

# ***Consumer Health Information: the Role of Hospital Libraries***

*Pam Bidwell and Gillian Oliver*

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## *Abstract*

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The Trustees of The National Library of New Zealand awarded a research grant to the authors to study the provision of consumer health information services by hospitals in New Zealand. The study was conducted during 1999. This report has been divided into two main parts: a literature review and our research into the current situation in New Zealand hospitals.

Part 1: The Literature Review is organised by country and charts the main developments in the United States of America, United Kingdom, Ireland and Australia. It concludes with a detailed investigation of the New Zealand situation.

The United States has a long history of providing hospital-based consumer health information services. The hospital library's role and responsibilities in this are clearly stated in quality accreditation standards. The literature documents a breaking down of the traditional boundaries between patient and professional information, due to the Internet and to wider publicity given to medical research. Collaborative projects between public and specialist libraries are also described.

Traditionally, hospital patient libraries in the United Kingdom focused on recreational reading and bibliotherapy (reading as a component of therapy in a treatment programme). Before the 1980s, medical librarians were reluctant to offer their resources to the public. The implementation of the Patient's Charter in 1996 was an important milestone for consumer health information as it was accompanied by government requirements for service provision. There is also evidence of hospital-based services. Recent research conducted in Ireland concluded that, in spite of increasing demand for information, access is inadequate. Again, very few hospital medical libraries allowed patient access.

Developments in Australia appear to follow the United Kingdom pattern. An Internet health information gateway has recently been established.

In the last two decades in New Zealand, various studies have been conducted in an attempt to determine responsibility for the provision of information to patients. The impact of the *Report of the Cervical Cancer Inquiry* (1988) on future directions in information services to patients is significant, but disagreements about the most appropriate way to progress have ultimately hampered development.

A variety of views have been presented on how medical consumers should receive information on their health care. There is general consensus on their right to information, and this is now enshrined in law. However, how this information is to be provided has not been established.

There are a number of initiatives that offer the public some degree of medical service.

Many medical libraries allow some degree of public access to resources, and there are a small but increasing number of subsidiary services based in hospitals. The Internet also plays a role, but there are concerns about the quality of some materials available through this medium.

Part 2: The Survey addresses the findings of our hospital survey conducted in New Zealand. Questionnaires were sent to over 300 public and private hospitals to determine which were offering a consumer health information service, and to establish the extent of the service. Opinions as to just what the requirements are were also canvassed. A 62.4 per cent response rate was obtained.

Twenty-eight per cent of hospitals responding indicated that they provided a library or information centre for patients. The extent of the service provided and scope of materials available varied widely, from fully staffed libraries to ad hoc collections of resources with limited accessibility.

Nearly two-thirds of respondents considered that doctors provide sufficient information during consultations. However, it is clear that this does not always apply, and comments from individual respondents suggested that some patients do not receive the information they need to be fully informed about their condition.

All respondents (i.e. hospitals with a library/information centre and those without) were asked to consider a series of statements and to indicate their agreement or disagreement. This section produced very interesting results and, because of the range of respondents (librarians, nurses, administrative staff, doctors), represents views from many sections of the health-care field.

The report concludes that, in view of the increasing access of information via the Internet for patients, and concern about the quality of that information by the medical profession, this is an ideal time for information management professionals to take a leading role in service provision.

Recommendations require strategic planning and a national focus. They address the need for standards (to include desired resource levels); using electronic records to tailor information to individual needs; establishing a model service; the need for marketing; using the Code of Rights as a basis and building on the interest shown in this research project. Further study should emphasise the cost-effectiveness of providing information to patients in terms of overall costs of health care.



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Gillian Oliver  
Pam Bidwell

The Open Polytechnic of New Zealand  
October 2000



# ***Consumer Health Information: the Role of Hospital Libraries***

## ***Introduction***

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When first presented with news of a medical diagnosis, patients usually want to know as much as possible about what this means for them. While some are happy to leave their care entirely in the hands of medical professionals, others may have a very strong need to explore their condition, and wish to share the responsibility for decisions about any medical treatments that may be necessary. Concerns and questions may arise during the first discussion with the medical practitioner, or occur later when patients have had time to absorb the news. Later discussions with family and friends can bring up new and unanswered questions. When ongoing treatment is required, additional information may be required at any stage.

Patients are often shocked when first given a diagnosis, and it can be difficult to absorb all of the information provided during the initial consultation. It may be difficult for patients to phrase their questions clearly, or to fully comprehend a complex technical explanation. Communication problems such as language difficulties or a hearing disorder can also interfere with the effective transfer of information.

The New Zealand Medical Council and the Code of Rights highlight the need for information sharing between patient and practitioner, and acknowledge the importance of information in achieving informed consent. However, there are still some medical professionals who do not volunteer much information to assist with their patient's understanding.

There has long been recognition in New Zealand of the need for an effective nation-wide health information service for the general public. Such a service would address the issues raised above, ensuring that patients and their families receive information sufficient for their needs regardless of where they live. However, although there have been a number of initiatives and suggested strategies to provide for this need, in reality the situation in New Zealand at the start of the second millennium can best be described as fragmented.

The literature review shows a wide institutional acknowledgement of the need for accurate and comprehensive medical information. However, patients may not know where and how to find the information they seek, and the availability of information services varies greatly.

Internationally, there have been a number of projects that provide an effective service in this area, and this report considers some of these. The present situation in New Zealand, and the historical developments that lead to the current status of health information services to the general public are described in detail.

The study surveyed public and private hospitals in New Zealand to determine the existing provision of health information services to patients, particularly the role fulfilled by hospital libraries. The results of this survey provided an overview of the current situation and suggest future initiatives.

Both researchers for this study have been actively involved in the provision of health information to patients, and are aware that there are patients who want better access to health information. However, the fragmented nature of the services currently available in New Zealand has caused problems. Some patients cannot easily access authoritative resources to inform themselves about medical conditions, and it is clear such inequalities should not continue. It is against this background that this survey was developed.

## **Definitions**

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The following definitions provide guidance on terms used in this report.

### **Consumer health information**

...any information that enables individuals to understand their health and make health-related decisions for themselves or their families...<sup>1</sup>

### **Hospital**

An institution for the reception and treatment of persons requiring medical treatment or suffering from any disease. This may also include a maternity hospital or convalescent home. (Based on the New Zealand Hospitals Act 1957.)

### **Private hospital**

Any licensed premises in which two or more patients are maintained at the same time, payment made or to be made in respect of medical treatment. (New Zealand Hospitals Act 1957.)

### **Patient**

Any person for the time being maintained in any premises for the purpose of receiving any medical treatment. (New Zealand Hospitals Act 1957.)

### **Day patient**

A patient admitted for healthcare with a length of stay less than one day, regardless of intent.<sup>2</sup>

### **Inpatient**

A patient admitted for healthcare, with a stay of more than zero days, and where the intention at admission was that this would not be a day case event. Includes patients who are transferred from another healthcare facility, but not interdepartmental transfers within the same hospital.<sup>3</sup>

### **Outpatient**

An outpatient is a patient who receives a pre-admission assessment, or a diagnostic procedure or treatment at a healthcare facility, and who is not admitted, and the specialist's intent is that they will leave that facility within 3 hours from the start of the consultation.

*Note:* When patients receive a general anaesthetic they are deemed not to be outpatients.<sup>4</sup>

## **Allied health professional**

encompasses those disciplines, other than medical practice or nursing, involved in patient care. These disciplines possess their own recognised qualifications and expertise.<sup>5</sup>

## **Health professional**

An individual with qualifications in medicine, nursing or a related area who is involved in patient care.

# ***Part I: Literature Review***

## ***Introduction***

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The requirement for consumer health information on the part of patients is widely recognised. The most appropriate forum for the delivery of that information, however, is subject to debate. Different patterns of service delivery can be distinguished in different countries. The literature review identifies the broad trends that have emerged, but concentrates on the role of hospital libraries.

## ***International initiatives***

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The major sources of literature on consumer health information in the hospital setting are the United States and Great Britain, and these are dealt with in some detail. In addition, the situation in Ireland and Australia is briefly considered. The findings of a major research project investigating the provision of consumer health information in Ireland have recently been published. As Australia is New Zealand's closest neighbour their literature was also the subject of scrutiny.

### ***United States***

The United States has a long history of providing hospital-based consumer health information services and patient education programmes. In 1972 the American Hospital Association (AHA) issued a bill of rights that specified the patient's right to information concerning diagnosis, treatment and prognosis.<sup>6</sup> This established a basic need on the part of hospitals to provide information to patients. During the 1990s the influential Joint Commission on Accreditation of Healthcare Organizations (the accrediting body for hospitals) added a requirement to its quality standard to the effect that:

hospital libraries provide information to patients, their families, and 'to those who need it.' Because of this regulation, most, if not all, hospital libraries will offer some consumer health services.<sup>7</sup>

In 1996 the Consumer and Patient Health Information section of the Medical Library Association (CAPHIS/MLA) issued a detailed policy statement setting out the role of health librarians in providing consumer health information and patient education. It covers collection management, knowledge and resource sharing, advocacy, access and dissemination of information, education and research. It unequivocally states that:

Health librarians, because of their knowledge of and skills in the identification, selection, organization, and dissemination of information, play an important role in both consumer health information services and patient education. The role of the librarian differs depending on the mission and policies of the organization.<sup>8</sup>



### ***Access to hospital and medical school libraries***

The American Medical Association conducted a survey of a random sample of hospitals in the early 1990s to determine how many hospital libraries allowed patient access. From the 307 libraries responding to the survey, 58.1 per cent allowed patient access without restrictions, while 19.9 per cent allowed access with restrictions such as physician approval. Sixty-seven per cent stated that their institutions had separate non-technical libraries for patients. Medical library access was supported by 89.6 per cent of the respondents, with only about 10 per cent opposed to providing access to patients.<sup>9</sup>

The American Hospital Association conducted a survey of all hospitals registered in the United States in 1990 to determine how many had health sciences libraries. Nearly 40 per cent of these libraries reported involvement in patient/consumer education.<sup>10</sup> Libraries also reported a wide spectrum of users, including patients and families. Nearly 50 per cent also provided services to members of the community.<sup>11</sup>

More recently, medical school libraries in the United States and Canada were surveyed by Hollander to find out whether they were providing health information to the general public, including patients. Although most libraries did not actively promote services to the public, 98.4% of publicly funded medical school libraries and 71.5% of those that were privately funded did provide access and service to all.<sup>12</sup> Hollander states that

...results of this survey suggest academic health sciences libraries today are, in fact, expanding their role as information providers to health-conscious consumers, ... and many are providing a greater level of service than they were able to provide in the early years of the consumer health movement.<sup>13</sup>

Numerous case studies describe information services offered to hospital patients (see, for example, Cain and Fuller, Calabretta, Gross, Moeller, Phillips and Zorn, and Tarby). But allowing access to medical information by patients is still debated in the literature. Collins and Sasser state very strongly that hospital librarians who do not consider consumer information services their responsibility '...may be overlooking a trend that could help to determine their own professional survival.'<sup>14</sup> They also state that the hospital library is likely to be the first access point for people seeking consumer health information.<sup>15</sup>

Current trends identified in the literature are:

- convergence of needs (health-care professionals and patients)
- the importance of collaborative projects.

## ***Convergence of needs***

There are indications that some of the traditional boundaries between patient and professional information are breaking down or becoming less clear. The Internet has played a key role in this. In the late 1990s The National Library of Medicine (NLM) made MEDLINE freely available to all, and health-care consumers are becoming increasingly sophisticated in their information requirements. In the first year of free Internet access not only did the number of searches drastically increase but it has been estimated that almost one-third of searches were conducted by consumers.<sup>16</sup> (Interestingly, however, it has been noted that the availability of end-user searching has not had a negative impact on the provision of a mediated search service for the public by medical librarians.<sup>17</sup>)

Exposure to medical literature is greater than ever before. Not only has the Internet helped to de-mystify the language of medicine, but health and medical research has also become much more widely publicised with, for instance, *New England Journal of Medicine* or *Journal of the American Medical Association* articles publicised by the mass media. This means that an important segment of the literature that used to be the exclusive preserve of medical professionals has now been opened up to the general public.<sup>18</sup>

A consequence of this convergence of needs is described by Cain and Fuller in their report on The Health Library at Stanford University. This library was established as a consumer resource for the local community with a branch at the Stanford Hospital for patients and their family members. However, hospital staff members now constitute about 60 per cent of library users. The authors conclude that electronic delivery systems can allow for an economical information service that can address the needs of a wide range of users.<sup>19</sup>

La Rocco points out that certain segments of professional literature are ideal for fulfilling consumer health information requirements. Nursing literature and that of allied health fields such as nutrition and physical therapy are particularly appropriate — they may provide more detail than traditional patient information resources and the language is generally easily understandable. 'Professional literature that is comprehensible and relevant to the topic at hand greatly expands the universe of health information for consumers.'<sup>20</sup>

## ***Collaborative projects***

From the 1970s onwards there are reports in the literature of collaborative projects to provide information to patients. In 1980 it was suggested that academic, public and hospital libraries all had an important role to play in the provision of health-care information to consumers and that this could best be done in partnership.<sup>21</sup>

Humphries and Kochi describe the participation of a health sciences library in their parent institution's programmes. The library was involved in

- the inventory and management of patient education materials
- a community health promotion task force
- planning a consumer health information centre
- establishing a consumer health information reference section
- obtaining funding to offer a networked health information system to local community libraries.<sup>22</sup>

Hollander describes a collaborative project between a health sciences library and community libraries to provide consumer health information to the public. She states that 'collaboration between [health sciences and public libraries] is rapidly becoming a necessity, as well as a reality.'<sup>23</sup>

The Public Library Association has recognised the importance of consumer health information and has stressed the necessity for collaboration between institutions. It encourages public librarians to cooperate with hospital librarians in collection building.<sup>24</sup> In 1998 the National Library of Medicine launched Medlineplus, a new consumer health Web site.<sup>25</sup> At the same time a project to increase public awareness of and access to health information via the Internet was initiated. The project will evaluate the degree to which public libraries and the Internet can meet consumer health information needs.<sup>26</sup> A recent article on health information in *American Libraries* again stressed the need for cooperation and collaboration between librarians in different types of libraries:

Although librarians of all types have been answering consumer health queries for years, a stronger alliance between public libraries and consumer-oriented medical collections will provide concerned consumers with more information options.<sup>27</sup>

## **United Kingdom**

The provision of consumer health information in the United Kingdom has followed a rather different course to that of the United States. Margaret Forrest recounts the history of patient libraries in the National Health Service (NHS), and most of her article deals with bibliotherapy and recreational library services for patients. The provision of consumer health information is, in general, a comparatively recent concern for the United Kingdom and, interestingly, Forrest states that:

It was, however, to the detriment of the patients' library movement that the majority of librarians were not willing to become involved in the dissemination of health information, preferring to leave this to the clinical staff.<sup>28</sup>

This goes some way towards explaining the different emphasis and system of delivery of consumer health information in the United Kingdom, and may also be a pattern that was copied by countries following the United Kingdom model — including New Zealand. However, in 1994 Bolton and Brittain recommended that 'every hospital should have a medical library or health information service which caters for patients as well as medical staff.'<sup>29</sup>

Gann provides a detailed account of the development of consumer health information services from the 1970s onwards. He states that at this time most medical librarians were reluctant to open their resources to the public.<sup>30</sup> During the 1980s two main services provided library and information services to health-care consumers (Lister Health Information Service and Help for Health), until the introduction of *The Patient's Charter*.

*The Patient's Charter* is an important milestone in the provision of consumer health information in the United Kingdom. The thrust of the Charter is to guarantee certain standards of care, and implicit in it is the need for information. It was accompanied by a government requirement to establish health information telephone help-line services in each regional health authority. The wording of the Charter indicates why a telephone information service is important. The Charter states that patients have the right to

have any proposed treatment, including any risks involved in that treatment and any alternatives, *clearly explained to you* before you decide whether to agree to it...<sup>31</sup>  
[italics added]

NHS Direct in the United Kingdom uses nurses to suggest management options based on caller needs, as well as referral to other agencies. Called 'telephone triage', this service first developed in the United States and has been found to be clinically effective, cost-effective and popular with consumers.

