

# Rencana-Rencana/Articles

## Sources of Consumer Health Information in Malaysia

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**Abstrak:** *Maklumat kesihatan pengguna adalah maklumat mengenai perubatan serta penjagaan kesihatan untuk keperluan orang awam. Rencana ini cuba memberikan maklumat ringkas tentang beberapa sumber maklumat kesihatan pengguna di Malaysia. Bagi menerangkan perkara ini secara perspektif, alasan bagi keperluan maklumat ini, isu tentang hak pesakit untuk mendapat maklumat, aspek undang-undang dan etika bagi maklumat ini, juga tanggungjawab serta etika pustakawan yang mengendalikan maklumat ini adalah dibicarakan secara ringkas.*

**Abstract:** *Consumer health information (CHI) is information on medical and health care that is specifically tailored to the needs of the general public. This article attempts to provide a summary of the various sources of CHI in Malaysia. To place the subject in perspective, the reasons and need for CHI, the issue of patients' right to health information, the legal and ethical aspects of CHI provision and the subsequent ethical and legal responsibilities of the CHI librarian are also briefly discussed.*

### Introduction

Consumer health information is considered to be information on health and medical topics relevant and appropriate to the general public. In addition to information on symptoms, diseases, diagnosis, and treatment of disease, it also encompasses information on health maintenance and promotion of good practices. Quality consumer health information is that which can assist the individual in effective decision-making about his or her own health and about the utilisation of health care services. CHI is recognised to be part of the educational process. Patient education and consumer health education differ in terms of setting in which the process occurs rather than in terms of the subject matter.<sup>1</sup>

This definition of consumer health information (CHI) taken from the Canadian Health Library Association's *Guidelines for the Role of Health Sciences Libraries in the Provision of Consumer Health Information* summarises the main objectives of CHI. This article will briefly review the major sources of consumer health information in Malaysia.

### The need for Consumer Health Information

The demand for CHI was first felt in the West in the early 1970s. This phenomenon followed very closely the consumerist movement of the 1960s in the United States which made consumers more health conscious and cost conscious. The seven-

ties was also the 'exercise and diet' crazed decade, with the young and the not-so-young attending classes in aerobics, jazz-dancing, yoga, tai-chi, jogging and other types of exercises, in order to 'burn' and be slim. Although many participated indiscriminately in some of the vigorous exercises and hurt themselves in the process, the movement was a healthy one and reflected the desire of ordinary people to assume responsibility for their own health. Consumers became aware that they needed information if they were to make appropriate decisions about their own health. This need was also prompted by the steep rise in the cost of health care. Adequate and accurate health information was thus vital if informed decisions were to be made about health such as the choice of healthy life-styles and to enable them to treat and manage minor ailments without the need to consult a doctor.

Increasing costs of medical care have also prompted many governments to place greater emphasis on preventive medicine rather than curative medicine. Individuals and communities are urged to assume greater responsibility for their own health and that of the community. Care within the community is to replace institutional care. In developed countries, governments have to battle with diseases of affluence such as those caused by smoking, drinking, obesity and drug abuse rather

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than diseases of poverty and ignorance faced by developing countries. In both situations, governments recognise the importance of health information towards the containment of the national medical bill, and many are now actively promoting health information at all levels in order to achieve the dual objectives of health maintenance and disease prevention.

Internationally, the World Health Organisation has been an active advocate for concerted global and individual efforts towards achieving "Health for All by 2000" through adequate provision of effective primary health care and greater emphasis on disease prevention. The growing importance of individual action is stressed by Dr. Jan Stjensward, Chief of WHO's Cancer Programmes, who pointed out that the long-term objectives of the world body is to "create a society which makes it easier for the individual to make healthy choices -- through legislation, education, and a much greater emphasis on prevention."<sup>2</sup>

The International Organisation of Consumers Unions (IOCU) at its 12th World Congress held in Madrid in September 1987 declared that the consumers play an active, prime role in health care and that they have the right to information. It urged the WHO to hold an expert meeting to consider the setting up of guidelines for patient information and for member organisations to press health authorities to implement education and training programmes for health consumers.

