

**Information Matters:
How do consumers
find out about pharmaceuticals?**

Report to the Ministry of Health

by

**Health Services Research Centre
Victoria University of Wellington**

**with
The Family Centre Social Policy Research Unit**

November 2004

Research Team

Research and writing

Marie Russell, Health Services Research Centre, Victoria University of Wellington
Peter King, Family Centre Social Policy Research Unit
Pauline Norris, School of Pharmacy, University of Otago
Brian Field, Student, Victoria University of Wellington
Hilary Stace, Health Services Research Centre, Victoria University of Wellington

Focus group facilitators

Flora Tuhaka, Family Centre
Kiwi Tamasese, Family Centre
Kasia Waldegrave, Family Centre

Other research team members

Marianna Churchward, Health Services Research Centre, Victoria University of Wellington
Tangihaere Walker, Family Centre

Acknowledgements

The researchers wish to acknowledge and warmly thank the people who took part in the focus groups for their time and contribution.

The Team also acknowledges:

Stephen Lungley and Saskia Patton of the Ministry of Health
The Director and staff of the Health Services Research Centre
Staff at Victoria University Library
Anonymous referees who reviewed and commented on the draft report
Ministry of Health editors.

Inquiries contact

Health Services Research Centre
Victoria University of Wellington
PO Box 600
Wellington
Ph: 04 463 6565
Email: hsrc@vuw.ac.nz

Citation: Health Services Research Centre, Victoria University of Wellington
and the Family Centre Social Policy Research Unit. 2005.

Information Matters: How do consumers find out about pharmaceuticals?
Report to the Ministry of Health, November 2004. Wellington: Ministry of Health.

Submitted in November 2004, published in December 2005 by the Ministry of Health, PO Box
5013, Wellington, New Zealand

ISBN 0-478-29608-8 (Book)
ISBN 0-478-29611-8 (Internet)

HP 4128 This document is available on the Ministry of Health's website: <http://www.moh.govt.nz>

Contents

Research Team	ii
Research and writing	ii
Focus group facilitators	ii
Other research team members	ii
Acknowledgements	ii
Inquiries contact	ii
Executive Summary	iv
Research brief	iv
Qualitative research findings	iv
Literature review	v
Focus group research	v
Introduction and Background	1
Literature Review	3
Method	3
Focus Groups	5
The focus group method	5
The six focus groups	6
Findings	7
Information is an important part of health services; there are many sources of information	7
More needs to be understood about information for consumers	8
Doctors and pharmacists are the most frequently used sources of information	9
Doctors	10
Pharmacists	12
Other health professionals	13
Advertising	14
The Internet	17
Libraries	18
Self-help groups, non-government providers, family and friends	19
Other media: magazines and radio	21
Information leaflets	22
Help lines	24
Information about complementary, alternative and traditional treatments	25
Different types of consumers	26
Ethnicity	26
Rural residents	28
Summary	29
Literature review	29
Conclusions	30
References	32
Appendices	
Appendix 1: Information sources identified by focus group participants	40
Appendix 2: Semi-structured interview schedule for focus groups	43

Executive Summary

Research brief

Information for consumers about health, illness and treatment is an important part of health services. In December 2003, the Ministry of Health (the Ministry) invited proposals for a study about choice of information sources on pharmaceuticals and related treatments by consumers. The Ministry was seeking qualitative research to add depth of understanding to existing quantitative information. The research was to “inform the development of policy by the Ministry on the sources of information available to consumers”.

The Ministry required a report that gave the research sample’s response to: “the various sources of information that consumers currently use in general to inform themselves, for example TV shows, advice from professionals, direct-to-consumer advertising (DTCA) or web-based information; the sources of information they currently use on pharmaceuticals and related treatments; the content and level of information required and accessed; variations between individuals or groups where such variations appear consistent rather than random, and the reasons for this; the sources of information on pharmaceuticals and related treatments used and that they would like to use; and the level of trust in different types of information and information providers”.

The report includes material from two main sources: a literature review and a report about six focus groups based on a range of demographic variables. Staff at the Family Centre Social Policy Research Unit undertook the focus group fieldwork, analysis and reporting. Ethical approval was obtained for the focus group interviews from the Wellington Regional Ethics Committee (04/03/018). The rest of the report was prepared by the Health Services Research Centre, Victoria University of Wellington (Marie Russell, Brian Field, Marianna Churchward); and Pauline Norris of the School of Pharmacy, University of Otago.