Preliminary findings of a study of this service by Sheffield University found that publicising the service has been a problem, calls to the service have been two-thirds lower than expected, and considerable differences exist in the information provided between different sites.<sup>32</sup>

It can be seen that there is still an emphasis on a requirement for a mediation role between the consumer and the information, which could be a reflection of contrasting attitudes to health care and its delivery in the United Kingdom, compared to the United States. Another feature of consumer health information needs that is linked to the public health service delivery system (as opposed to the United States private system) is a requirement to make information available *about* health services (e.g. waiting times, how to find a general practitioner (GP) and so on).

The most recent development (December 1999) in the United Kingdom is an Internet gateway to health information: NHS Direct Online <<http://www.nhsdirect.nhs.uk>>. The main sections are

- Health features — focuses on a different topic each month, and includes an online chat facility with a guest expert
- Conditions and treatments — a database of conditions containing contact details for self-help groups, details of patient information leaflets and booklets, and some audio clips
- Healthy living — health promotion information
- Guide to the NHS
- Healthcare Guide — a triage facility, covering the 20 most-asked-about conditions by free-phone callers.

Another significant area of study in the United Kingdom has focused on treatment outcomes. Five pilot projects were commissioned by the King's Fund to improve the delivery of treatment outcomes information to the public.<sup>33</sup>

There is also some evidence that current hospital-based consumer health information services exist,<sup>34</sup> although this is not the major focus of the literature. Stevens et al. describe the operation of a service at a major city hospital which aims to provide information to patients and their visitors. The authors point out that, although there are other high-profile consumer information services in this city,

it is clear that each health information service has a different set of users and thus, rather than duplicating services, the local health information services complement each other.<sup>35</sup>

## **Ireland**

The provision of consumer health information in Ireland has been the subject of recent research. The main findings are along familiar lines:

- There is an increasing public demand for information.
- Provision of information has been ad hoc.
- Access to information is inadequate.<sup>36</sup>

The provision of consumer health information by hospital medical libraries is similar to the situation in New Zealand — there is generally very little available and very few libraries encourage public access. However, it was also noted that hospital librarians are facing increasing demands from patients for information, and the recommendation has been made that cooperation between public libraries, health boards and medical libraries should be developed.<sup>37</sup>

## **Australia**

In 1996 Robert Gann compared the provision of consumer health information in Australia to that of the United Kingdom in the late 1980s. He identified the following consumer health information services in Australia:

- a poisons information service
- maternal and child health helplines
- tape-recorded information services
- local and state telephone helplines.

Services provided by hospital libraries to patients are not identified.<sup>38</sup> A more recent development is the launch of *HealthInsite*. This is an Internet health information gateway that aims to provide Australian health consumers with the most current and reliable information, and is funded by the federal government.<sup>39</sup>

Two articles mention the role of hospital libraries in providing information to patients. Virginia Walsh has given a brief overview of the importance of the library service within a hospital and mentions in passing that libraries help patients and their families in making informed choices.<sup>40</sup> Beverley Johnson has tackled this area in more depth, exploring why health-care consumers are so often the information poor in the health-care system. She identifies the main

reasons put forward by librarians to justify not offering information services to health-care consumers:

- It is unethical because librarians have no medical training.
- It is the role of health professionals, not librarians.
- Medical literature is too technical and difficult to understand.
- Health consumers may misuse the information.
- Medical information can be devastating.
- Medical and hospital libraries are primarily for the use of health-care professionals.
- Libraries are understaffed and underfunded and cannot take on additional services.

Johnson discusses these reasons in the light of the provisions contained in the Australian Library and Information Association (ALIA) code of ethics. She suggests that understaffing and underfunding could be attributed to librarians failing to convince their parent organisations that they are an essential component in the health-care system. She concludes by stating that the

service ethic for health librarians is top quality, professional service, or put another way it is effective, timely, helpful, informative, customer-based services for all health care information seekers.<sup>41</sup>

## ***The future***

Developments in the United States, United Kingdom and Australia indicate an increasing use of technology to deliver health-care-related information to consumers. A review article in the *British Medical Journal* identifies recent advances as:

- inclusion of consumer health informatics in national health-care policies
- adaptation of systems aimed at professionals for use by patients
- development of computer technology to assist patients in making informed decisions
- electronic medical records, accessible by the patient

- development of initiatives to address the quality of health information on the Internet.<sup>42</sup>

Nevertheless, the author acknowledges that, although there is tremendous potential to reduce the knowledge gap between professional and patient, there is also the very real risk of widening the gap between the information-rich and the information-poor — those who have access to the new technology and those who do not.<sup>43</sup> Deering also notes that, even with increasing numbers of personal computers in homes, networked health information may further disadvantage those with fewer resources but greater need for information.<sup>44</sup>

There is a danger that an emphasis on Internet availability of consumer health-related information will divert attention from the question of whether or not library services should be involved in its provision and, if so, to what extent. Analysis of the overseas literature shows that although some newer services have a very high profile there is still a need for library provision of information to patients, particularly in hospitals.

## ***New Zealand***

### ***History***

It is appropriate to cover the history of New Zealand hospital library services to patients in some detail, as doing so clearly shows the different positions taken by library sectors. This review provides a useful background to the current situation as demonstrated from the results of the current survey. The time period covered extends from the beginning of the 1970s until the present day.

In a 1972 *New Zealand Libraries* feature on New Zealand medical libraries Mary Ronnie discussed library services to patients. Recreational reading appears to be the main focus, with the suggestion that public libraries should bear the main responsibility for this service, and at least some proportion of the cost.<sup>45</sup> Other articles written in this journal at that time also focus primarily on patients having access to recreational resources.

However, in 1973 G Dunbar, Librarian in Charge at Canterbury Medical Library, raised the issue of public access to medical information. The article contributed to the ongoing debate on public access. Dunbar noted that some international medical libraries were considering broadening their 'medical library clientele to include members of the general public seeking medical



information.’ However, his personal view was that, while this was feasible, it would involve considerable change, including ‘enlarging of facilities, augmentation of staff, etc.’<sup>46</sup> Concerned at the limited amount of health and medical information in public libraries at the time, he suggested that these libraries could provide medical information for patrons, and that this could be easily achieved by liberalising and re-prioritising their book selection policies.

In response to the argument that medical information is not always easily understood by the public, he noted that public libraries purchase in areas such as engineering and electronics, in spite of the fact that specialised knowledge is required to read these. He believed that both medical and public libraries should ‘re-examine a long-held belief that members of the general public should not enjoy free access to the great bulk of medical literature.’<sup>47</sup>

Dunbar asked ‘how well is the medical profession ... providing medical information to members of the public upon demand?’<sup>48</sup> He concluded that the medical profession is not effectively meeting this need.

Our study provides some further insight into this issue, more than 25 years after Dunbar first raised the question.

A New Zealand Library Association (NZLA) submission on hospital services in 1978 acknowledged patients’ needs for information. A questionnaire circulated to Area Health Board hospitals found that, where no professional library staff had been employed, there was a limited understanding of the potential for patients’ needs that could not be met by existing services. However, in Dunedin, which at the time offered the only professional service to patients, over 700 patient requests were satisfied in the previous year.<sup>49</sup> The clear implication was that, if given the opportunity, patients would make use of information services.

In 1976, two years before *Standards for Library Services in Health Authorities* was published, Ann Rimmer, one of those involved in its preparation, said:

Library services to patients are excluded from these standards [under development]. This does not mean that these services aren’t as essential as those for medical or paramedical staff, but simply that we consider them more a public library function and as such, none of us feel qualified to comment.

She adds that ‘There is, of course, the possibility of combining library services to patients and staff’,<sup>50</sup> but noted that these were considered to be separate types of service and attempts to combine them must therefore be carefully planned.

By the time the final standards were released in 1978, this stance had changed, and the standards included many references to services to patients. The Council of the NZLA published *Standards for Library Services in Health Authorities*. The authors stated:

The hospital and health sciences libraries provided for in these standards will ... assume new dimensions especially in relation to the expanding programme of health education to the public.

They continued:

An integrated service for both patients and health sciences personnel can provide ... therapeutic and educational reading for patients and general reading for staff and patients in a single administrative unit.<sup>51</sup>

Patient library services should 'provide for ... therapeutic, rehabilitative, educational and recreational needs....' A library, it was stated, 'is an essential part of a health authority's provision for its patients.'<sup>52</sup>

The standards establish that educational material includes the 'provision of material on a wide range of medical conditions written for the layman.'<sup>53</sup>

Our study gives an indication of the level of patient service provided within New Zealand hospitals, both private and public. Later sections of this report reveal that, 20 years after these standards were produced, just over a quarter of surveyed hospitals considered that they provided a library or information centre for patients.

Ten years on from Dunbar's article, another medical librarian, D G Jamieson, noted there had been an explosion in public health and medical literature and argued that, although there might be a concern about librarians coming between a doctor and their patient by providing advice, providing published information to patients raised no ethical or legal questions.<sup>54</sup>

A 1986 study by Dewe found medical information was the most heavily requested subject within the National Library of New Zealand, with requests frequently fulfilled by libraries with strong health collections. However, many requests were unfulfilled if information was not held within New Zealand.

A 1987 discussion paper, commissioned by the National Library and the Department of Health from Australian library consultant Paul Hodgson, investigated strategies for more effective coordination of services in this area. The study found that New Zealand's medical library collections generally did not perform well against international counterparts. The report made a number of recommendations, including that there be 'funding ... of a single existing

strong medical library to function as a library of first resort.<sup>56</sup> Journal holdings were deemed to be the most pressing need, with the focus on filling gaps in the national collection by the acquisition of important medical journal titles indexed by the medical database MEDLINE but not currently held within New Zealand medical libraries. The need for popular health material was briefly acknowledged, with Hodgson suggesting that demand for materials in public libraries would result in improved collections; a clearinghouse for health education materials was also suggested.<sup>57</sup>

Dewe discusses the preferred choice of the National Library: a single existing medical library funded to hold sufficient specialist journals to meet a high proportion of medical information requests, and staff to administer this service. The cost of such a service was acknowledged, with an acceptance that unless charges were low enough to encourage use, a collection held in one location would not provide a national benefit.<sup>58</sup>

Submissions made following the Hodgson report indicated that public libraries were also considered to be a useful venue for health information.<sup>59</sup>

However, research by Jill Harris revealed a need for health information among hospital outpatients that was not fulfilled, and that 7 to 10 per cent of enquiries received by Wellington Public Library and Wellington Citizens' Advice Bureaux were for health and sickness information.<sup>60</sup>

In 1988, following the controversial treatment of cervical cancer patients at National Women's Hospital in Auckland, the *Report of the Cervical Cancer Inquiry* was published. The subsequent inquiry and report raised the issue of patients' information needs into the news media. In the Report Dame Silvia Cartwright said:

...I have come to consider that the patient is entitled to all relevant information concerning her treatment, [and] the options for treatment.<sup>61</sup>

and later:

If the patient's consent to treatment, research, examination or teaching is a prerequisite, then she must have **adequate information** [her emphasis] on which to base her decision. It is obvious from the evidence that I have heard that some doctors do not believe that it is really possible to provide this information, given the constraints of time and the level of the patient's understanding.

In my opinion the latter is more a fault of the doctor's ability to communicate and the perception of the extra time it takes. The former can be addressed by far greater commitment to providing patients with more written and visual information before the doctor discusses the procedure, treatment or research with her.<sup>62</sup>

The report recommended that procedures be put in place to ensure that this process can occur. Since the report was published, there have been a number of initiatives that have attempted to fulfill patient needs for information. There is also an increasing acknowledgement of the need for effective access to information to assist patients and families with their decisions. There is a direct link from the Report and other initiatives and the release of a Code of Rights in 1996 (discussed below).

In 1989 the Health Information Association of New Zealand (HIANZ) was set up to

coordinate communication and cooperation among all users and providers of health information...to provide an avenue for addressing the concerns and aspirations of all health professionals ... with an interest in the publication, acquisition ... retrieval and dissemination of health information.<sup>63</sup>

This new body was to prove a strong advocate for health information services to patients.

In the early 1990s, the issue of the provision of appropriate health information to the general public was hotly debated, and additional publications from this period represent the continuing range of views on how this could be achieved. The role and level of involvement of medical libraries in any planned service were controversial.

By 1990 the National Library had opted for a smaller scheme than its original plans, with more emphasis on information for health consumers. The idea of a strong, single medical library had been replaced by the decision to purchase a number of health-related journals in support of the popular: *Consumer Health and Nutrition Index*.<sup>64</sup>

The need for consumer health information services was also noted in Wellington, and a working party coordinated by HIANZ was set up in 1990.<sup>65</sup> Also in that year, a consumer health seminar attended by representatives of different library environments was held in Auckland. Participants advocated 'the development of local collections of consumer health information in public libraries or hospitals'<sup>66</sup>, with basic collections also available within doctors' surgeries. However, medical libraries were seen as a secondary source of information for 'the more unusual subjects or in-depth inquiries.'<sup>67</sup> Medical librarians were noted as willing to accept these requests, 'as long as the demand on their staff and resources is not unreasonable.'<sup>68</sup> Quality of resources was a concern, and suggestions included the option of an advisory panel to recommend resources, to ensure they were acceptable for New Zealand treatment practices. Coordinated distribution of material (such as pamphlets) was proposed.

Also in 1990, the *National Minimal Health Standards* were released to update those published in 1978. Although the main focus of the standards was library service to medical professionals, patient needs were acknowledged as 'additional recommended patient/consumer health information services'<sup>69</sup> for both Category 1 and 2 libraries. Category 1 covered larger libraries within medical schools, and also provided formalised services to hospitals or Area Health Board staff. Category 2 included general Area Health Board libraries, as well as private general hospital libraries.

The qualitative standards section included the underlying principle:

The library will offer appropriately organised services to meet the information needs of all staff and of other affiliated health professionals and students ... It may be appropriate to extend services to meet the needs of patient/consumer health information groups. This may be done directly or in cooperation with public/polytechnic libraries within the particular health service region.

The Department of Health also published guidelines in 1990, entitled *A Model for Health Sector Library Services*. In section 2, 'Who is to be served?' consumer health needs were clearly acknowledged as a valid area for the provision of information services:

- (e) any lay groups working in the health field
  - voluntary agencies
  - self-help and patient support groups
- (f) Area health board clientele
  - patients and their families
  - the healthy general public.<sup>71</sup>

The report states:

Patients are just as much part of the health care team as are doctors and nurses. Patient education and information services may serve the Area Health Board's goals just as much as drug therapy.

However, the report adds that:

The library has a role in providing health education literature and information though other information providers may be more appropriate, e.g. public libraries, voluntary agencies, or the community health departments or health development units of area health boards.<sup>72</sup>

Clearly, ambivalence about who should be providing these services is still an issue, and it has perhaps been one of the key problems in the development of an equitable service in this area.

Under the section of the report, 'What activities are to be supported?' the statement is made that 'A library should aim to provide literature and information to meet needs in relation to decision making.' This was seen in relation to patient care '... which may include services to patients.'<sup>73</sup>

On the next page the report maintained the ambivalent position demonstrated earlier:

3) The library service may support health education of the general public.

If the library is involved in this area, it should be in co-operation with other agencies involved, eg. The community health department of the area health board, public libraries, the Department of Education and the news media. The library may function as a backup to the other services.<sup>74</sup>

In 1991, *A Question of Health*, guidelines prepared by Jill Harris on information services for the public were published. They acknowledged that many people wanted an active role in their health care and required information to support this. However, although a number of sources for health information existed, the coordination of these services was limited. Suitable locations, including a hospital, were suggested for a health information service. This option had the potential to draw on medical expertise. Although it was suitable for patients, however, the hospital location could deter the wider public. Moreover, other locations such as public libraries and shopping centres may not benefit from the experience of in-house medical staff.<sup>75</sup>

### ***The role of the general practitioner***

The difficulty of expanding services was discussed in a 1994 article on medical libraries as an underused resource for GPs. Valerie Broadbent from Canterbury Medical Library acknowledged that services to GPs had not been marketed strongly because of staff overloading.<sup>76</sup> Could provision of information to patients be an even lower priority?