### **CHI and health practitioners**

The Royal College of General Practitioners states that a good doctor should employ opportunistic health education and should constantly reinforce advice on life-style by giving relevant information freely to patients to encourage them to share responsibility for their own care.<sup>3</sup> It is admitted that these additional responsibilities are time-consuming but because of their vital importance, a reorientation in general practice towards health promotion is suggested.<sup>4</sup> Team approaches and information systems using microcomputers to assess life-styles as well as better links between community medicine and general practice are suggested to facilitate effective health promotion on a wider scale. These remarks are relevant to the Malaysian situation. Malaysian health consumers have found that their doctors are often non-communicative about their health problems. Many do not bother to explain to their

patients about their sicknesses or the treatment or medication prescribed to them, let alone advise them on healthy living or proper diet.

The development of CHI services in developed countries like **Help for Health** in the United Kingdom and **Community Health Information Network (CHIN)** in the United States in response to the demand for health information, can also be seen as reactions to the absence or lack of suitable information from the traditional providers - the medical practitioners. Patients complained that their doctors were very uncommunicative, unwilling or unable to explain to them about their medical condition or their treatment. Often doctors underestimate the ability of patients to understand. They may be right since many do not take the trouble to simplify medical jargon into layman language. However, whilst there is evidence that doctors do not provide as much information as they should, it is equally clear that patients often forget a large proportion of what they were told as soon as they leave the clinic. This may be caused by emotional or physical reasons. They may not understand the doctors because of dialect or language problems. They may also be too afraid, reluctant or even too embarrassed to ask for clarifications or further explanations either because they are in awe of the 'busy' man or he is simply too unapproachable.

"Information to enable participation in our health is important at all stages of our lives, but never more so than when we are faced with illness and become patients."<sup>5</sup> Patients need information about their condition, its treatment and management. They are often dissatisfied with the amount of information that they receive. The lack of information often makes them anxious. Studies have shown that information helps to reduce stress among patients and improves patients' compliance with medication. Research at Southampton showed that the provision of information leaflets on penicillin and anti-inflammatory analgenics increased patients' satisfaction and their recovery.<sup>6</sup> It is now recognised by the health services and many members of the health profession that the layman requires information on specific diseases and medical conditions to enable him to participate fully in his own health care or that of his sick or elderly relatives.

The provision of health information can therefore have significant and desirable effects on health care. However, providers of CHI have a

serious responsibility to ensure that information is accurate and up-to-date, and where possible, overseen and approved by a health professional. Accuracy and reliability of information is vital in all areas of knowledge but more so in the health and medical sciences since lives and health are involved.

### **Legal and ethical aspects of CHI provision**

The right to information has legal standing in the United States and in the Scandinavian countries. In Sweden the law even places responsibility on the local health authority to provide information to patients and to assist voluntary and self-help organisations publish health information booklets, brochures and posters. In 1987 the Association of Community Health Councils of England and Wales published a 17-point **Patients' Charter** which includes the right of all patients to written information about the health services; to be informed about all aspects of their condition and proposed care (including available alternatives) unless they express a wish to the contrary; and have access to their medical records.<sup>7</sup> However the Charter has no legal standing. While the British government encourages doctors to keep their patients informed, they are not obliged to do so. The British courts presently continue to support the test case of **Sidaway v the Board of Governors of Bethlem Hospital** where the House of Lords dismissed Mrs. Sidaway's case on the grounds that deciding what information to give to a patient was an exercise of professional skill and judgement similiarly as important as other areas of medical expertise and should not be questioned by those outside the medical profession.

The American Hospital Association's **Patients' Bill of Rights** (1973) affirmed that the patient has the following rights:

1. The patient has the right to considerate and respectful care.
2. The patient has the right to obtain from his physicians complete and accurate information concerning his diagnosis, treatment and prognosis in terms the patient can understand. When it is not medically advisable to give such information to the patient, his next of kin or an appropriate person should be informed on his behalf. The patient has also the right to know by name the physician responsible for coordinating his care.

