They can be the conduit for internet information to reach those without internet access.

For consumers, the illness-based consumer health organisations are often the most useful sources of information on their condition because the information is tailored for consumers. These sites have social and support information, which is as important as the medical information because it helps them understand and live with their condition. Most have downloadable fact sheets. They contain personal stories of living with the condition, and some have interactive blogs or offer telephone counselling.

Furthermore, they have research findings, policy statements, information papers and submissions to governments. Most also provide links to national and international research and related websites. CHF encourages librarians in the health area to visit its website, www.chf.org.au, and follow the links to each member's website. Some excellent examples of clearly presented information are the Arthritis Australia and Diabetes Australia websites.

Consumers are also involved in, and respect, the Cochrane Consumer Network, part of the international not-for-profit Cochrane Collaboration (www.cochrane.org.au), which supports collaborative review groups to develop systematic reviews of the strongest evidence available about particular health care interventions. This includes consumer experiences and knowledge. The reviews are published electronically within The Cochrane Library and are freely accessible in shortened versions. Consumers and health professionals use them when making decisions about health care.

There are also many consumer-oriented websites where people can get information and links to more information. HealthInsite is the main consumer resource of the Australian Government Department of Health and Ageing. Apart from departmental information, it largely comprises links to credible organisations. Most state and territory health departments have similar sites, such as Victoria's Better Health Channel.

In recognition of the importance of consumer involvement in health care, many government, non-government and industry-based organisations publish material for consumers. For example, the

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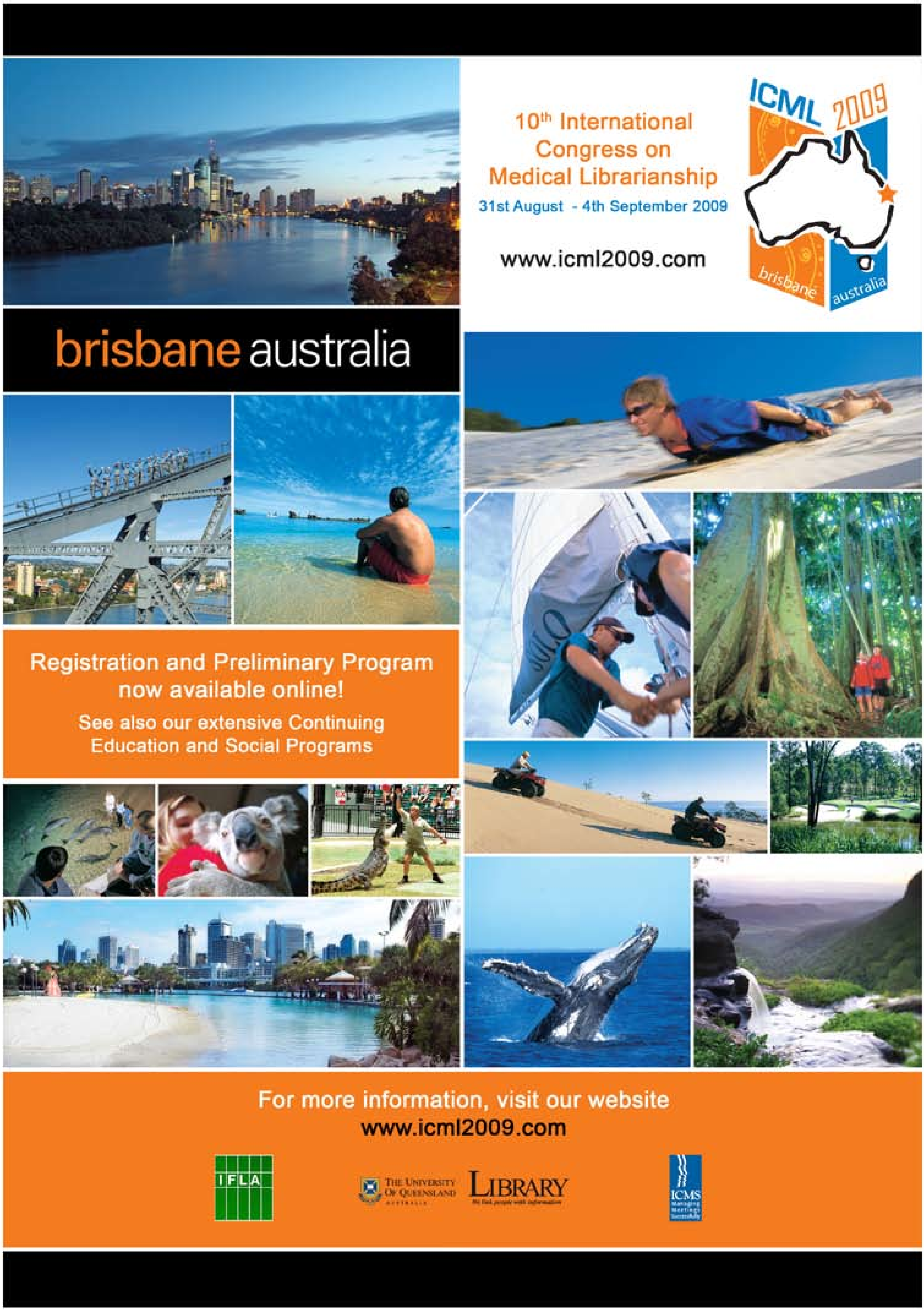

Consumer Health information services
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Therapeutic Goods Administration has an easy-to-find section for consumers, as does the National Prescribing Service, the National Health and Medical Research Council and Australian Self Medication Industry. More Divisions of General Practice are including consumer information on their website; for example, the Peninsula General Practice Network.

Others, such as Medicines Australia, work with CHF to develop publications or run workshops that strengthen relationships between industry and consumer organisations. However, more are encouraged to do so.