The rights of patients are acknowledged by the Medical Council of New Zealand, which stated in 1990 that except in emergency situations:

...the proper sharing of information, and the offering of suitable advice to patients, is a mandatory prerequisite to any medical procedure instituted by a medical practitioner.<sup>78</sup>

The Medical Council again acknowledged the same requirement in 1999:

A doctor must now communicate enough information to such a degree and depth and in such a manner and environment so as to be able to enable a reasonable patient to make an informed choice in the circumstances.<sup>78</sup>

Pullon discusses the issue of informed consumers in relation to the potential volume of information on health topics and the limits to understanding of a patient not well versed in an understanding of health issues. Pullon says:

It is quite unrealistic to expect a sick person to instantly educate themselves to a point where they can make a truly informed decision, often in the unfamiliar environment of the hospital.<sup>79</sup>

Her argument is that GPs have a role in ensuring the patient has achieved a level of knowledge 'before the crisis requiring hospital admission arises.'<sup>80</sup> She is also concerned about the quality of resources and comments that 'Too much of what we find on the library shelves is biased information coming from a narrow viewpoint.'<sup>81</sup>

She notes that doctors are used to decoding specialists' information for patients, and that much of the information that consumers can access is best interpreted in unison with their GP. She argues that GPs need to present their credentials more clearly to effectively compete with resources that have only a superficial authority.

Conversely, in a more recent article by Soar and colleagues, it was argued that by providing health information, cost reductions could be made elsewhere: 'Savings could result, for example, through a reduction in visits to health professionals where the purpose is simply to obtain health-related information.'<sup>82</sup>

However, Cullen advocates that the GP should 'guide their [patients'] choice of material.'<sup>83</sup> Clearly there are opposing views on the issue of how independent the consumer should be in interpreting health information.

There exists one New Zealand study on public expectations of where patients should go to obtain health information. In this study by Solomon,<sup>84</sup> the two highest sources named to obtain information on specific health matters were GPs and self-help groups. Public libraries were the third highest source selected by respondents.<sup>85</sup> A number of other library types were mentioned, including university, polytechnic and school libraries. It is not clear whether medical libraries fit into the category of academic library or whether this was not considered as a viable source by those surveyed. The preference for GPs reflects Pullon's premise that GPs are an appropriate source of information, it is clear that many consumers agree.

Solomon's study found that GPs were considered by respondents seeking treatment information in 99 per cent (209) of cases and were a primary source for many of the health topics mentioned in the survey. By contrast, only 105 people thought to mention public libraries, although this was still the second most frequently mentioned service overall. It was the third most popular choice in two lifestyle categories. The medical library had a significantly lower profile overall.<sup>87</sup>

Solomon argues that there is a real need to market services for some current information providers — particularly where a source is not currently perceived to be a *likely* source of information. She specifically cites the Dunedin Disability Service and Citizens' Advice Bureau in Dunedin as organisations that need to promote this aspect of their services,<sup>88</sup> particularly by identifying market segments. Libraries are also specifically mentioned as potential sources of wellness information. Solomon also argues that they too need to market this aspect of their service more effectively. While public libraries are particularly well placed to provide wellness information on topics such as stress reduction and nutrition, they are never seen to be the first source of information in these or any other of the categories examined during this survey. Solomon concludes with the recommendation that GPs (as the most commonly perceived health treatment information providers) should be encouraged to work more closely with libraries in a symbiotic relationship.

### ***New Zealand consumer health initiatives***

Many doctors' surgeries include pamphlets that provide details on a number of medical conditions and health issues produced by a number of organisations. Some are derived from official bodies such as the Health Funding Authority (HFA) and the Ministry of Health, while individual support groups have produced a range of others. It has often been difficult in the past to obtain the full range of these resources, and it would be ideal to hold these in a number of easily accessible locations around New Zealand.

There have been several attempts to offer an information service that includes not only a comprehensive range of pamphlets, but also resources such as books, encyclopaedias, videos and other items for consumer use. The following examples describe some of these initiatives.

Telephone helplines attempt to provide the general public with easy-to-understand information about medical conditions. Some private providers run



helplines, sometimes on a fee-paying basis. A 1996 *NZ Herald* article considered the value of these, and commented:

you can spend up to four minutes listening to general information gleaned largely from published material provided free by health authorities here and in the United States.<sup>89</sup>

Telephone services provide a service at a national level (in this case as a fee paying service), however, there have also been a number of regional initiatives that offer some form of face to face service, as well as a wider range of resource options.

In 1988 a patient information service 'to give the public greater access to health information' was proposed as a combined project between Canterbury Public Library, Canterbury Medical Library, Citizen's Advice Bureau and the Christchurch School of Medicine. This two-year pilot project was to be sited within Canterbury Public Library, with a special focus on information to the general public and patients. This *Consumer Health Information Service* (CHIS) was to provide information, but not advice or counselling.<sup>90</sup> In 1990 lack of funding was reported, with sponsorship being considered.<sup>91</sup>

Following a consumer health information seminar in late 1989, a pilot study was proposed to provide 'written information which would reiterate and reinforce the advice given by the GP during the consultation.'<sup>92</sup> The GP could give out this information during the consultation (but the impracticalities of each practice maintaining comprehensive and up-to-date collections were acknowledged), or patients could be sent information at no cost. The content of each leaflet was to be approved by the New Zealand Medical Association (NZMA).

The pilot was carried out by Margaret Gibson Smith, Medical Librarian at the University of Auckland, under the auspices of HIANZ and the NZMA. The pilot involved 20 GPs and the information was derived from the patient information columns of the *New Zealand Family Physician* and other authoritative sources. It also included feedback from GPs and an evaluation form to be completed by the patient. At a later stage these pamphlets were serialised for publication within the *New Zealand Medical Journal* (allowing for national distribution) but leaving the onus for retention and distribution on individual medical practitioners and their staff.

The *Parent and Family Resource Centre* (based in Auckland and, until recently, part of Greenlane Hospital), was established in 1990 to 'provide support and skill development for parents.'<sup>93</sup> The service provides information on conditions and treatment, as well as access to education services, support services and support groups.

Later and very similar is the hospital-based consumer health information service, *Family Information Service* (FIS), at Starship Hospital in Auckland. Funded by the HFA, this free service provides 'information for families about children and young people's conditions and disabilities, and [puts them] in contact with parent support groups and other support agencies.'<sup>94</sup> The service has been operating since November 1997, is available to any family in New Zealand, and took 800 requests in its first year of operation.

The result of five years of lobbying by the advocate group, Children's Health Liaison Group, FIS provides families with lay materials on conditions and treatment, as well as information on coping with emotional issues. Although the library is open to anyone, only families receive direct assistance. Hospital staff and students must search for information themselves.

Items in the catalogue are not available for loan, and the current librarian notes that many resources are available elsewhere — notably in public libraries and specialist disability collections such as IHC and NZCCS libraries and the NZ Disability Centre Library.

National Women's Hospital in Auckland runs a unit called *Health Information for Women* which is available to all, including patients and their family/whanau. Situated by the main hospital entrance, it is open weekdays and offers database searching and the Internet, as well as books, journals and video material.<sup>95</sup>

*NZ Health Online* went live on the Internet in March 1997. Seventy-five guides to diagnostic, treatment, lifestyle recommendations and support were initially offered.<sup>96</sup> These were written or endorsed by health professionals through *Inform New Zealand*, and funded by the *Researched Medicines Industry Association* although the health information was developed separately to avoid the suggestion of bias. A CD-Rom covering 258 medical conditions<sup>97</sup> was also made available. *HIANZ Highlights*, in which this initiative was announced, also mentioned the introduction of free MEDLINE on the Internet, citing examples of patients who had used this database to enhance their own health and treatment options.

The *Allan Bean Centre* (ABC) is a newly established centre based in the spinal rehabilitation unit of Burwood Hospital in Christchurch. The Centre offers services to support recovering patients and family around New Zealand.<sup>98</sup>

Healthline is a two-year pilot telephone service initiated by the Ministry of Health and the HFA in May 2000. It will offer 'an effective and safe way for New Zealanders to gain access to expert health advice.'<sup>99</sup> The pilot will cover four regions: Northland, the East Coast, Canterbury and the West Coast,

allowing comparisons with regard to socioeconomic status, ethnic background, rural and urban needs, and distance from a tertiary hospital.

It is intended that health professionals answering calls to Healthline will provide information on medical conditions appropriate to the New Zealand environment, assessment of medical problems (including a treatment timeframe), advice on illness prevention, and act as a referral point to other agencies.<sup>100</sup> Benefits of the service include reducing unnecessary consultations and hospital admissions, providing affordable access to information and advice regardless of physical location, and allowing people to take more responsibility for their health care.

These examples of consumer health education initiatives serve to demonstrate that a wide range of information services are available throughout New Zealand. However, these services are often based in large urban centres, and although some will respond to requests from anywhere in New Zealand, in reality requests are most likely to come from those living in the same region. The specialised nature of some of these services (families or rehabilitation, for example) adds to the likelihood that while the local region will be well served, geographic distance from other regions make effective national use less likely.

There is also a potential for unnecessary duplication of services (as in the case of the Family Information Service and the Parent and Family Resource Centre, both based in Auckland, but developed independently). Marketing of such services is clearly difficult, and it is likely that for most services there will be limited funds available for this purpose — insufficient to market effectively on a national level, even where this is appropriate.

### ***Code of Rights***

In 1995 HIANZ made submissions to the Health and Disability Commission in preparation for a draft Code of Rights. The barriers faced by consumers in receiving information were raised, particularly the poor coordination of information, including the significant acknowledgement that ‘perspectives regarding information needs differ between staff and patients, and influence whether information is available at all, and if so, whether available *to all* [our emphasis].’ The submission went on to note that these ‘problems result from poor communication between clinical staff; an approach to communication based on clinician’s subjective views’.

Other points made in the same submission included:

Good information services improve clinical outcomes, increase efficiency.

HIANZ holds that patients have a right to appropriate, available, accessible, accurate, timely, comprehensible information delivered in a manner that takes into account patients' needs and circumstances.

It is important to recognise that information may be delivered in a variety of forms, and the face-to-face communication between patients and health care provider is not the only, nor even necessarily the best, form.<sup>101</sup>

When released in 1996, the Code included three rights specifically relating to health information:

Right 5 : The Right to Effective Communication

Right 6 : The Right to be Fully Informed

Right 7 : The Right to Make an Informed Choice and Give Informed Consent<sup>102</sup>

In the United Kingdom, the introduction of *The Patient's Charter* required that treatments, including risks and alternatives, should be clearly explained to patients. This led to the development of enhanced information services to medical consumers.

In New Zealand, however, the patient's right to information, while acknowledged in the Code, has not resulted in the same development of national initiatives for the provision of consumer health information.

The Code of Rights, and its requirement for patients to be fully informed on their medical care, presented an opportunity to highlight the need for a national health network. However, in the four years since the Code came into force, the capability to provide for the health information needs for the general public has not advanced significantly, in spite of some very promising regional initiatives.

### ***The Internet***

The impact of the Internet is an issue globally and within New Zealand. A recent study found that a high proportion of GPs (68%) used the Internet monthly, primarily for work-related tasks.<sup>103</sup> Although the Internet has provided medical consumers with enhanced access to information about medical concerns, the information that can be obtained from this source is not necessarily authoritative or accurate. Sixty-four per cent of doctors in the study believed that the Internet had affected the doctor-patient relationship, or would do so in future. Seventy-one per cent of doctors in the Internet study reported

that they had patients who had sought medical information from the Internet. Forty-nine per cent expressed some anxiety about this, particularly with regard to inadequate or incorrect medical information.<sup>104</sup>

The Internet does add another option in providing appropriate resources to patients and their families. However, the current level of access in the community is still low, and unless free services can be provided in many centres around New Zealand, there will still be a potential for some to miss out on this service. Recent initiatives in the United Kingdom (mentioned above) may provide a future model for service.

### ***The current situation and the future***

In 1997 the National Library's Trustees received a research proposal from HIANZ. The proposal, to identify and manage health information needs, was turned down, leading Donna Jarvis to write of her concern that a 'national direction [in health information] is lacking'.<sup>105</sup>

Jarvis also raised her concern that changes to the staffing and collection management areas in the National Library may see a reduction in access to health information: 'The people who need health information are powerless, poor or unassertive and who cares?'<sup>106</sup>

Soar and colleagues spell out the benefits of the provision of consumer health information from a health funding perspective:

Consumer health information services are expected to offer benefits in the areas of public perception, cost-effectiveness, access, equity, promoting evidence-based approaches and improving provider performance.<sup>107</sup>

New Zealand's change of government in late 1999 saw the release of a new national health strategy, which acknowledged that:

Communities with access to better (non-personal) information about their own health or health care services are able to play a greater role in maintaining their own health and accessing appropriate health services, and in contributing to decision-making on local health services.<sup>108</sup>

Currently, the situation of health information services to patients and the general public in New Zealand is represented by patchy, regionalised services developed as individual initiatives. There is no consensus on the direction in which to move to improve this situation, and this lack of direction has seen the requirement for patient information marginalised and lagging behind international initiatives.



# ***Part II: The Survey***

## ***Scope***

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The purpose of this survey was to establish the range of patient information services provided in New Zealand hospitals. We wanted to survey institutions offering medical services that could involve a need for patients, or their family members, to research health information. Areas for patient research could include general information on a condition or aspects of their medical treatment, but also could include alternative treatment choices and ethical decisions on continuing care. The main focus of the survey was, therefore, hospitals offering services to inpatients, day patients and/or outpatients.

By means of our investigations we hoped to identify how many hospitals currently offered some form of information service to patients beyond that which occurs in medical consultations, to establish the extent of these services and to obtain details of funding for such a service. We wanted to identify groups that were given access to a health information service such as this, the level of assistance that was provided, and the hours of access and relevant qualifications of staff working in this area. We were also interested in whether information on alternative or complementary medicine was provided, and the extent of assistance from medical staff in the selection of materials for a patient information collection.

We were keen to canvas respondents on their opinions on the provision of medical information to patients. Did they feel that medical practitioners provided sufficient information during consultations? When patients expressed a need for more information beyond that provided by their primary medical practitioner, should it be provided? If so, where should resources for patient research be located?

Regardless of whether they offered health information services to patients, all of those who responded were asked whether patients were referred to institutions such as support groups and public libraries for information on health matters.

This information would allow us to gauge the level of support for health information services to patients, and may indicate future directions.

## *Methodology*

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As a result of these requirements, we developed a questionnaire in four sections (see Appendix). Section A asked general questions about funding, whether a library or information centre (LIC) was provided for medical, nursing and allied health staff, and general details about the medical services provided to inpatients and outpatients. A feeder question at the end of this section was used to direct respondents to the next appropriate section. Based on whether they considered that their hospital provided an information service for patients, respondents were directed to complete either section B (for those who offered an information service to patients) or section C (for those who did not).

Section B explored the kinds of information resources available within the library or information centre; who was eligible to use these resources, and what specific services were provided (for example, assistance with locating materials).

Section C canvassed respondents from hospitals that did not currently offer a library or information centre to patients. They were asked whether they had arrangements with other institutions for health information services, and/or referred to other organisations such as support groups. The questions used in section B were also asked, to establish how effective medical practitioners were in providing sufficient information to patients during the consultation.

The final part of the survey, section D, sought the level of respondents' agreement with statements on the provision of medical information to patients. All respondents were asked to complete this section.

The statements included in the later sections were used to gauge opinion on a variety of controversial issues. We were able to make use of earlier research by Australian Beverley Johnson<sup>109</sup> (see literature review) in developing our own statements. These statements, while subjective, do give an indication of the range of views that exist. The provocative nature of some of these statements resulted in considerable interest in these sections, and has helped to enhance our understanding of views that may not have been expressed clearly in the past. Because people from different areas of hospital operations completed this questionnaire, a wide cross-section of views is represented.

There were also many opportunities for respondents to add their own comments at the end of the statements, and many did so. This has added a valuable qualitative component to the results, and we have been able to examine these individual comments in some detail. The comments could be valuable in developing consumer health information services, and also provide considerable food for thought for the medical profession.



The questionnaire was pre-tested by four subjects to eliminate ambiguous questions and improve overall validity. Two testers were actively involved in the provision of health information and assessed the questionnaire from the perspective of information suppliers. One tester worked in an academic institution, and the final tester, currently working in the area of general health and medicine, was able to consider the questionnaire from a nursing and medical perspective.