3. The patient has the right to receive from his physician information necessary to give informed consent prior to the start of any treatment or procedure. He should also be informed of the specific operation and any significant risks involved, probable duration of incapacity and when requested, alternative care or treatment.

### **Ethical and legal responsibilities of the CHI librarian**

In its statement of **Professional Ethics** (1985), the American Library Association states that the librarian should provide information regarding health and medicine if that was what their clients need, for whatever reasons they require it and at whatever level of understanding that it is required. It is the professional responsibility of the librarian to ensure that only quality information is given to the user. Librarians should remember at all times that they are not subject specialists and should impress strongly to their clients that as librarians they can only try to supply them with the most current, accurate and relevant information but are in no position to interpret or evaluate this information or offer any medical advice. At best they can refer them to medical experts for further clarification and advice. If this advice is taken seriously, librarians are reassured that they should be safe and free from any litigation from their clients.

### **Sources of Consumer Health Information in Malaysia**

The desire of Malaysians to know more about health and self care is evident from the large number of enquiries sent to the popular press, magazines, the radio and the large number of health and child care publications sold annually. We have, however, yet to come to the stage of asserting our rights to demand and expect information from our doctors as a matter of course rather than a privilege. Fortunately, the consumer movement is slowly changing this state of affairs in the larger cities, and efforts to raise consumers' awareness on many issues relating to health and medical care is also being disseminated to the rural communities.

### **Libraries**

Libraries have always been regarded as places where information can be obtained. However currently, this is not so with health information.

Malaysian libraries do not specifically provide health information to consumers since they do not have funds allocated for CHI services.

### **Public libraries**

The public library system is well established in Malaysia. There are public libraries in almost every large town, and mobile libraries serve most villages and secluded communities. The National Library of Malaysia is now directing its resources towards the provision of community health information but health information is not yet a priority issue. This is probably due to lack of funds and professional expertise. Most enquiries for medical and health care information are referred to the medical school libraries or the libraries of the Ministry of Health or the Institute of Medical Research.

### **Medical school libraries**

The largest medical libraries belong to the three medical schools sited at the University of Malaya, the Universiti Sains Malaysia and the Universiti Kebangsaan Malaysia. However, the primary duty of these libraries is to serve the educational, teaching, research and clinical needs of their parent organisations. They are not normally open to the public although most librarians will not disallow a member of the public to use their collections given a valid desire to locate some specific information. Nevertheless, as sources of CHI, these libraries are not very suitable as their collections are often research and clinical materials and are thus either too technical or theoretical for the general public.

### **Hospital libraries**

Most hospitals do not have proper libraries. In many hospitals doctors depend on a small collection of benchbooks for their reference. These may be kept in the department or in the common room of the hospital. A few large hospitals allocate some money to purchase new titles but have no professional staff to organise the collection or provide library and information services. The Kuala Lumpur General Hospital is the only hospital which employs a professional librarian. Hospital libraries do not have much to offer in terms of patient information.

### **Medical institute libraries**

These include the libraries of the Institute of Medical Research, Institute of Public Health, the National Population and Family Development Board and other special health centres such as the Tuberculosis Centre and the Leprosy Centre. Many of these libraries are manned by qualified librarians. They are not accessible to the general public. However their special collections are valuable sources of information and support the government's health promotion programmes.

### **Primary health care professionals**

Primary health care professionals such as the general practitioners (GPs), dentists, nurses, medical assistants, and other categories of community health workers who provide basic medical care to patients are also their first point of contact with the health system. As persons of first contact, they are ideal prime providers of health information. Unfortunately most GPs and dentists do not perform well in this role as information providers. Nurses, midwives and community workers are proven competent health educationalists. They are more approachable and more willing to discuss and answer questions that are troubling patients. They promote good health practices by teaching mothers cleanliness, hygienic methods of food preparation, food nutrition, child care, family planning, immunisation, basic self care and emergency care such as oral rehydration in cases of severe diarrhoea.