Where health consumer organisations and their networks are involved in the development of information, it is more likely to meet consumer needs and be relevant and useful to other consumers. It is therefore more likely to help achieve better health outcomes for individuals and the nation at large.

Credible information

Of all the health information published, and the millions of websites, how do consumers – and, indeed, health professionals and librarians – know which to trust? Safety and quality of health care may be compromised where health information is unreliable, out-of-date, not from a reputable source or not secure.

CHF recommends sites that have been accredited by HealthInsite (www.healthinsite.gov.au) or the Health on the Net Foundation's HON Code (http://www.HealthOnNet.org), as shown by their logos on website's home page. HealthInsite is run by the Australian Government and provides a portal channel to health information that is assessed to be reliable, accurate, easy to access and up-to-date. It only provides links to approved Australian organisation websites. HON Code is an international not-for-profit organisation that assesses reliable websites that seek accreditation from it.

The CHF e-health assessment criteria is another tool for consumers and health care providers to assess websites. Developed, following requests and suggestions from consumers at its e-health workshops, the criteria outline how to use the internet to access health information (http://www.chf.org.au/Docs/Downloads/fac-health-websites-info-oct08.pdf). However, the principles apply to all documents.

Anyone, regardless of their qualifications, can publish information, but consumers can test its standard by checking if it comes from a reputable source, if medical advice is provided by qualified professionals with details of who they are and their qualifications, and if the information is complete. It should be clearly stated when health or medical advice does not come from a qualified professional.

A trustworthy website lists the names and contact details of the people and organisation involved in its development and commercial and non-commercial interests. For example, consumers want to know if a pharmaceutical company sponsors a website as that helps them put the information in context. Governance of the site should also be clear.

Even if the information comes from a reliable and appropriate source, it may be compromised if it is out of date. Consumers want to know the date information was written and updated and what process is in place to ensure the information remains current.

Information should be easy to read and understand and accessible to special needs users. This includes writing in a simple and easy to understand manner, preferably with a glossary of terms and jargon used, and meeting vision accessibility standards.

Conclusion

By its very nature, health consumer information is diverse and hard to categorise. Those interested in health consumer information need to have some understanding of the system and of how to search for information that is relevant to their needs. However, once they get in to the system, they will see interconnections and trends.

Health consumer organisations, such as CHF members, are an amazing source of information about their own area of specialty and focus on the needs of consumers with medical and social support information. They also have their own libraries and links that can take the reader down many different avenues of information.

These organisations were built by consumers, for consumers. They recognised the need for state and national advocacy to promote consumer involvement in health care and were the driving force behind the establishment of peak health consumer advocacy organisations such as CHF that go beyond illness-related matters to become involved in shaping health at the systemic policy and program level.

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Want to keep receiving your issue of HLA News?

ALIA National Office recently announced that ALIA members can update their member details online. Please ensure 'HEALTH' is selected as your group to continue receiving HLA News and any other direct communication from the HLA Executive.

To log on you will need your 6-digit ALIA membership number and password. If you have forgotten, or don't know, your password follow the 'forgotten your password?' link at the log in screen to have it e-mailed to you, or phone the membership team on 1800 020 071.

drug info@your library

drug info@your library provides access to up-to-date, accurate, easy to read information on drugs and alcohol to the NSW community, with a particular focus on parents and carers of young people and secondary and TAFE students.

How it operates

drug info@your library operates through NSW public libraries and a dedicated website. The service provides a regularly updated collection of books, booklets and free pamphlets for community use through 363 NSW public libraries. The drug info@your library website, www.druginfo.sl.nsw.gov.au, provides a range of information on how to talk to your teenagers about drugs and alcohol, what to do if you are concerned about the drug or alcohol use of another person and where to go for help. A-Z Drugs provides links through an alphabetical list of over 30 drugs. Drug Issues includes information on legal issues, mental health, and drugs and alcohol in the workplace. The In Community Languages section has links to a range of information in 32 languages.

drug info@your library is a joint partnership between NSW Health and the State Library of NSW. The service is managed by the State Library of NSW.

Background

drug info@your library was launched in October 2002 by the then Premier Bob Carr. The service, formerly known as drug info @ your local library or di@yll, was one of the NSW government strategies developed after the 1999 Drug Summit.

Reviewed in 2005, the major finding of the di@yll review was that while the service was a valuable initiative, it needed to be better known within the community. There was broad agreement about the need for a new brand that would be instantly recognisable to target audiences and increased awareness of the service within public libraries and the broader community. All promotional material, including the website, was redesigned in line with the new name and look. The website was restructured to make it easier to use and more comprehensive.

Funding

drug info@your library is jointly funded by NSW Health and the State Library of NSW. The service is currently operating under a four year funding agreement until June 2011. The service runs on a modest budget that covers staffing (one full time position), books and booklets and promotional material and displays. Public libraries in NSW work collaboratively with drug info@your library and make a significant financial contribution (indirect costs) to state-wide service delivery.

Partnerships in action

The State Library hosts annual drug info@your library Forums for public library staff. Discussions at the Forums provide invaluable feedback for the State Library to help improve the service for public library staff and the NSW community.

The drug info@your library Collection Advisory Group has members who are experts in the drug and alcohol field. The Group helps assess the suitability of books to be included in public library collections.

Evaluations

The drug info@your library website will undergo changes over the next year. Focus testing of the website in June 2008, with two groups of high school students and one group of parents, showed that the website was appealing and easy to use but could be improved to make it even more useful to the community. Keep an eye on the drug info@your library website at www.druginfo.sl.nsw.gov.au

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HLANEWS DETAILS

Published by
Health Libraries Australia – A group of the Australian Library and Information Association,
PO Box E441, Kingston ACT 2604

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