Our initial selection of hospitals for this survey was based on two directories produced by the Ministry of Health: *Licensed CHE Operated Hospitals and Old People's Homes in New Zealand* and *Licensed Privately Operated Hospitals in New Zealand*. However, since their publication a number of details (such as hospital names) have changed and, as a result, the most significant source used was the hospital pages from New Zealand telephone directories. These were then checked against the more detailed directories to ensure they met our study requirements. Where there was insufficient information (particularly with new facilities), each hospital was contacted directly to ensure it met our requirements.

Survey forms were sent to 314 hospitals. However, three institutions returned the forms when it became clear they did not meet the definitions used for hospitals.

In order to maximise the number of completed and returned responses, a variety of strategies was used with considerable success. Before the questionnaires were posted, each hospital was contacted to identify the most appropriate person/s to complete the survey, and to obtain an undertaking that they would do so. It was hoped this would encourage responses and, as the survey was not anonymous, we could contact them again if no response was received. Those who had not returned their form were contacted later, and this follow-up resulted in a number of additional responses.

Each questionnaire included a free pen which respondents were encouraged to use to complete the questionnaire. A draw of a boxed pen was also offered for five of the surveys that were received within the specified time frame — two weeks from the approximate date the survey would have been received within the institution. However, ultimately, everyone who returned a completed questionnaire was included in the draw. These strategies appeared to be successful in achieving an acceptable response rate.

The research assistant (Sarah Welland) and one researcher (Pam Bidwell) entered the survey data into an Excel package. A 5 per cent spot check of responses was made by the researcher to ensure that data had been entered

correctly; this revealed a very high level of accuracy. Each response was assigned a number that proved to be very helpful during the checking process. An Open Polytechnic statistics lecturer (Lois Curry) undertook data tabulation with assistance from one researcher. Both researchers wrote the final analysis.

# **Results**

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This section looks at the overall findings from the study. The first part is a quantitative analysis of results from the first three sections of the survey. Overall statistics from all of the responses are provided; these results include the combined responses from all participants on specific questions about the provision of information to patients during consultations.

The second part of the survey results focuses on individual responses to questions in Section D, and covers a range of issues. These results are derived from a series of statements given to all respondents to determine their level of agreement in each case. Many additional comments that were provided in support of responses to specific statements have also been examined, and a selection of these is included. Finally, we explore issues raised when we invited respondents to add further comments.

## **Numerical results**

### **Survey participants**

Of the 314 questionnaires sent out, 196 (62.4%) were completed and returned. As a result of this comparatively high percentage, we have been able to obtain a reasonably clear picture of the range of information services offered by hospitals around New Zealand. This result is pleasing considering somewhat jaded attitudes to surveys in recent years, and we believe we were assisted by the strategies mentioned in the methodology.

A wide variety of people representing a number of different sectors of the hospital system responded, allowing us to capture a range of views originating from many hospital sectors. Some responses came from medical librarians and health information coordinators, but most were from managers, chief executives or principal nurse managers. A variety of other nursing roles was also represented, including charge nurses, midwives, community health nurse and ward managers. Occupational therapists and diversional therapists also represented allied health professionals. Other groups included a social worker, an accountant and several working in the area of quality assurance.

Responses from private and public hospitals were very evenly spread; there were 62 public and 66 private hospitals. An additional 54 institutions offered both public and private facilities, and a small number reflected other

arrangements that included charitable trusts and a religious and welfare focus. Hospital bed numbers ranged from 3 to 650. One hundred and seventy-nine hospitals cared for inpatients, 76 looked after outpatients and 115 provided services for day patients.

One hundred and fifty-seven of the hospitals had a library or information centre for nursing staff, and 91 hospitals provided a service for allied health professionals.

Medical students and physicians were less likely to receive services — only 55 hospitals provided physicians with a library or information centre, and medical students could access a library or information centre in only 43 cases.

### ***Questionnaire completion***

In general, the questionnaire was well answered. As with any survey, there were a few ambiguous responses, but the overall number was low and should not affect the final results. One question from the final section was possibly ambiguous, and this fact has been noted in the final results.

It was difficult for some respondents to decide whether their service qualified as a library or information centre. As a result, they struggled to answer specific questions because the service involved did not really meet the criteria. In a few cases it seems likely that the service was restricted to recreational reading, but these numbers were not high enough to skew final results.

In five cases only two sections were completed, and 17 respondents completed all sections although this was not required. In these cases, the researchers eliminated the inappropriate section — a decision based on the response to the question regarding the provision of a library/information centre for patients. In only one case did these responses differ for questions that were common to both sections.

In some cases, one person completed a response for more than one facility, and duplication such as this was eliminated from the opinion sections.

### ***Do health-care professionals provide sufficient information?***

All respondents were asked whether they considered that doctors or other caregivers provided sufficient information during consultations. Of the responses from the 54 hospital-based patient library and information centres, 62.9 per cent (34) agreed with this comment, although only 18.5 per cent (10) strongly agreed. A further 14.8 per cent (8) were undecided, and 22.3 per cent (12) disagreed (although only one person strongly disagreed).

The figures for hospitals *without* information services that were dedicated to patients (127 responses from the 142 in this category) demonstrated very similar views. Overall, a similar proportion - 61.5 per cent (78) agreed that physicians do provide sufficient information during consultations, with a higher proportion of respondents 15 per cent (19) strongly agreeing.

There was a small difference in the number of undecided responses for this question, with 14.8 per cent (8) of those offering library and information centres undecided on this issue. This was lower than for those who do *not* provide an information service, where 22 per cent (28) were undecided on the level of information provided by physicians. There was also a similar difference between those who disagreed with the statement — slightly higher numbers 20.4 per cent (11) of hospitals that provided patients with information services did not believe that patients received sufficient patient information during consultations, compared with 15.7 per cent (20) of hospitals that do not provide information services.

Overall, 61.9 per cent (112) of those responding agreed that doctors do provide sufficient information during consultations, 19.9 per cent (36) were undecided, and a significant proportion of respondents 18.2 per cent (33) disagreed, although only two of these strongly disagreed.

These results indicate some concern about the level of information provided for patients at the time of consultation, and demonstrate a need for information services to meet the shortfall of information that some patients might experience. However, it is clear that a number of doctors perform well in this area, and many make some effort to provide additional material to patients.

Hospitals *without* LICs (142 of 196 responses, or 72.4%) were asked for details on what types of information physicians and other health-care professionals provided for patients. Listed in order of frequency, the following types of information were reported:

Pamphlets	78.2% (111)
Addresses of support groups	69.7% (99)
Articles	63.4% (90)
Videos	49.3% (70)
Books	47.2% (67)

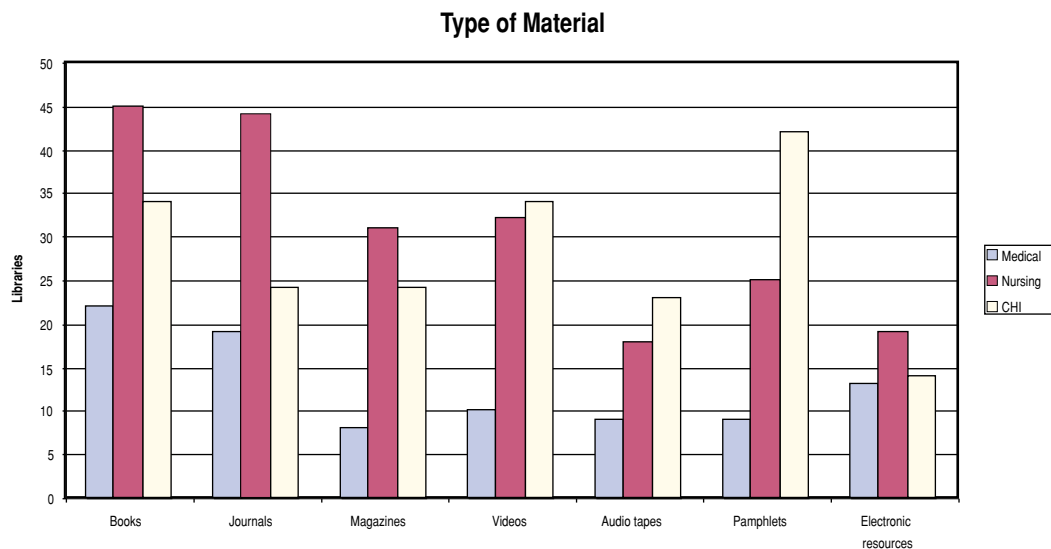
### ***Library and information centres***

Fifty-four (27.6%) hospitals reported having an in-house LIC for the use of patients. Details of the service within hospitals varied widely, from operations dedicated to patient and family member needs, with full-time staff and regular opening hours, to resources that could only be accessed when staff could leave their other duties to supervise.

Most LICs have a variety of not-particularly-descriptive names such as ‘the library’ or ‘resource room’, with just one called a ‘consumer health information service’. In an attempt to determine where patient libraries fitted in the organisational structure, respondents were asked which sections they reported to, or were part of, within the hospital. It was not possible to draw any clear conclusions from the answers given beyond the fact that five LICs clearly reported to the clinical side of the hospital, two specifically to nursing, and nine to administration departments.

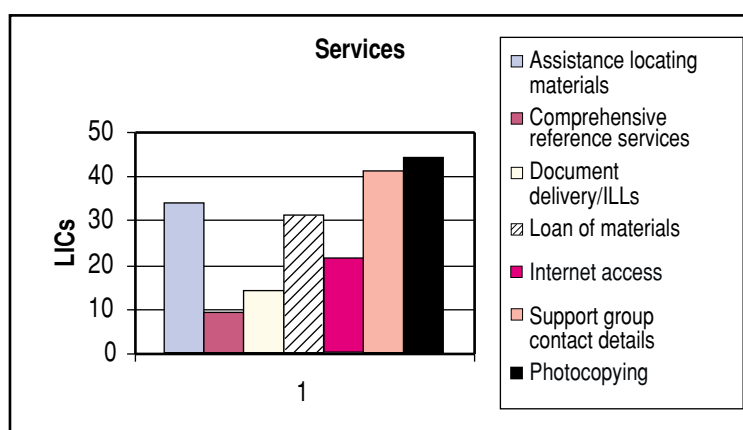
***Materials and services provided:*** Replies indicated that the LICs provide a range of materials (books, journals, audio-visuals, electronic resources) to patients. The most frequently supplied types of material were books, followed by journals and pamphlets. Electronic resources were least likely to be provided. Respondents were asked to categorise their stock by material type (books, journals and so on) according to three categories:

1. medical (information intended primarily for use by physicians)
2. nursing (information intended primarily for nurses)
3. consumer health (information intended primarily for patients).



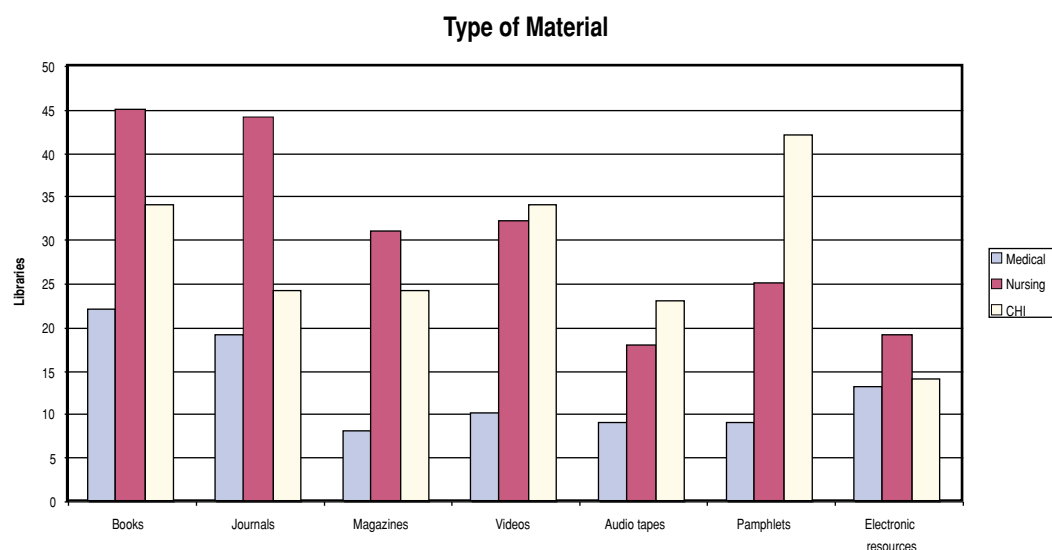
With the exception of videos, audio tapes and pamphlets, the largest proportion of resources available for patients was categorised as ‘nursing’. This finding bears out La Rocco’s comment that the nursing literature is particularly suited to answering consumer health information queries.<sup>110</sup> Four hospitals with libraries/information centres also reported providing recreational reading to patients.

Forty-four (81.5%) hospitals with patient libraries/information centres indicated that photocopying facilities were available to patients. The next most frequently reported service was supplying contact details for support groups 41 (75.9%). Thirty-four libraries (62.9%) provided assistance in locating materials, but only 9 (16.6%) considered that they provide comprehensive reference services to patients. Thirty-one libraries (57.4%) reported that they loan materials to patients, and 21 (38.8%) provide Internet access.



Libraries were asked whether they provided information on different viewpoints — that is, alternative or complementary health-care and traditional medicine. Forty-six (85.2%) libraries said that they provide information that

reflects traditional medicine, with exactly the same number stating that they do, or *sometimes* will, provide information on alternative medicine.



**Who uses the information centres?** Of the hospitals *with* patient libraries/information centres, 81.4 per cent (44) provided access to inpatients, although only half allowed access to outpatients (27). Thirty-three (61.9%) hospitals gave day patients access to these facilities. Eighty-nine per cent (48) of the hospitals with LICs allowed family members to have access. This figure may be the highest because some hospitals serviced patients who were not able to investigate medical information for themselves. Twenty-five (46.3%) also reported use by the general public.

Four libraries noted that health-care professionals (both hospital staff and those practising in the community, such as independent midwives) also used collections. The type of information that was being accessed by staff cannot be determined from this survey, but it would be interesting to investigate whether this represents a similar trend to that described by Cain and Fuller. They describe a resource that was established for consumers but is now also extensively used by staff, who comprise 60 per cent of their users.<sup>111</sup>

A few hospitals reported that restrictions were sometimes or always applied to patient access to the LIC. Of the 17 respondents who answered 'yes' or 'sometimes' to this question, two stated that staff must give approval, and one that a member of staff has to be responsible for loans.

**Resourcing:** Twenty-two (40.7%) hospitals reported that the LIC was staffed for one hour or more per week, with 13 of these (59.1%) staffed for more than 30 hours per week. A selection of the comments made about staffing indicate the often ad-hoc nature of services:



'key held in nurses' station'  
'maintained informally by staff members'  
'help yourself service'  
'staffed by nursing staff on duty'.

Twenty-five hospitals (46.3%) reported that inpatients are allowed 24-hour access to resources. Fourteen hospitals (25.9%) reported that the LIC was staffed by full-time personnel, while 21 (38.9%) reported part-time staff. Surprisingly, the number of volunteers reported as working in patient information centres was quite low — only 10 (18.5%) hospitals reported using volunteers. The numbers of qualified librarians involved in supplying information to patients was small — just 11 individuals and one person working towards a qualification. Backgrounds of other staff included teaching, nursing and midwifery.

Thirty-seven (68.5%) LICs were either fully or partially funded from the internal hospital budget. Five hospitals reported that they were either fully or partially funded by the HFA, and 18 were partially funded by charitable donations. Three libraries charged fees for service, with one charging certain non-hospital personnel a library membership fee.