### **Hospitals**

The Kuala Lumpur General Hospital (KLGH) has recently publicised its facilities and expertise towards educating people on various health issues and problems. It is felt that a hospital should not be treated as merely a diagnostic and treatment centre but also as a place to learn about one's health. The KLGH health education services are implemented as an integral part of patient care by various levels of staff at the hospital, including specialists, medical officers, nurses, dieticians, pharmacists, psychologists and therapists. The health education department organises patient education programmes where patients and families are counselled by the health care team to participate in their own treatment and care. Advice from the dieticians, for example, is important when

the patient is discharged. Patient education resources such as pamphlets, handouts and posters are developed by the department which also organises various exhibitions, talks and seminars within the hospital premises. The hospital also started a health column entitled **Heartbeat** in a local daily (*Malay Mail*), which seeks to promote healthy trends and life-styles with practical guidelines on good living habits. It has a question and answer section, called **General Health**, in which a panel from KLGH answers questions of a general nature that are of public interest. Readers are reminded that the section cannot be a substitute for personal consultation with a doctor.

The University Hospital also has an active programme of patient education. Exhibitions and public forums are regularly organised on specific health topics to highlight medical care in the hospital. Medical and dental students of the University of Malaya also work with the medical and nursing staff of the hospital to provide medical and dental care as well as health education to schools, urban squatter settlements and rural districts. The newly established Department of Primary Care, Faculty of Medicine, University of Malaya, has an active patient education teaching course in which patient-doctor communication skills among students are emphasised.

### Mass-Media

The influence of radio and television on the general public is shown in the latest survey reports issued by the Ministry of Information (1987) which indicated that 90% of the Malaysian population listen or watch radio and television programmes while 30% owns a video recorder. The Ministry of Health capitalises on this to disseminate health information to the masses and especially those in the rural areas. Other important media include newspapers and magazines, health publications and lately viewdata services.

### Newspapers and magazines

Most newspapers publish articles of general medical interest. *The Star* runs a **Health** column on Mondays and Fridays, while the *New Straits Times'* **Woman** column includes many health articles for its readers every Thursday. The two major Malay dailies, the *Utusan Malaysia* and the *Berita Harian*, also include many health care articles for their readers. They appear in the *Utusan Malaysia's* **Kesihatan Keluarga** column on Fridays and

Saturdays, and **Ibu** column every Wednesday. The *Berita Minggu's* **Wanita** column on Wednesdays and Fridays feature many health and medical issues relating to women and the family. *Berita Minggu's* **Sains Perubatan** highlights many current medical topics such as dangers of smoking, AIDS and stroke every Sunday. The *New Sunday Times* also has a weekly **Dear Doc** column where questions from readers are answered by a doctor, and as we have seen earlier, the *Malay Mail* has the **General Health** column. The large number and variety of questions received is a very good indication of the seriousness of health information needs that have not been adequately met by both health professionals and librarians. However, it is also a positive sign as it reflects the strong interest and desire of consumers for health information since this will enable them to take responsibility for their own health.

Women's magazines and health journals are also popular with readers. Most of these publications such as *Wanita*, *Her World*, *Female* and *Jelita* have regular health care articles. The potential role of these publications for conveying information is great because they are written in simple and non-technical language. Often practical suggestions for self-care are provided and advice is given as to when the doctor should be consulted. Question-and-answer columns also allow the shy reader to find out more about many health problems that may be troubling her and which she may never ask the doctor or even her closest friend.

### Health care publications

The wide range of popular health care and medical publications that are available in the bookshops indicates their saleability since they are often written and published in response to the demand for more health information from readers. Many of these titles are imported and are in English. Increasingly many local publications are published to cater for a growing non-English reading public. Major foreign titles such as *Woman* by Derek Liwewellyn-Jones, have been translated into Bahasa Malaysia (*Rahsia Wanita*), while new titles are written by local doctors and academicians to cater for local needs and situations. Publications on child care and child health are very popular in the local market, as can be seen in the large number of titles available in the bookshops. Examples of such titles are Abdul Halim Abdul Jalil's *Panduan Kesihatan Kanak-Kanak* (Kuala

Lumpur: Berita Publishing, 1987), Fatimah Arshad's *Makanlah Sayang* (Kuala Lumpur: Times Book International, 1988), Abd. Hamid Arshat's *Titisan Zuriat* (Kuala Lumpur: Pustaka Wira, 1988) and Kasmimi Kassim's *Panduan Jiwa Kanak-Kanak* (Kuala Lumpur; 'K' Publishing and Distributors, 1990).