Qualitative research findings

- Consumers show clear preference for information to be provided by medical and health professionals.
- Consumers prefer verbal information followed up by written information from the same source.
- Health professionals or health related organisations such as the Cancer Society are seen as the most reliable sources of information.
- Consumers want information on side effects, cost, reliability and content of medicines.

While an extremely wide range and large number of sources of information (201) were identified by the focus groups, there was a clear preference for information to be provided by medical and health professionals. This preference, which came through in the overall discussion, was reinforced when people were asked specifically about how they would prefer to receive information. The responses to this question revealed a widely shared preference for receiving information from a health professional of some kind and for this information to be received verbally initially and for the verbal information to be followed up with written information in the form of a pamphlet or booklet also provided by the health professional. This finding is in general accord with the international literature. Preferences were expressed for detailed and comprehensive information about the side effects, cost, reliability and content of medicines and treatments. It was important to people that information about medicines and treatments be accessible and understandable and, where necessary, available in different languages.

The preference for information to be provided by medical and health professionals (in some cases through health-related organisations such as the Cancer Society, for example) was associated with the view that there needed to be assurance that the information would be accurate and reliable. The concerns expressed about other sources of information, such as the popular media, the Internet, friends and family, were really based on uncertainty about the accuracy, reliability and potential bias of the information and the motives of those providing the information.

The discussion includes implications for practice and research.

Literature review

- A wide range of databases was searched for New Zealand and overseas material, using key terms.
- Published literature, quantitative reports, government reports and unpublished material were included in the review.
- Most information included in the review was published since 1990.

The review selected relevant, available New Zealand information and overseas material. The Ministry of Health's provision of useful materials is acknowledged. This review is not a systematic review of literature; some relevant information may have been missed.

The research took place in the context of expanding sources of information, especially through the Internet, advertising by pharmaceutical companies and the development of complementary and alternative treatments. It took place against the background of recent health system reforms, in a sector that includes a broad range of stakeholders.

In this context of change and expanding information sources, the international and New Zealand literature shows that the traditional providers, doctors and pharmacists, generally remain the most used and trusted sources. They are responsible for prescribing and dispensing prescription and non-prescription medicines, but there are demographic variations in use of these primary health providers and in access to and use of sources of health information as well. Existing inequalities based on ethnicity, income and literacy are of concern. The New Zealand literature shows that those who are missing out in the area of health in general are less well served in terms of information sources about pharmaceuticals and related treatments.

Focus group research

- Six focus groups covered a range of ages and ethnicity as well as rural and urban residents.
- Group interaction encouraged in-depth discussion of issues.

Six focus groups were convened in the first part of 2004, comprising:

- Older people aged 65 and above (eight members)
- Māori adults (seven members)
- Pasifika adults (eight members)
- Pākehā adults (nine members)
- Rural adults (nine members)
- Young people aged between 16 and 24 (eight members).

People of the appropriate ethnicity facilitated the three ethnically specific groups. The groups composed of older people, rural adults and young people were not ethnically specific and were facilitated by a Pākehā researcher.

The focus group discussions were guided by facilitators, who followed a semi-structured interview schedule that was designed to find out:

- where people obtain information about things, in general, and medical matters, in particular
- people's views about different information sources
- where people would like to be able to obtain information
- what format people would like the information to take.

Introduction and Background

In December 2003, the Ministry of Health invited proposals for a study about consumers' choice of information sources on pharmaceuticals and related treatments.

The Ministry of Health noted that it “recognises that consumers need balanced and useful information on pharmaceuticals and related treatments. Satisfactory access to consumer health information can improve health, reduce costs and is a basic consumer right.” The New Zealand Health Strategy (Minister of Health 2000) notes the importance of providing consumer health information in “empowering individuals and their families to manage their own health better”. The New Zealand Health Strategy notes a proposed Health Knowledge Strategy with a vision that includes “all the accurate information you could possibly want (and which you are allowed to have), when you want it, and how you want it, to ensure quality care” (Minister of Health 2000: 39). The strategy focuses on the broader health sector's information capacity rather than consumer health information, and the Health Information Management and Technology Plan was published as the report on the WAVE project (WAVE: Working to Add Value through E-information) (WAVE Advisory Board 2001).