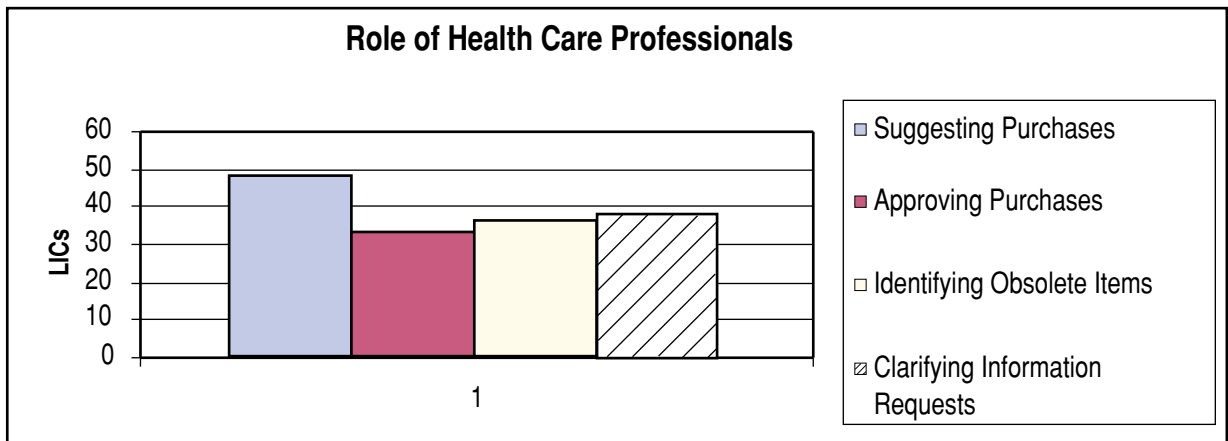
Four hospitals reported that 'patient information' had funding that was earmarked for this service, while three others stated that it was a distinct line item in the overall library budget.

**Liaison:** Hospitals were asked if the information centre worked in conjunction with other departments within the hospital in providing information to patients. Twenty-two (40.7%) replied that they did. This ranged from the reactive to proactive approach:

'Information is given to patients via requests from hospital personnel'  
'Constantly collaborating with other departments to ensure complementary resources held'.

Hospital staff referred patients to the information service frequently or sometimes in 77.7% (42) of cases, or never 20.4% (11) of the time.

Health-care professionals have considerable input into collections and services, with only one hospital stating that staff had never suggested purchases. Six hospitals reported that staff did not have an approval role in purchasing materials. One hospital reported a collection development policy team, with staff members being consulted for their recommendations.



Thirty-one hospitals (57.4%) reported that there were other patient information services in the hospital in addition to the LIC. Where details are given, 'leaflets' and 'pamphlets' are frequently mentioned:

- 'just the usual hospital pamphlets'
- 'most departments have some sort of information service — pamphlets'
- 'departments often have pamphlets for patients'.

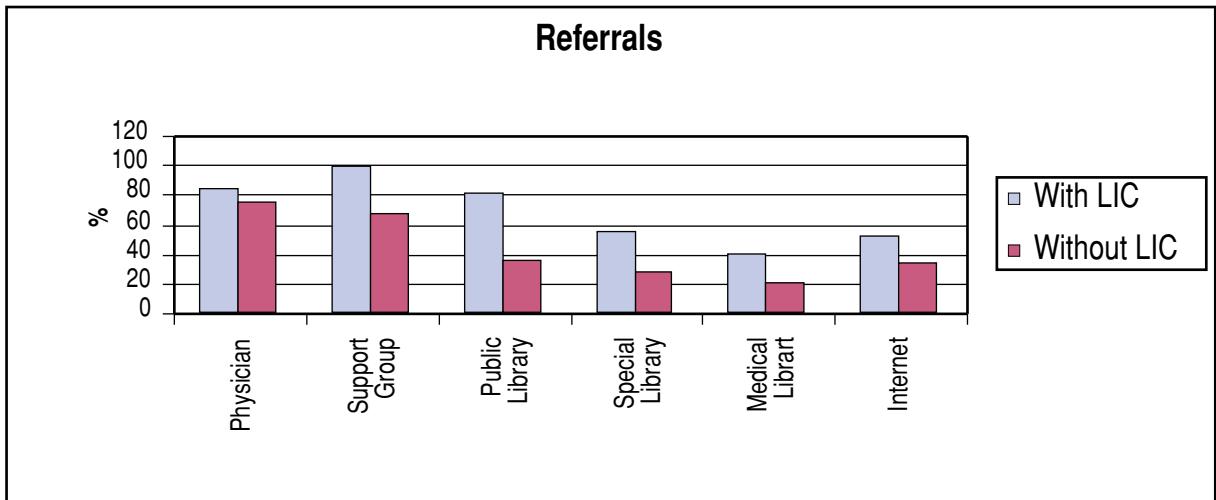
Fifteen hospitals (27.7%) stated that there is central coordination of all patient information programmes.

### ***Beyond the hospital***

If patients require further information, hospitals with a LIC report referring them to the following facilities frequently or sometimes:

Support group	96.3% (52)
Physician	83.3% (45)
Public libraries	79.6% (43)
Special library	55.5% (30)
Internet	51.9% (28)
Medical library	38.9% (21)

Referrals from hospitals *without* LICs followed a slightly different pattern to those *with* LICs.



Physicians were seen as an important source of information in all instances. Support groups were also well regarded, particularly by hospitals *with* LICs (96.3%). However, the status of public libraries as sources of health information was considerably lower for hospitals *without* information services. Medical libraries were also not seen as very significant sources of information for patients.

Twenty-three hospitals (42.6%) *with* an LIC reported having a formal service agreement with another library. Other libraries included medical schools, public libraries and Healthlib for inter-library loans.

Of the remaining hospitals (those *without* an LIC) 43 (30.3%) indicated that they had a formal service agreement with a library, but eleven of these were with a public library or for recreational reading.

### ***Individual responses***

The final section of the questionnaire included a number of statements, and respondents were asked to indicate their level of agreement or disagreement in each case. This section was to be completed by all respondents, and overall this was completed by 89% of those responding.

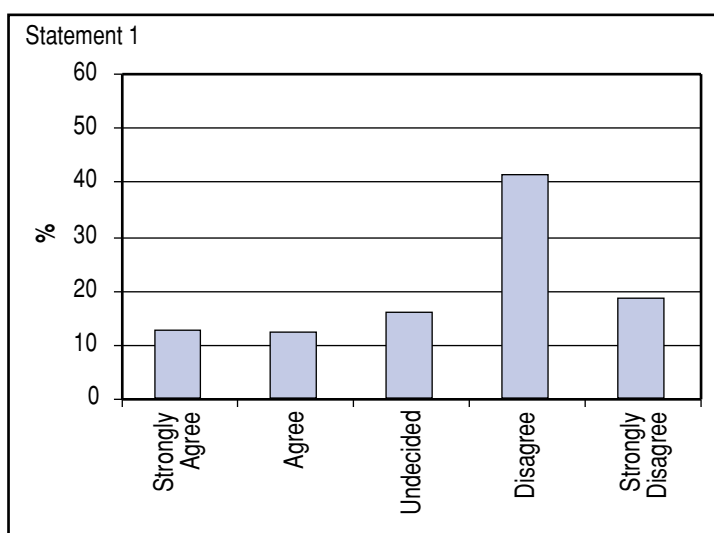
The statements raised considerable comment, with many respondents including additional remarks for clarification. Selections of their remarks have been included to illustrate the points made. A few respondents felt that these statements reflected the researchers' bias, and a few also felt that the wording was ambiguous. However, others commented that it had made them think about issues they had not previously considered.

Australian Beverley Johnson explored the reasons why health-care consumers are often poorly served.<sup>112</sup> She identified a number of explanations that were used by librarians to justify *not* offering information services. The statements used in the final section of the questionnaire were based on these explanations.

These statements may not represent definitive views from respondents, and so must be viewed with some caution. However, they allow us to see the range of views that exist on these issues, and the additional comments have added considerably to our understanding of the issues involved. Overall, these responses provide some guidance on possible strategies to provide effective health information services to the general public.

Six statements were included, and respondents chose the ranking that most closely matched their view on the issue raised.

**Statement 1: A librarian should not provide information to patients because librarians have no medical training (175 responses)**



Over half (59.4%) of all respondents disagreed or strongly disagreed with this statement, with 16 per cent (28) undecided. A smaller proportion of respondents, 24.6 per cent (43) agreed or strongly agreed. There is clearly an acceptance amongst many of those responding that librarians could have a role in the provision of health information to patients. However, there are also some concerns about this. Additional comments from respondents provide some extra clarification on this issue:

Information given to patients should be able to be validated by medical professionals.

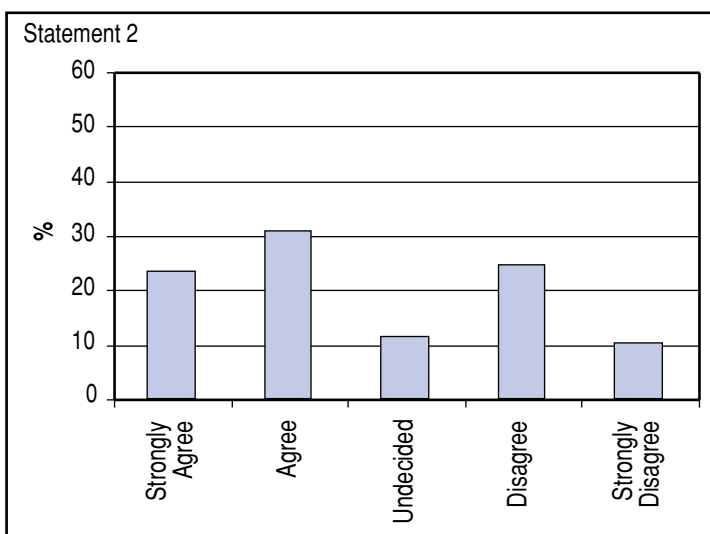
(Hospital Coordinator, private hospital)

In my opinion it is the responsibility of the healthcare professional to provide informative information to their patients, following this they could then recommend some reading material to consolidate what has been said. (Manager, Principal Nurse, private hospital)

Providing the information from medical literature is one thing — but if a librarian is to provide advice for patients, that would not be acceptable. (Quality Facilitator, public hospital)

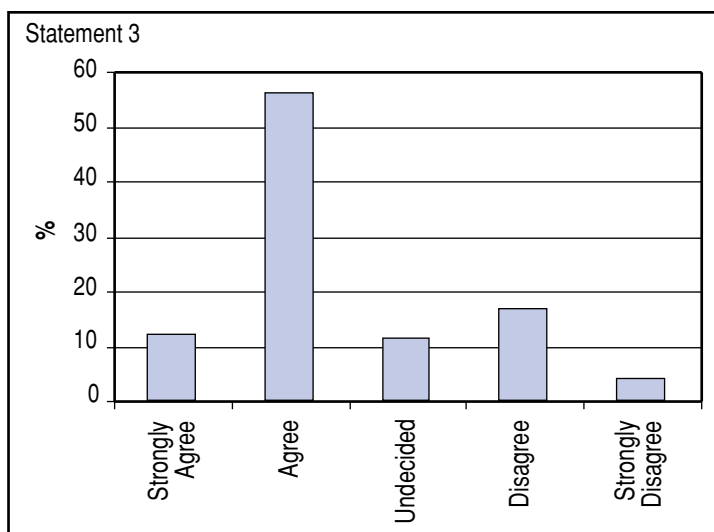
Usually more effective and useful when the printed information is given to support the explanation of the condition and the treatment. (Library Manager, public hospital)

**Statement 2: Health professionals, not librarians, should provide information for patients (176 responses)**



Results showed that 54 per cent (99) agreed with this statement, with 23.3 per cent (41) strongly agreeing. Sixty-one (34.7%) disagreed, and 10.2 per cent (18) of these strongly disagreed. Twenty (11.4%) were undecided. The high support for physicians as the most appropriate source of information for patients is not reflected in these results, and may indicate some confusion as to the meaning of the statement.

**Statement 3: Medical literature can be too technical for patients to understand  
(175 responses)**



One hundred and nineteen (68%) agreed or strongly agreed with this statement, although only 12 per cent (21) strongly agreed. Twenty (11.4%) were undecided, with 20.6 per cent (36) either disagreeing or in strong disagreement. The complexity of medical resources is clearly a concern for many, with only one-fifth of respondents considering that the technical nature of medical information is not a serious issue for patients. This raises the vexed issue of the potential need for interpretation of any health and medical information that is provided, and suggests that strategies are required to deal with this issue in the provision of information services to patients.

Information that is written primarily for medical professionals can be confusing to those not familiar with the writing style. Conditions may be presented in 'worst-case scenarios' that do not relate well to an individual with the condition. This point is well made by a library manager in a public hospital:

...we have patient information but the patients themselves do not have direct access, this is because a lot of the time they want to access very clinical material they have no understanding of and it confuses...

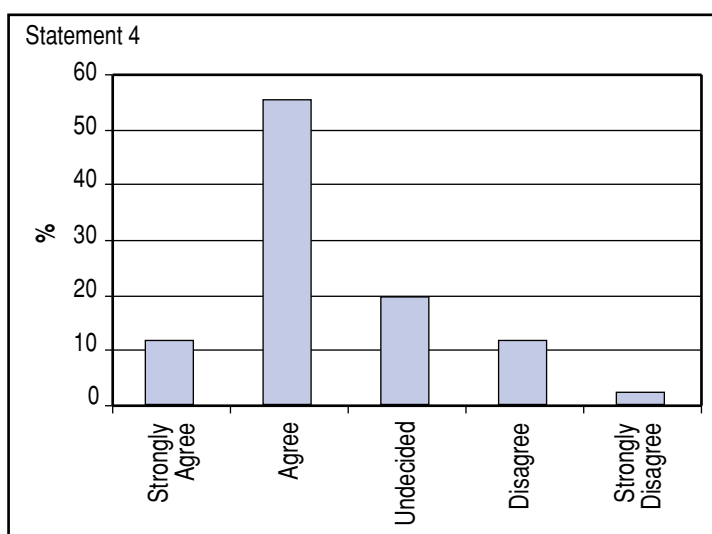
Public information is, by definition, not individualised, and so may not be applicable in all cases and this can lead to unnecessary concern/confusion. (Education Coordinator, partially publicly funded hospital)

Others hold similar views. One principal nurse manager considered that 'information ideally should be patient-specific in the first instance and they can then seek other input,' and another public hospital librarian commented:

Medial literature would not be supplied to patients. Specially written information — such as pamphlets supplied by Arthritis Foundation, Heart Foundation etc should be available to patients, also the name and address of support groups.

Blanket statements such as these, however, ignore the reality that some patients understand technical medical information, with or without the assistance of their medical professional. The motivation to understand technical information is also greater when nothing else is available on an unusual or a complex condition.

**Statement 4: Patients may misuse or misunderstand the information given to them (174 respondents)**



One hundred and sixteen (66.6%) agreed or strongly agreed with this statement, with 11.5 per cent (20) strongly agreeing. Thirty-four (19.5%) were undecided. Only 2.2%(4) strongly disagreed with this statement, and 13.8 per cent (24) disagreed overall. One respondent made the comment that this statement should have been split in two. We are aware that these figures should be viewed with some caution, as their validity depends on whether the respondent was more concerned about the risk of misuse or misinterpretation.

An education coordinator for an aged residential facility makes the point that information on specific medical conditions covers general characteristics and information, but that these details may not apply for an individual patient:

Public information is, by definition, not individualised, and so may not be applicable in all cases and this can lead to unnecessary concern/confusion.

This potential for misunderstanding medical information was enlarged upon by a number of respondents:

I think medical information should be given to the patient, but adequate provision for understanding of that information should be made. I agree patients misunderstand most medical information or don't absorb it at the time of receiving it through various reasons.' (Staff Nurse, public hospital)

Rather than deny access, some health professionals prefer to emphasise the interpretation of information, so that patients are encouraged to 'discuss with their doctor any concerns they might have, or if they do not understand anything.'

Just as there are different levels of patient need for additional information on their condition, there is also a requirement for a range of resources that will meet different levels of understanding. Some people can absorb and understand technical information more easily than others, and this point is clearly made by a number of respondents:

I feel it is the responsibility of the caregiver, medical, or midwife to ensure the client/patient is given as much material, written, audio-visual etc as they need/request to be able to understand their condition and be able to make informed decisions regarding their treatment, ongoing care.... However, information should be at various levels to cater for all levels of understanding. (Midwife, public hospital).