The Ministry of Health, the National Population and Family Development Board and the Health Education Department of the KLGH, drug companies and consumers' organisations also produce a wide range of booklets, leaflets and posters on topics related to health. The extent of the demand for consumer health information can be gauged by a recent report in a local newspaper that about 1,100 sets of health leaflets and pamphlets covering 12 topics were mailed to individuals at their request by a multinational drug company. The pamphlets and leaflets are prepared by a panel of doctors and specialists, and provide information on topics like bronchitis, sinusitis, dysmenorrhea, arthritis and sexually transmitted diseases.<sup>8</sup> Patient organisations such as the Epilepsy Association and the Breast Cancer Association, also publish leaflets on coping with specific handicaps and illnesses. The National Population and Family Development Board produces a large number of pamphlets and booklets in Bahasa Malaysia, Chinese and Tamil for the laymen covering such topics as pap smear tests, child development, care of babies, child abuse, happy families and congenital disorders.

### Radio and television

For many years, radio broadcasts have been the sole means of communicating and disseminating health information to the general public. Radio is still the most important medium since it is cheaper and more portable than television. However, television is a more effective tool for health education because information can be conveyed better visually and more vibrantly. The television media is increasingly being used by the Health Education Unit of the Ministry of Education to implement its health education programmes which are aimed at attaining the attitudinal and behavioural changes in improving the health of the individual and the community through their own as well as through organised community efforts. Nevertheless, the radio continues to serve the rural areas and homes that cannot afford television. Phone-in programmes on

radio are also very popular with listeners. This is seen from the response whenever the **Radio Doctor** programme is scheduled on Radio Malaysia.

### Viewdata services

Malaysia's first computerised drug-cum-poison hotline was launched in June 1988. The **Integreted Poisons and Drugs Information Service (Idpis)**, available to Telita (the Malaysian public viewdata service) subscribers, is set up by the staff of the Universiti Sains Malaysia's School of Pharmacy. Subscribers can get instant information on more than 3,000 types of drugs and 1,000 poisons by calling on the Drugline hotline using their personal passwords connected to their television sets or personal computers. Questions can be directed to **PharmEd**, a section of the system, designed to update published information and counselling on pharmaceutical drugs. **PharmEd** also updates such information as the banning of traditional tonics, the withdrawal of contact lens solution, harmful heart drugs and the latest statistics of AIDS carriers. Since 1988, **Idpis** has implemented four modules, namely **Poisonline**, **PharmEd**, **Pestinfo** and **Public Infoline**, and there are plans to implement two more - **Food Additives** and **Chemicals**.

The service also has a more technical section on drugs and poisons, code-named **Drugline** and **Poisonline**, which is restricted to those in the medical and pharmaceutical fields only. This is to prevent self-medication among the public. The objective of **Drugline** is to provide an unbiased drug information service to all health care professionals who prescribe, order, dispense or administer medicine. **Poisonline**, a toxicology database is used to identify and provide treatment information regarding listed poisonous substances. It includes a section on classification of poisons, with details of lethal dosage, antidotes and drugs to be used in an emergency.<sup>9</sup>

### Consumers' organisations

Consumers' organisations are actively concerned with health education and health promotion. They are involved with efforts to educate consumers regarding their rights for better health and medical care and to demand better and safer foods, health products and a cleaner environment.