The Ministry of Health also noted the existence of quantitative information available about sources of information for consumers, including the 2002/03 New Zealand Health Survey (Ministry of Health 2004a) and a 2003 survey by Colmar Brunton for the Christchurch School of Medicine (Colmar Brunton 2003).

The Ministry of Health was seeking “additional qualitative information to add depth of understanding to the information already available”. The report was to “inform the development of policy by the Ministry on the sources of information available to consumers”. The research was to report on the “sources of information that consumers use, would like to use and that they trust when they are seeking information on pharmaceuticals and related treatments”. The Ministry of Health required a literature review and qualitative data collection and suggested that focus groups based on a range of demographic variables be used.

The Ministry of Health required a report that gave the research sample's response to:

- “the various sources of information that consumers currently use in general to inform themselves, for example TV shows, advice from professionals, DTCA or web-based information;
- the sources of information they currently use on pharmaceuticals and related treatments;
- the content and level of information required and accessed;
- variations between individuals or groups where such variations appear consistent rather than random, and the reasons for this;
- the sources of information on pharmaceuticals and related treatments used and that they would like to use; and
- the level of trust in different types of information and information providers”.

Existing sources of information initially identified by the Ministry of Health included public health units, Medinfo, patient information groups, pharmacists, the Internet, DTCA by pharmaceutical manufacturers, various media and printed sources and consumers' friends and other people with similar health conditions.

The government also provides general health information, for example through HealthEd (Ministry of Health) and public health education campaigns. Information specifically about therapeutic products is delivered via Medsafe, New Zealand Medicines and Medical Devices Safety Authority, which is responsible for regulating therapeutic products in New Zealand. There are also telephone triage and help lines, for example, Healthline (Ministry of Health). Other agencies also provide information, for example, District Health Boards (DHBs) and Primary Health Organisations (PHOs), set up under the New Zealand Public Health and Disability Act 2000. Government health information is available through a range of institutions, including schools and pre-schools and primary health care providers.

Non-government and community organisations provide services and/or information either to specific population groups, for example the Royal New Zealand Plunket Society (mothers and babies); Māori health care providers; or to “condition” groups, for example, Cancer Society of New Zealand Inc; National Heart Foundation of New Zealand.

Other issues of interest, research and debate in the consumer health information environment include the following.

- Direct-to-consumer advertising (DTCA) and other prescription drugs promotion and debate about the appropriateness of DTCA (Saunders 2003; Toop et al 2003). New Zealand and the United States are the only two OECD countries that permit DTCA of prescription drugs
- The increasing medicalisation of normal life experiences and social problems (Coney 2002; Moynihan et al 2002; Toop et al 2003), where “the only solution offered ... is a medical one: visiting the doctor and obtaining a prescription” (Coney 2002: 221). Contrasting aspects of the argument that DTCA is medicalising normal human experience are given by Mintzes et al (2002) and Bonaccorso and Sturchio (2002)
- Promotion of self-care, for example in the New Zealand Health Strategy and other government strategies
- Increased opportunities for consumers to access a wide range of information sources; for example, through the growth and availability of Internet websites
- Patients’ reservations about pharmaceuticals and standard medical practice (Benson and Britten 2002)
- Growing interest in complementary and alternative medicine (CAM) and treatments. According to the Ministry of Health’s 2002/3 national health survey “one in four adults ... had seen a CAM health care provider in the last 12 months” (Ministry of Health 2004a).

For this project there were two main phases, a review of literature and interviews of focus groups. Ethical approval was obtained for the focus group interviews from the Wellington Regional Ethics Committee (04/03/018).

Staff at the Lower Hutt-based Family Centre Social Policy Research Unit (Peter King, Flora Tuhaka, Kiwi Tamasese, Kasia Waldegrave) organised, conducted, analysed and reported on the meetings of focus groups. The rest of the report was prepared by the Health Services Research Centre, Victoria University of Wellington (Marie Russell, Brian Field, Hilary Stace, Marianna Churchward) and Pauline Norris of the School of Pharmacy, University of Otago.