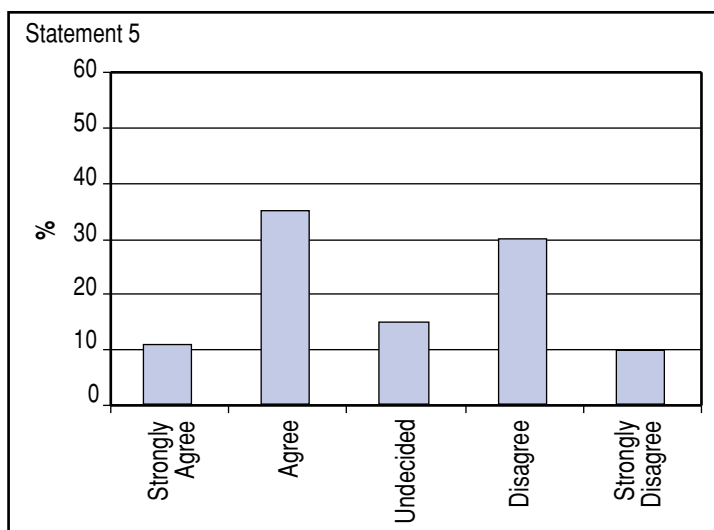
Some patients are too ill to clearly comprehend written information, and this point was made by a number of respondents based in geriatric hospitals

The patients in our hospital are unable to request or understand information. They are continuing care patients who have either dementia, strokes, MS or other illnesses. Their family occasionally will see the in-house doctor or myself for information required. (Principal Nurse, private hospital)

This second point, that it is often family members who require information on behalf of an ailing relative, is also made by a number of respondents. At times this information can assist them to make ethical decisions about the level of care that should be given.



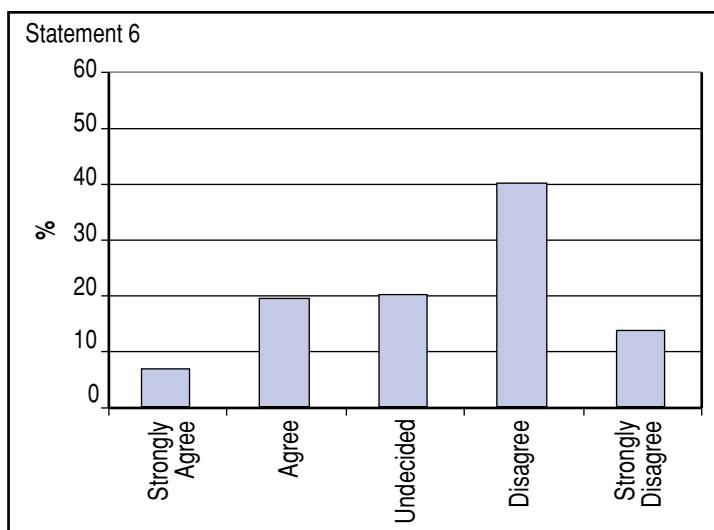
**Statement 5: Medical and hospital libraries are primarily for the use of health-care professionals (177 responses)**



Eighty-one (45.8%) respondents agreed with this statement. However, only a slightly smaller proportion of 39.5 per cent (70) disagreed. Twenty-six (14.7%) were undecided. The debate on who should have responsibility for the provision of health information services to patients is reflected in the similar number of respondents agreeing and disagreeing with Statement 5.

The resources held in medical libraries clearly provide assistance for the health professionals in the medical decision-making process. This is reflected in the 1990 Department of Health guidelines, *A Model for Health Sector Library Services*: 'A library should aim to provide literature and information to meet needs in relation to decision making...' However, the report also notes that patients 'are just as much part of the health care team as are doctors and nurses.'<sup>113</sup>

**Statement 6: Hospital libraries should not take on the additional responsibility of providing information to patients (175 responses)**



This statement extends the previous response on whether medical libraries are primarily for the use of health-care professionals. Over half, 53.7 per cent (94), believed that hospitals *should* take on the additional responsibility of providing information for patients. However, it is clear from additional comments that many would only recommend this approach if funding was increased to meet the costs involved.

Additional comments reflect the different levels of awareness and opposing views of this issue. For some this is a new issue:

As health professionals we are meant to be encouraging self responsibility for patients but the thought of allowing patients to have the same access to information that we have somehow frightens us. The concept of patients utilising the medical library is something I had never thought of prior to this questionnaire. (Unit Manager, public hospital)

Some believe the medical library is inappropriate because of the kinds of material that could be identified by patients.

If medical libraries were funded to supply consumer health information I am sure they would and could do it. The need is overwhelming. It would be most appropriate in an area frequented by patients — not the medical library. (Librarian, public hospital)

Patients shouldn't have access to the medical library but should have a small room with appropriate material, e.g. books, pamphlets available written in terms they can understand. (Medical Librarian, public hospital)

Funding was clearly an issue, and participants frequently mentioned their concerns. This is reflected in the following comments:

I cannot think a patient information service can be based in a hospital library without considering resources in both library staff and resources. (Library Manager, public hospital)

The use of the library by patients/members of the public is very rare, and the library is certainly not advertised to these groups as staffing levels are not adequate and most of the library collection is not suitable for consumer health info. (Medical Librarian, public hospital)

We are keen to assist patients achieve a desirable 'informed consent' and practice status but are not funded to provide a sensitive and appropriate service. (Librarian, public hospital)

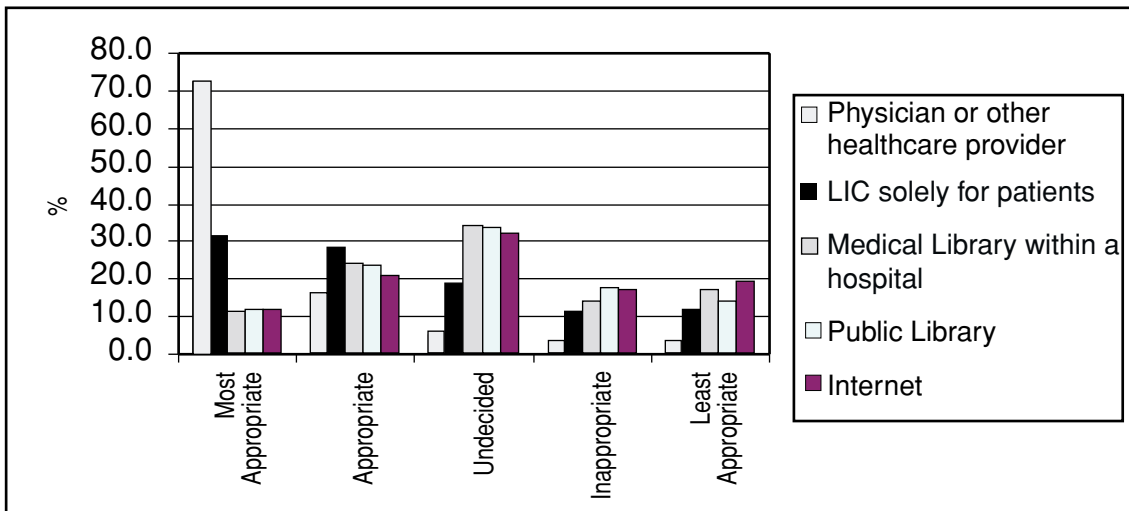
The medical library is not funded to supply this. Usually the public see this as unfair and discriminatory, but no funding = no service.' (Medical Librarian, public hospital)

### ***Health information options for patients***

Respondents for the last question in Section D were presented with a list of a number of possible sources of patient information, and asked to rank these from most appropriate to least appropriate. This question was not answered quite so well as the previous question involving statements but, overall, 80 per cent of those returning the questionnaire chose to complete this section. The range was between 1 and 5, with 5 being the least appropriate source. Respondents could choose to give only one source for each ranking, but others rated more than one source equally. As a result, these represent a range of preferences.

Options given were:

- library or information centre solely for patients within the hospital
- medical library within a hospital
- public library
- Internet
- physician or other healthcare provider.



***Physician or other healthcare provider (156 responses)***

Overall, 88.4 per cent (138) of responses considered that physicians were appropriate or very appropriate as a source of health information. One hundred and thirteen (72.4%) of those considered that they were their first choice as an appropriate source of patient information, and an additional 25 (16%) felt they were appropriate.

Eight (5.1%) were undecided, and five (6.4%) considered them inappropriate or very inappropriate. Only five nominated the physician as their last choice as a source of information for patients, and it is possible that the instructions for the question were misinterpreted in these cases.

***Library or information centre solely for patients within the hospital (164 responses)***

As a first choice, 51 (31.1%) respondents considered the LIC to be the most appropriate source for patient information. However, this is significantly lower than for physicians. An additional 46 (28%) rated this as an appropriate source — 97 (59.1%) overall. Thirty (18.3%) gave this a neutral rating, indicating some concern or indecision about this option. Thirty-seven (22.6%) felt this was either inappropriate or very inappropriate, with the latter scoring a comparatively high disapproval rating of 19 (11.6%).

***Public library (159 responses)***

The public library was the third highest choice for most appropriate resource, but of those ranking this choice, only 19 (11.9%) considered it to be the *most* appropriate source. An additional 37 (23.3%) people considered this source to be appropriate. A total of 56 (35.2%) respondents considered this an appropriate choice. A significant 53 (33.3%) participants gave this a neutral ranking — many are clearly undecided on this issue. Public libraries received a high disapproval rating, 50 (31.4%) did not consider the public library to be an appropriate source, with 22 (13.8%) of this group ranking this as most inappropriate.

### ***Medical library within a hospital (159 responses)***

The medical library was almost third equal with public libraries as the most preferred choice, with 18 (11.3%) giving this the highest rating. Thirty-eight (23.9%), slightly more than for public libraries, considered the medical library to be an appropriate choice. Overall, the rating of these libraries as an appropriate source was the same: 56 (35.2%). A similar number of 54 (34%) gave this a neutral ranking. The disapproval rating also followed a similar pattern, with 19 (30.8%) considering this to be an inappropriate or very inappropriate source — 27 (17%) ranked this as a most inappropriate source.

### ***Internet (158 responses)***

The Internet rated slightly higher than the medical library as an appropriate alternative, with 51 (32.3%) considering this either an appropriate or a most appropriate choice. However, nearly a third 50 (31.7%), were undecided, and over a third 57 (36.1%), considered this an inappropriate choice. This was considered a most inappropriate source by 30 (19%).

### ***Other Suggestions***

Respondents could also nominate their own alternatives. Of these, a 'one-stop shop' was preferred. Other options included pamphlets and support groups, an independent set-up in a shopping centre with Web-based support; community-based health centres, and there was one vote for hospital libraries linked to public libraries.

## ***New issues raised***

A number of the additional comments made by participants raised new issues that have been drawn together into different categories for this final part of the results section. This comments feature provided an excellent opportunity to gauge a range of opinions on the issues raised in the pre-selected statements, and the individual statements allowed the researchers to explore the differing views in some detail.

As discussed previously, a variety of people completed this questionnaire. When hospitals had a form of library or information service, staff members associated with this service completed the survey. However, if this service was not offered, the person completing the questionnaire could be the head nurse, receptionist or the hospital director. Consequently, the results are not simply a thin slice of the opinions of a single sector of the hospital community, but represent a range of views from a variety of hospital sectors.

In addition, individual responses to the questionnaire may represent the views of one individual, or could attempt to represent the views of the organisation. The survey tried to draw out both elements, and responses indicate that this has been at least partially successful. However, at times it can be difficult to judge whether the comment is an institutional view, and this should be considered when reading the following comments.

### ***Patients and the need for information***

Do patients want medical information? A number of responses indicate that, unless incapacitated, they definitely do.

A clinical coordinator clearly saw the value of information, and commented that providing support information both for patients and relatives 'decreases patients' recovery times and expectations of pain.' One hospice education director stated that:

We hear time and time again from patients and families about lack of access to timely, informative information. They like to read as well as hear as often they are under great stress and often need to refer to written information, or be encouraged as to how to find it.

And from a librarian in a public hospital:

Our staff feel the better informed people are the better they will respond to treatment. Many patients say what a relief it is to know and understand what is wrong with them.

This need to read as well as hear is echoed by other responses. A private hospital support services coordinator commented:

A lot of information is given to patients verbally at the time of treatment etc. This needs to be in the written form, people don't remember. There is so much going on.

A quality improvement coordinator in a partially public hospital said:

Our residents are all elderly and written information is an inappropriate means of giving information, however it can be used as a backup e.g. a pamphlet.

This issue is also reflected in a comment from the CEO of a partially public funded medical/geriatric faculty, where staff do not:

generally provide medical/nursing info in written form as info — usually carefully explained verbally, due to [problems with] sight, understanding and comprehension.

The most appropriate time to provide information to a patient is also an issue. As one nurse manager in a partially public funded facility comments:

Often judgement must be used in the amount of time that information is offered. Health professionals can abuse this, but often they are in the best position (with exclusive knowledge of their patients/residents) to know the right time/right information. E.g. Some people want immediate information, some need more time.

Is there a certain category of person who seeks medical information beyond the consultation? There is some evidence that these people may indeed be a particular type. One medical librarian in a public hospital network certainly felt this was the case:

I find only the most 'inquisitive type' patients come to the library after pushing their health professional for further info.

The same librarian also added

We do not get many patients using the library. However, we do get quite a few members of the public...

There is a strong tendency in New Zealand to keep patients in hospital for short stays only, with post-procedural recovery in the patient's home if possible. Consequently, people may visit a hospital information service as inpatients, but could also make use of it later, as outpatients. Outpatients may visit the library in anticipation of an appointment or for further information following a consultation. However, a librarian running a publicly funded consumer health information service made the comment:

A lot of health consumers never actually enter a hospital and yet they should still have access to information, so hospital information centres should also serve the general public and work closely with the public libraries.

### ***The potential for information overload***

The overwhelming amount of material on many medical conditions is also a concern. A clinical coordinator comments:

Whilst I feel that patient information is very important, there are times when too much information does not help patients or their relatives.

Some do not believe that patients should necessarily have full access to information. Speaking about families of Alzheimer's patients, a private hospital manager said:

I certainly do not think to have a library available within the hospital for use by families would be of any help at all — I believe health professionals only, should access the knowledge and pass it on to families.

### ***The right to information***

A charge midwife in a publicly funded maternity centre commented that:

Historically I feel patients/clients have only been told on a need to know rather than want to know basis, i.e. Caregiver has claimed ownership on the knowledge.

The Code of Rights was referred to only once, by the coordinator of a consumer health centre, but the point raised is applicable in all hospitals:

A key feature of our service is that it provides a safety net for busy practitioners unable to meet all the information requirements of a patient and their family as required by the Code of Rights... Patients are more likely to feel they have the information they need and less likely to make a complaint about this aspect of their care.

Overall there was a view among a number of respondents that patients (and the general public) have a right to information about their medical care. A director of nursing in a partially publicly funded facility said:

Ideally all patients should receive as much information as they require to assist in decision making and for acceptance (if realistic) of their diagnosis.

The fact that this does not always happen was clearly expressed in the individual comments discussed here and in general question responses:

We hear time and time again from patients and families about lack of access to timely, informative information.

Patients should be able to access information as they choose, not as prescribed by a health professional.

There is the possibility that some people may misuse or misunderstand library information. But then there is a lot that don't understand the doctor either because they don't always take time to fully inform their patients. (Manager, geriatric hospital)



### ***Role of the medical professional in providing information***

Respondents also further emphasised the importance of health professionals as the most appropriate source of patient information. A librarian working in a patient information facility commented:

Our medical staff are in full agreement with patients being totally informed and having as much information as possible on their condition.

However, it is not always possible to provide all the information that patients may need to fully achieve informed consent. A clinical manager in a public hospital commented:

In my view there is not enough time to give adequate information to some hospital patients. With minimal staffing levels, options and decisions to be considered are made with minimal information.

It was often felt that health professionals should also have the role of filtering out inappropriate information. The library manager of a patient information facility commented:

The policy of this hospital is that all patient information be supplied via a health professional for screening purposes.

Printed medical information can be seen as an effective supplement to the patient-doctor interaction. A clinical resource nurse believed information is:

usually more effective when the printed information is given to support the explanation of the condition and the treatment.

A staff librarian in a rural public hospital commented that:

They (medical staff) would need to be a back-up source of information for when patients needed further information or clarification of information.