The Federation of Malaysian Consumers' Associations initiated the **Know Your Medicine** campaign in 1984 to increase awareness among consumers of the need to take a greater interest in their own health care treatment. It advocated for compulsory labelling of all drugs to ensure that consumers have all the necessary information to use medicines correctly. A checklist of 20 questions that consumers should ask their doctors was prepared and distributed to both doctors and patients. Doctors were urged to answer these questions which include information on the name, purpose, side-effects of the drug and precautions to take. A number of pamphlets were circulated to consumers in this campaign such as *Keeping Your Medicines- How and How Long, Recognising Drugs and Supplies that are Spoilt* and *Properties and Storage of Some Dangerous Chemicals and Drugs*.

The Consumers' Association of Penang (CAP) is one of the most active consumers' associations in the country. It publishes a fortnightly paper (*Utusan Konsumer*) in the three major languages-- Bahasa Malaysia, English and Chinese. It is a strong advocate of self-care and traditional (natural) alternative medicine and treatment, and has contributed much to the increased health awareness of consumers. It has also published a number of important but low cost publications which it has now collected and sold as *Consumer guide for daily living* kit and comprises such titles as *Healthy cooking methods for fruits and vegetables, Chemicals in your food, Too much salt is bad for you and your baby* and *Colds and flu*.

### **Voluntary and self-help organisations**

There are many voluntary organisations in Malaysia that provide financial and medical assistance to the poor and disabled like the Malaysian Council for Rehabilitation, Resource Services for the Disabled of Malaysian CARE, and the Malaysian Association for the Blind. However, there are few self-help organisations, although their numbers are growing as patients and their families become conscious of the need to reach out to co-sufferers and share mutual experiences and information for mutual support and comfort. The Society for the Blind is one of the earliest self-help group. Its members felt that only the visually handicapped know their own needs and aspirations, hence the Society is run by the blind for the blind.

Many of the self-help groups such as the Epilepsy Association, Stomacare Association, Breast Cancer Association and the Malaysian Diabetes Association were initiated by doctors who were working with patients suffering from particular diseases or conditions. These doctors normally stay on as advisors while patients run the groups. Group members meet regularly to share common problems and offer mutual support and advice. The Malaysian Diabetes Association for instance organises an annual four-day Diabetic Camp where members are counselled on how to manage their condition. During those four days they are taught the importance of regular exercise and proper diet control. Most important they meet others who suffer the same condition and are able to exchange mutual experiences and problems.<sup>10</sup> Self-help groups also raise funds to provide financial assistance to members, organise exhibitions and publish leaflets and booklets to inform the general public. A problem faced by these groups is that many of them disband when the doctor who initiated the group leaves the hospital or the state.

An exception to the above groups is the Cancerlink Foundation. The Foundation was set up in July 1989 by the family of a former cancer patient. One of the aims of the Cancerlink Foundation is to try and educate people on the disease, so that many myths and misconceptions will not stand in the way of treatment and recovery. Telephone counselling is given when people call about their conditions and need reassurance. About eight to ten calls are received daily seeking information and advice. The Foundation has a group of trained volunteers who give caring and competent counselling to those who come to them. They see patients in hospitals or their homes, or if they prefer, at the Foundation's office. A number of counsellors are former cancer patients who have been through the trauma themselves and understand the need for a support group. The Foundation has also plans for the setting up of a resthouse to accommodate out-station patients who come to the city for treatment and to provide financial aid to patients who may be the sole breadwinners in the family.

### **Conclusion**

It can be seen from the above discussion that people need health information to make informed

decisions concerning their health and that easy access to health information plays an important role towards improving and upgrading their health status and the overall quality of their lives. Health information enables consumers to take charge of their own health and participate in their own treatment. In Malaysia, consumers seek information from the health columns of newspapers, magazines, radio and television. The government is also actively disseminating health information through its various health education and promotion programmes via the radio and television media as well as making use of the local community leaders such as *ketua kampung* (village headman)

and the traditional health providers, the *bidan* (midwife) and *bomoh* (medicine man) to deliver the health messages. However, there is no health information service specially established to provide health care information to the public such as can be found in the United Kingdom or the United States. Currently health information is generated by many government and non-government organisations but there is no systematic coverage of CHI. The health sciences librarians have an important role to play in providing such services, but they need the support of the public librarians, the health professionals and the government.

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