The personal nature of the doctor-patient interaction is also seen as desirable. A clinical manager in a public facility said:

People want a 'face' when they ask questions and will want to reflect and evaluate their decisions based on information given.

### ***Criticisms of health professionals and patient interactions***

There was considerable concern over the fact that not all health professionals currently fulfil the information needs of their patients:

Doctors are often too busy or may only give their view. (Nurse Care Coordinator, private hospital)

Health care professionals should provide information to the patients — but they don't! (General Manager, hospice)

Often judgement must be used in the amount of time that information is offered. Health professionals can abuse this, but often they are in the best position (with exclusive knowledge of their patients/residents) to know the right time/right information. (Nurse Manager, partially public funded hospital)

Some doctors give out very good information. Some none at all. (Support Services Coordinator, private hospital)

Because medical staff have such a 'closed shop' mentality, care would be needed when setting up a patient information centre, that their cooperation was given, and that they didn't feel threatened. (Staff Librarian, public hospital)

### ***Nurses and allied health professionals***

Nurses were also seen as having a crucial role in providing access to information. In smaller hospitals in particular, nursing staff often hold the physical key to the resources available within the hospital, and may also offer to interpret the information provided. In a public consumer health service a staff member commented that:

...nursing development team would have their own budget and consumer info is a large part of their job.

This was also acknowledged in situations where patients could not express their own needs clearly:

Many of our patients are unable to read and the staff must often be both their eyes and their advocate. (Nurse/Manager, mainly private geriatric hospital)

A principal nurse manager in a private hospital commented that:

Often things need to be discussed, that are read, so hence feel it is more appropriate, through a health team member, but people still have the right to access libraries of their own free will even if they don't understand all they read.

This comment alludes to a juggling act for health-care professionals who want to help patients to understand but also know there is potential for confusion during the research process.

### ***Medical library patient access***

A range of views exists on whether a hospital library is the most appropriate place for consumer health information. Some, such as this public hospital medical librarian, believe that medical information should not be made available to patients:

Patients shouldn't have access to the medical library but should have a small room with appropriate material e.g. books, pamphlets available written in terms they can understand.

This view is partly endorsed by a medical librarian when talking of her own collection: 'some pamphlets are too simple and the medical literature too complex.'

There is also concern about both patients and clinicians using the same research facilities. This view is most clearly expressed in the following comment from the manager of a private hospital:

Having worked in a large metropolitan teaching hospital, it would be inappropriate to have patients sharing a medical library with health professionals — i.e. conflict of interest, trying to seek curbside advice etc.

This nurse manager in a small public hospital agreed:

The type of material held in a public library is quite different to that held in a medical library — a medical library should not have unrestricted access to all members of the public, but some material could be available with supervision from the patient's medical advisor. Maybe written authorisation of access would be appropriate in some cases.

This is not an issue for others, as this hospice administration director demonstrates:

We would recommend that hospital libraries cater for patients and families alongside the needs of health professionals.

Another public hospital library manager considered that this service would be acceptable if funds were available:

Many medical libraries would like to be able to provide a service to patients but are constrained by lack of staffing and physical resources. There also needs to be a willingness on the part of medical staff to be involved in assisting with determining what sorts of information are appropriate and to devolve this service to health information professionals.

This theme was echoed by another library manager:

I cannot think a patient information service can be based in a hospital library without considering resources in both library staff and resources. I have found that where I have assisted the public, they need considerable library support (1–2 hours) to find their way around the literature...

Ad hoc services were frequently mentioned by librarians:

Although our policy is to provide health information to consumers when requested it is not well advertised.

The coordinator of a consumer information service argued that:

A lot of health consumers never actually enter a hospital and yet they should still have access to information, so hospital information centres should also serve the general public and work closely with the public libraries.

Although patients' access to hospital libraries can be good, it is not so for an increasing number of people undergoing medical treatment as outpatients, or for those who are cared for in the community by their GP. The issue of access is still, therefore, of concern for these groups.

Pullon says that it is unrealistic to expect an ill person to undertake sufficient research to allow informed consent, particularly in the unfamiliar environment of a hospital. In addition, Harris comments that hospitals are seen as being under the control of the medical profession, and health consumers not currently under hospital care may not expect to find consumer health information within a hospital environment.

The range of comments that have been made on the issues covered by this survey provide valuable food for thought. This survey has provided an excellent opportunity to canvass opinion on these issues. While no clear direction has been established, the responses provide useful material for the future.

## *Discussion*

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There is an increasing public demand for information about health, but provision of services by hospitals varies widely. Although many medical professionals are effectively meeting the challenge to fully inform their patients, this is not a universal practice as yet. Patients can require more information than is provided within the confines of medical consultations, and many hospitals responding to our survey made some acknowledgement of this.

Although there are a number of successful initiatives for providing health information to consumers and their families in New Zealand, these are scattered throughout the country, and there is no national health information service available for everyone who may need it.

The rising cost of medical care has caused considerable pressure on the medical system in New Zealand and, partly as a result of this, the establishment of separate libraries to meet the needs of both professional and lay-persons may be less feasible. This possibility is also undermined by the existence of the Internet, with the expectation thus created of universal access to professional information. However, this study found concerns about the quality of information from the Internet, and demonstrates the need for consumer health information services.

Alternative methods for providing information to patients have been considered in some detail, often at the expense of each other. For example, a free phone helpline may be promoted at the expense of a library service. In reality there is a role for a combination of different services to suit different consumer needs and environments.

Until now, discussion of the provision of consumer health information services in New Zealand has been side-tracked by focusing on questions such as:

- Should information be provided at all?
- Should medical professionals be intermediaries?
- Who has ultimate responsibility for providing information?
- Which library type (public or medical) should be responsible?

Results from our survey provide interesting food for thought on these issues.

In 1973 Dunbar questioned how well the medical profession performed in providing information to the public, and concluded that they were not meeting

this requirement effectively. Nearly 30 years later, our survey has found that most respondents consider that physicians and other health-care professionals provide sufficient information for patients. However, a large group still have reservations, with over a third (37.1%) having some concerns about this statement. Each hospital type responding to our survey raised these concerns in a similar proportion.

Both the Code of Rights<sup>117</sup> and Medical Council statements<sup>118</sup> emphasise the need for doctors to convey information clearly. Individual comments also suggest that fully informed patients respond better to treatment. Legislation and medical guidelines have had an effect on practitioners in the years since Dunbar asked his question. However, the collective response and additional individual comments indicate that some medical staff may not be effectively meeting patient needs in this area.

Some specific groups need additional information about their state of health. For example, patients with doctors who are reluctant to supply sufficient information are more likely to require help to meet their information needs. Those who are not able to fully comprehend or absorb the information they are given during the medical consultation may also require assistance. There is also a significant group who want to be actively involved in their health care, and who may require considerable medical information on an ongoing basis in support of their goal of retaining control.

Just over a quarter (27.6%) of hospitals provide some form of library or information centre that can be accessed by patients, although the service offered varies widely. In some cases patients receive, from dedicated staff, a wide range of services including pamphlets, journals, books and electronic resources. The main purpose of other collections is recreational reading, although some health material may also be included. These results indicate that there is no uniformity in the information services that patients can access through their hospital and, in some cases, there is no service at all.

Nearly three-quarters of New Zealand hospitals do not provide a library or information service to patients. In most cases they try to provide information that would be suitable for at least some of their patients. Just under half of those without

LICs refer patients to books and videos, but the most common formats for information are pamphlets and articles. Contact details for support groups are frequently mentioned, and in many cases these would be a source for health information as well as support and assistance.

Even after a consultation is complete, most hospitals accept that patients may require reinforcement of the information they have been given, and hospitals themselves make at least some attempt to meet this need.

Consumer health resources produced primarily for patients (such as pamphlets and videos) are the most valuable source of information in the hospitals that offer information services. However, it appears that resources produced for nursing staff are also quite heavily used to provide information for patients. Where books are provided, for example, nursing books rather than consumer health titles are most commonly provided. This confirms La Rocco's view that nursing literature is an ideal source of consumer health information. La Rocco suggests this is because they provide more detail than many consumer health resources, but are written in clear and understandable language.<sup>119</sup> They thus serve two purposes within a hospital library collection, meeting the information needs of both patients and nursing staff.

Our results do not compare favourably with countries such as the United States. A 1990s survey of hospitals in the United States showed that 67 per cent of hospitals provided separate non-technical libraries for patients, while 58.1 per cent allowed public access to the main medical library without restriction.<sup>120</sup> A more recent survey by Hollander found that 98.4 per cent of publicly funded hospitals in the United States, while not necessarily actively promoting services to patients, did provide access to patients on demand.<sup>121</sup>

In her description of information services in Ireland, MacDougall says that, while there is an increasing demand for information, access to information is not adequate and services have been provided in an ad hoc fashion.<sup>122</sup> Her findings show similarities with the situation in New Zealand.

When asked about the most appropriate places for the patient to find medical information, our respondents overwhelmingly preferred physicians and other health-care professionals. Solomon also documented this expectation that medical consumers in New Zealand believe their physician to be the most appropriate source of information.<sup>123</sup> However, although physicians are the preferred information source, time and financial constraints limit the number of times that patients can access their services.

If the patient needs to go beyond his or her physician, the second preferred option amongst respondents was a library or information centre solely for patients and located within the hospital. While this option can be less accessible for patients who do not need to attend the hospital regularly (and for those who are cared for entirely in the community), the hospital environment was seen by many to be a suitable location for this service, particularly because the expertise

of health professionals can be used where necessary for additional information or clarification.

Public libraries were seen as another viable source of information, although two-thirds of those responding had some reservations. Several respondents suggested that public libraries should work with medical libraries to share resources and expertise.

These findings were also similar to those in Solomon's study, which found public libraries were the third-highest ranked choice for medical consumers, after physicians and self-help groups. However, medical consumers ranked medical libraries poorly in the Solomon study.<sup>124</sup>

Although the current study showed medical libraries to be almost equal with public libraries in ranking, a similar proportion of respondents indicated that they had some reservations with the medical library as a source of information. Comments in the second part of the results indicated some of their concerns, which include the technical nature of material held within medical libraries, concerns about librarians providing medical information (especially advice), and the matter of information overload. It is possible that a consumer health information service that specifically selects materials for patients is more likely to provide the information that is required at the level required. Medical libraries cannot make the same guarantee, as their resources are selected primarily to meet the information needs of medical professionals.

There were mixed views on the position that medical libraries are primarily for health-care professionals. Almost half (45.8%) felt this was the case, but only a slightly smaller proportion (39.5%) disagreed.

When hospitals refer patients to other organisations, the two most common referral points are physicians and support groups. However, it is interesting to note that hospitals *with* an information service dedicated to patients refer patients to the public library in nearly 80 per cent of cases, despite stated concerns about the public library as a source of health information. However, libraries who do *not* provide information services are much less likely to refer patients to their public library. While it is still a choice for referrals, overall only a third would make such a referral.

It is not clear why such a division exists between the two sectors. There may have been some liaison between public library services and hospital patient services, but such arrangements were rarely mentioned. It is also possible that staff in these patient centres are more aware of the resources held in public libraries and may feel more confident in making referrals. This issue may be a



suitable subject for further research.

For all hospitals responding, medical libraries were not a popular choice for referrals. No more than a third of patients would be referred by patient information services to medical libraries and, where no patient information service is provided, less than one-fifth would be referred to a medical library. This reflects the concerns about the medical library as a suitable resource for patient information needs.

The technical nature of medical information is an issue for many, with two-thirds (68%) of respondents indicating that they have concerns about this. The potential for misunderstanding can be an issue for all resources, although more technical and complex material may require more interpretive assistance. Internationally, however, there is an acceptance that, with increasing use of medical terminology within mainstream literature, and the increasing sophistication of medical consumers, problems with the technical nature of materials may be diminishing, and may have been overestimated in the first place. Hollander, for example, found that public access to MEDLINE via the Internet has resulted in a rise in searching overall, and estimates that a third of searches are conducted by consumers.<sup>125</sup>

Consumers do appear to find this online service useful, and a recent New Zealand study found that 71 per cent of GPs reported that their patients had sought medical information from the Internet.<sup>126</sup> While this figure does not relate specifically to Internet-based MEDLINE sites, they are likely to have had some impact. Pullon suggests that GPs are well suited to decoding information for patients,<sup>127</sup> and this skill can be applied to technical materials or misleading material derived from the Internet.

There is a danger of regarding the Internet as an answer to all consumer health information needs, but the solution is not that simple. This would be a good time to acknowledge the growing unease amongst the medical profession about patient access to information on the Internet and use it as a positive factor in establishing the need for consumer health information services. A recent article in the *New Zealand Medical Journal* reported that nearly 50 per cent of general practitioners surveyed expressed some anxiety about the Internet and its potential effects on the doctor/patient relationship.<sup>128</sup> The authors note that:

... perhaps the explosive growth of medical information via the Internet has shattered once and for all the fantasy of the all-knowing doctor. Doctors preparing to practice in the 21st century may find that patients are becoming less interested in GPs who impart 'book knowledge', and more interested in clinicians who will work together with them to make sense of the extensive information the patients already have.<sup>129</sup>

Additional comments from participants included an acceptance by many that, while librarians can provide medical information to patients, this should not extend to advice or interpretation. As Pullon also suggests, this is seen as the province of health professionals.

In 1990, New Zealand Department of Health guidelines argued that patients are just as important in the health-care team as are the doctors and nurses. Medical libraries provide literature and information in support of decision making, and services to patients are included within this decision process.<sup>130</sup>

There is scope for different interpretations of this matter. However, if concerns over the use of technical material are decreasing, and patients are taking a greater role in the decision-making process, there will be a requirement for patients to have good access to information resources. It may be that collaboration among public libraries,

hospitals and other interested organisations will meet this need. Such cooperation is in keeping with the international trend for partnerships as discussed in the literature review.

This is an opportunity for information management professionals, together with medical professionals, to take up the challenge of providing information services to patients. Eberhart-Phillips suggests that GPs will have to become information brokers in order to ensure that patients obtain accurate and appropriate information. This obviously has implications for resources (not to mention skill and expertise!) and it is time for information management professionals to claim responsibility for this specialist area.

Over half (53.7%) of respondents believed that hospitals should take on the additional responsibility for information services to patients, but there is some debate on the shape such a service should take. Some further comments argued for separate sections for patients within hospitals; others felt that access to medical library resources was acceptable. This issue needs to be resolved before an effective national service can be developed. Our research shows that concerns about funding for such a service remain: concerns that were mentioned in 1990 by those attending a HIANZ consumer health seminar,<sup>131</sup> and mentioned by Dunbar in 1973.<sup>132</sup> This issue must be tackled and solved collectively by interested parties.

Soar and colleagues suggested quality health information services may be more cost-effective and enhance provider performance. It would be useful to undertake further research to validate these claims. If Soar is proven correct, health funding agencies may be more likely to fund such information services.<sup>133</sup>

The difficulties of providing the most appropriate information for patients at the right level at the right time are recurring themes within this survey. However, there is also a strong view that patients need this information, and that they have a legal right to have their information needs satisfied. The survey and literature review show that, although some people can easily access the information that they need, many miss out.

Several groups have an interest in the effective provision of health information services to patients. These include the library associations LIANZA and HIANZ, as well as organisations such as the Ministry of Health, Medical Council of New Zealand, Royal College of General Practitioners and the New Zealand Medical Association. In addition to these there are myriad support and welfare groups currently offering information services to patients. It is crucial that there is agreement among all these groups on the best way forward for patient information. While there is a need to promote the services currently available on a regional basis, the greatest priority is to develop and implement an effective national strategy.

## *Recommendations*

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The provision of consumer health information services requires strategic planning and a national focus. Existing professional bodies (both in information management and health care) and consumer groups should be consulted as to future direction and, specifically, the implementation of our recommendations. We will inform organisations such as the office of the Health and Disability Commissioner, Ministry of Health, National Library, Medical Council of New Zealand, HIANZ and LIANZA about this research, as such organisations need to work together to achieve the following recommendations:

- Develop a model of information service provision based on a collaborative project approach. It is necessary to establish common ground by consensus and compromise in order to present a united front to press for action. There must be recognition of alternative, non-traditional library delivery in the final model.
- Trial a pilot project of the desired model.
- Establish new minimum standards for the library provision of consumer health information services. Standards should be detailed and address resourcing as well as materials and services.
- Build on the principles established in the Code of Rights to lobby for detailed consumer health information service policy at a national level. Incorporate information services to patients in quality programmes.
- Investigate the provision of targeted consumer health information in conjunction with patient-accessible electronic medical records. Overseas electronic records programmes that provide this type of additional information should be investigated and monitored.<sup>134</sup>
- Develop a national strategy to market services. New Zealand does not have an established tradition of any single type of organisation providing consumer health information, so marketing and promotion will be essential components of establishing and maintaining services. Solomon and Harris have shown that the general public has poor recognition of medical libraries as a source of information.
- Make full use of the expertise of health sciences librarians in establishing consumer health information services. Medical librarians play a key role in medical informatics. Their skills and knowledge should also be utilised in consumer health informatics.

- Undertake further study to emphasise the benefits of consumer health information services (particularly their cost-effectiveness) in terms of overall health costs.
- Build on the interest shown in this research project. Send an outline of results to respondents, and ask if they would like to be kept informed of further developments and/or be more actively involved. If individuals agree, a database of their names and contact details could be passed to HIANZ or any other interested group.

## End notes

- <sup>1</sup> Patrick, Koss, quoted in Deering, 210
- <sup>2</sup> New Zealand Health Information Service
- <sup>3</sup> *ibid*
- <sup>4</sup> *ibid*
- <sup>5</sup> National Minimum Standards for Health Services in New Zealand: 4
- <sup>6</sup> American Hospital Association
- <sup>7</sup> Moeller, 38
- <sup>8</sup> CAPHIS/MLA, 238
- <sup>9</sup> Hafner, 65
- <sup>10</sup> Wakeley, Foster, 126
- <sup>11</sup> *ibid*, 125
- <sup>12</sup> Hollander, 'Providing Health Information to the General Public,' 64
- <sup>13</sup> *ibid*, 67
- <sup>14</sup> Collins, Sasser, 65
- <sup>15</sup> *ibid*, 67
- <sup>16</sup> Hollander, 'Providing Health Information to the General Public,' 62
- <sup>17</sup> *ibid*, 67
- <sup>18</sup> Collins, Sasser, 60–61
- <sup>19</sup> Cain, Fuller, 263
- <sup>20</sup> La Rocco, 48
- <sup>21</sup> Eakin
- <sup>22</sup> Humphries, Kochi
- <sup>23</sup> Hollander, 'Consumer Health Information Partnerships,' 248
- <sup>24</sup> Calvano, Needham 253
- <sup>25</sup> Miller, Lacroix, Backus
- <sup>26</sup> National Library of Medicine
- <sup>27</sup> Earl, 44
- <sup>28</sup> Forrest, 275
- <sup>29</sup> Bolton, Brittain, 130
- <sup>30</sup> Gann, 'Consumer Health Information,' 64
- <sup>31</sup> United Kingdom, Department of Health
- <sup>32</sup> Ministry of Health, 'Experience of Overseas Healthlines,' 3
- <sup>33</sup> Buckland, Gann
- <sup>34</sup> Sweetland
- <sup>35</sup> Stevens, Morris, Rolinson, 353
- <sup>36</sup> MacDougall, 91
- <sup>37</sup> *ibid*, 94
- <sup>38</sup> Gann, 'Health Information for the Australian Public,' 124
- <sup>39</sup> Smith, Jill Buckley, 1
- <sup>40</sup> Walsh, 109
- <sup>41</sup> Johnson, 271
- <sup>42</sup> Eysenbach, 1713
- <sup>43</sup> *ibid*, 1716
- <sup>44</sup> Deering, 215
- <sup>45</sup> Ronnie, 295
- <sup>46</sup> Dunbar, 382
- <sup>47</sup> *ibid*, 382
- <sup>48</sup> *ibid*, 384
- <sup>49</sup> NZLA, 'Submissions to the Caucus Committee on Hospital Services,' 198
- <sup>50</sup> Rimmer, 41
- <sup>51</sup> *Standards for Library Services in Health Authorities*, 1.3–4, 2
- <sup>52</sup> *ibid*, 3.3, 6
- <sup>53</sup> *ibid*, 5.21, 10
- <sup>54</sup> Jamieson, 78
- <sup>55</sup> Dewe, 137
- <sup>56</sup> Hodgson, 8
- <sup>57</sup> *ibid*, 17
- <sup>58</sup> Dewe, 137
- <sup>59</sup> Mosley, 9
- <sup>60</sup> Harris, 'Informing the Public About Health and Sicknes,' 76

- <sup>61</sup> *Report of the Cervical Cancer Inquiry*, 136
- <sup>62</sup> *ibid*, 137
- <sup>63</sup> 'Aims and Objectives,' 3
- <sup>64</sup> Mosley, 9
- <sup>65</sup> 'Minutes of the Annual General Meeting: Consumer Health Information Initiatives,' *HIANZ News*, no. 5 (1990), 17–18
- <sup>66</sup> Mosley, 9
- <sup>67</sup> *ibid*, 9
- <sup>68</sup> *ibid*, 9
- <sup>69</sup> *ibid*, 9
- <sup>70</sup> HIANZ, *National Minimum Standards for Health Library Services in New Zealand*, 4
- <sup>71</sup> New Zealand, Department of Health, *A Model for Health Sector Services*, 5
- <sup>72</sup> *ibid*, 6
- <sup>73</sup> *ibid*, 6
- <sup>74</sup> *ibid*, 7
- <sup>75</sup> Harris, *A Question of Health*, 11
- <sup>76</sup> Townsend, 15
- <sup>77</sup> Medical Council of New Zealand, *Statement for the Medical Profession on Information and Consent*, 1
- <sup>78</sup> 'Informed consent,' 95
- <sup>79</sup> Pullon, 26
- <sup>80</sup> *ibid*, 26
- <sup>81</sup> *ibid*, 27
- <sup>82</sup> Soar, 22
- <sup>83</sup> Cullen, 39
- <sup>84</sup> Solomon, 82–88
- <sup>85</sup> *ibid*, 86–7
- <sup>86</sup> *ibid*, 87
- <sup>87</sup> *ibid*, 87
- <sup>88</sup> *ibid*, 88
- <sup>89</sup> Jessup, G:1
- <sup>90</sup> Robertson, 6–7
- <sup>91</sup> 'Minutes of the Annual General Meeting: Consumer Health Information Initiatives' *HIANZ News*, no. 5 (1990):17
- <sup>92</sup> Gibson Smith, 4
- <sup>93</sup> 'The Parent and Family Resource Centre,' [5?]
- <sup>94</sup> Parkinson, 11
- <sup>95</sup> *Health Information for Women Unit* [pamphlet]
- <sup>96</sup> 'This is IT: Health Goes Online with Useful Guide,' 3
- <sup>97</sup> 'This is IT: Every Body: Health Information for Every Body,' 5
- <sup>98</sup> *Burwood: Leading the World in Rehabilitation* [pamphlet]
- <sup>99</sup> Ministry of Health, 'Healthline Factsheet,' 1
- <sup>100</sup> *ibid*, 2
- <sup>101</sup> HIANZ, 'Submission to Health and Disability Commission,' 2–3
- <sup>102</sup> Health and Disability Commissioner
- <sup>103</sup> Eberhart-Phillips, 135
- <sup>104</sup> *ibid*, 136
- <sup>105</sup> Jarvis, 1
- <sup>106</sup> *ibid*, 1
- <sup>107</sup> Soar, 23
- <sup>108</sup> Ministry of Health, *New Zealand Health Strategy 2000*, 26
- <sup>109</sup> Johnson, 271
- <sup>110</sup> La Rocco, 48
- <sup>111</sup> Cain and Fuller, 261
- <sup>112</sup> Johnson, 271
- <sup>113</sup> New Zealand, Department of Health, *A Model for Health Sector Services*, 6
- <sup>114</sup> Pullon, 26
- <sup>115</sup> Harris, *A Question of Health*, 11
- <sup>116</sup> Dunbar, 384
- <sup>117</sup> Health and Disability Commissioner
- <sup>118</sup> 'Informed Consent,' 95
- <sup>119</sup> La Rocco, 48
- <sup>120</sup> Hafner, 65
- <sup>121</sup> Hollander, 'Providing Health Information to the Medical Public,' 64
- <sup>122</sup> MacDougall, 91

- <sup>123</sup> Solomon, 86–7
- <sup>124</sup> Solomon, 82–8
- <sup>125</sup> Hollander, 'Providing Health Information to the General Public,' 62
- <sup>126</sup> Eberhart-Phillips et al, 136
- <sup>127</sup> Pullon, 27
- <sup>128</sup> Eberhart-Phillips, 136
- <sup>129</sup> Eberhart-Phillips, 137
- <sup>130</sup> New Zealand, Department of Health, *A Model for Health Sector Services*, 6
- <sup>131</sup> Mosley, 9
- <sup>132</sup> Dunbar, 382
- <sup>133</sup> Soar, 22–3
- <sup>134</sup> see, for example: <[www.aboutmyhealth.net/aboutmyhealth/tour/index.html](http://www.aboutmyhealth.net/aboutmyhealth/tour/index.html)>



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# ***Appendix: The Questionnaire***



## Hospital Patient Information Facilities

Please tick boxes unless otherwise specified:

### SECTION A

1. Name of Hospital \_\_\_\_\_

2. Your name \_\_\_\_\_

3. Your position \_\_\_\_\_

4. Phone number (04) \_\_\_\_\_ Email \_\_\_\_\_

5. This hospital is

Publicly funded  Privately funded

Other (please specify) \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

6. The hospital has treatment facilities for:

Inpatients  Daypatients  Outpatients

7. The hospital has  (please enter number) of beds

8. In this hospital a library or information centre is provided for:

	Yes	No	N/A
Nursing Staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physicians	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical Students	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Allied Health professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other (please specify) \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

9. Does the hospital provide information for patients via an in-house library/information centre?

Yes  No

**If YES, please continue with Section B. If NO, please turn to Section C.**

## SECTION B: Library/Information Centre (LIC)

10. Sufficient patient information is provided by a doctor or other caregiver during consultation.

1 = Strongly agree

2 = Agree

3 = Undecided

4 = Disagree

5 = Strongly disagree

1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11. The library or information centre (LIC) which serves patients is called:

---

12. The LIC is part of or reports to:

*(enter Dept or Section name)*

13 Please tick the kinds of materials provided for patient use. Note: 'medical' refers to information that is intended primarily for use by physicians; 'nursing' refers to information that is intended primarily for nurses; 'consumer health information' refers to information written or intended primarily for patients.

	<b>Type of Material</b>		
	Medical	Nursing	Consumer health information
Books	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Journals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Magazines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Videos	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Audio Tapes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pamphlets	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Electronic resources	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other *(please specify)* \_\_\_\_\_

---

14. Please indicate the services provided for patients:

	Yes	No
Assistance locating materials	<input type="checkbox"/>	<input type="checkbox"/>
Comprehensive reference services (eg MEDLINE searches)	<input type="checkbox"/>	<input type="checkbox"/>
Document delivery or inter-library loans (eg copies of articles from other libraries)	<input type="checkbox"/>	<input type="checkbox"/>
Loan of materials (eg check-out books)	<input type="checkbox"/>	<input type="checkbox"/>
Internet access	<input type="checkbox"/>	<input type="checkbox"/>
Support group contact details	<input type="checkbox"/>	<input type="checkbox"/>
Photocopying facilities	<input type="checkbox"/>	<input type="checkbox"/>

Other *(please specify)* \_\_\_\_\_

---

15. The LIC provides the patient with information that reflects the following viewpoints or practices of medicine:

	Yes	No	Sometimes
Conventional or orthodox medicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alternative of complementary healthcare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify) _____			
_____			
_____			

16. The LIC may be used by:

	Yes	No	N/A
Inpatients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Daypatients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Outpatients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family members of patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General public	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify) _____			
_____			
_____			

17. Are access restrictions (eg only with physician authorisation) applied to any of the patient user groups?

	Yes	No	Sometimes
Inpatients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Daypatients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Outpatients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family members of patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify) _____			
_____			
_____			

18. The LIC is staffed  hours per week, and this includes:

	Yes	No
Weekdays	<input type="checkbox"/>	<input type="checkbox"/>
Evenings	<input type="checkbox"/>	<input type="checkbox"/>
Weekends	<input type="checkbox"/>	<input type="checkbox"/>
Other staffing arrangement (please specify) _____		
_____		
_____		

19. There is 24 hour access for

	Yes	No	N/A
Inpatients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Daypatients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Outpatients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family members of patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)	_____		
	_____		
	_____		

20. Please state how many members of staff there are for the LIC:

There are  full-time employees working in the LIC

There are  part-time employees working in the LIC

There are  volunteers working in the LIC

21. Qualifications of LIC Staff

	Yes	No. of staff
Library qualifications	<input type="checkbox"/>	<input type="text"/>
Nursing qualifications	<input type="checkbox"/>	<input type="text"/>
Other relevant qualifications (please specify)	_____	
	_____	
	_____	

## Liaison

22. Does the LIC provide information to patients in conjunction with any other hospital department?

	Yes	No
	<input type="checkbox"/>	<input type="checkbox"/>
If yes, please explain	_____	
	_____	
	_____	

23. Do hospital staff refer patients to the LIC?

Frequently	Sometimes	Never
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

24. Input by health care professionals (doctors/nurses etc.) into LIC collection/services includes:

	Frequently	Sometimes	Never
Suggesting purchases	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Approving purchases	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Identifying material no longer required	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clarifying information requests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify) _____			
_____			
_____			

25. Are there other patient information services in the hospital in addition to the LIC?

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>
If yes, please explain _____	
_____	
_____	

26. Is there central coordination of all patient information programmes?

Yes	No	N/A
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If yes, please explain _____		
_____		
_____		

27. If patients require further information, we refer them to the following:

	Frequently	Sometimes	Never
Public Library	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialty library (eg IHC)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other medical library	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Internet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify) _____			
_____			
_____			

28. We have a formal service agreement with another library

Yes	No	N/A
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If yes, please specify _____		
_____		
_____		

## Funding

29. This LIC is funded by:

	Yes	No	Partially
Health funding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Authority (direct allocation)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Internal hospital funding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Charitable donations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fee for service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other (please specify): \_\_\_\_\_

30. 'Patient information' is a separate line item in the LIC budget:

Yes	No	N/A	Don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

31. Patient information has its own budget:

Yes	No	N/A	Don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Thank you for completing Section B, now please go to Section D.**

## SECTION C: Answer these questions if you DO NOT have a library/information centre in this hospital

32. Sufficient patient information is provided by a doctor or other caregiver during consultation.

1 = Strongly agree

2 = Agree

3 = Undecided

4 = Disagree

5 = Strongly disagree

1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

33. If patients require further information, we refer them to the following:

	Frequently	Sometimes	Never
Public Library	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialty library (eg IHC)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other medical library	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Internet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other (please specify) \_\_\_\_\_



34. Does your hospital have a formal service agreement with a library?

Yes    No    N/A  
       

If yes, please specify \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

35. Physicians and/or other healthcare professionals provide patients with the following types of information:

	Frequently	Sometimes	Never
Books	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Copies of articles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Videos	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Addresses of support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pamphlets	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify) _____			
_____			
_____			

**Thank you for completing Section C, now please go to Section D.**

**SECTION D: This section to be completed by ALL respondents**

36. Your opinion matters! Please indicate whether you agree or disagree with the following statements by circling the number which most closely reflects your opinion:

- 1 = Strongly agree
- 2 = Agree
- 3 = Undecided
- 4 = Disagree
- 5 = Strongly disagree

A librarian should not provide information to patients because librarians have no medical training	1	2	3	4	5
Health professionals, not librarians should provide information to patients	1	2	3	4	5
Medical literature can be too technical for patients to understand	1	2	3	4	5
Patients may misuse or misunderstand the information given to them	1	2	3	4	5
Medical and hospital libraries are primarily for the use of health care professionals	1	2	3	4	5
Hospital libraries should not take on the additional responsibility of providing information to patients	1	2	3	4	5