Literature Review

- A wide range of databases was searched for New Zealand and overseas material, using key terms.
- Published literature, quantitative reports, government reports and unpublished material were included in the review.
- Most information included in the review was produced since 1990.

Method

The team undertook a brief literature search and review on the sources of information that consumers use when seeking information about pharmaceuticals and related treatments. This was not a systematic review encompassing critical appraisal of the literature; rather a selection was made of relevant, available New Zealand information and overseas material that might shed light on the topics listed by the Ministry of Health. The contract with the Ministry of Health specified a literature review to “identify and summarise the available information, which addresses the Research Questions” from published literature (peer reviewed and other); existing quantitative reports; appropriate Ministry reports and other unpublished New Zealand material.

The team had some literature already to hand and completed a search in May 2004 to update this collection. This revealed a large literature on particular aspects of the topic, for example, on DTCA, and as this has been controversial in New Zealand recently, some detail is included about the literature on this issue. Key terms used for database searches included: *consumer or patient; drug or drug information; information or access to information; patient information; pharmaceuticals.*

Databases searched, and sources approached, included:

- PubMed
- *British Medical Journal*
- Embase
- International Pharmaceutical Abstracts (IPA)
- National Bibliographic Database
- Index New Zealand
- Ministry of Health website
- New Zealand newspaper organisations
- New Zealand research companies
- Pharmaceutical companies
- Pharmac
- Medsafe
- Researched Medicines Industry Association of New Zealand.

Several hundred references were accessed and scanned for relevance. Time limits were not imposed, but few materials published before the 1990s were included, since the field has been in a state of rapid change, associated with technological developments. Searches focused on New Zealand, Australia, Canada and the United Kingdom, on the basis of broad similarities in medical practice and culture and health systems in these countries, but some United States literature was also reviewed, especially about DTCA.

We observed that the literature on consumer choice of information sources in New Zealand is not large. Much of the existing research in New Zealand specifically on consumer health information has been based in library studies or informatics (the study of gathering, sorting, retrieving, classifying and storing information). The topic lends itself to both quantitative and qualitative research methods, but the most commonly used methods for researching the topic here have been quantitative, particularly using random-sample telephone surveys. There is increasing reference in recent years to consumer health information in Ministry of Health strategies and reports.

The literature we have included presents a mix of large, quantitative survey reports and other smaller studies; examples of both are included from the international literature. The material is diverse and challenging to organise. The headings under which the material is arranged include: people and places that are sources of information (such as pharmacists), physical formats in which information is received by the consumer (for example, information leaflets) and generators of information (such as pharmaceutical companies through advertising). In some cases, data from the same report appear in several different places in the review.

Focus Groups

- Six focus groups covered a range of ages and ethnicities as well as rural and urban residents.
- Group interaction encouraged in-depth discussion of issues.

The focus group method

There is an extensive literature on the advantages and disadvantages of different research methods for different topics, which we did not review because the Ministry of Health suggested a qualitative approach as the option to follow. As can be seen below, this approach provided insights when researching consumer health information, which quantitative methods have not been able to do.

It appears also that quantitative findings – naturally enough – very much reflect the disciplinary interests of the researchers. For example, Solomon (1996), who used library studies in her research, asked about consumer health information sources and included ‘library use’ in her results. In contrast, the Colmar Brunton survey for Christchurch School of Medicine (2003) did not offer such a source of health information in its multi-choice questions. This underlines the need for open-ended questions in qualitative research to discover the full range of consumers’ information behaviour. In a similar vein, a report from the United Kingdom suggests that “traditional patient satisfaction surveys” are much less valuable than “semi-structured interviews” in “... finding out what it is like to be a person with a particular condition” (Mahony 2003).

The focus group method was chosen for this study because focus groups allow for discussion at a more in-depth level than most research techniques allow (Stewart and Shamdasani 1990). The data and insights gained would have been less accessible without the interaction found in this method of interviewing (Morgan 1989). Another advantage of the method is that it facilitates systematic comparisons of an individual’s experience with those of others in their group (Krueger 1988; Morgan 1989) and the group context provides opportunities for clarifying responses, probing opinions, and following up questions (McLennan 1992). These all enable the topic to be discussed fully and the various points of view aired.

A focus group has a facilitator whose role is to loosely guide discussion, attempting to gather clear and useful responses while allowing the participants to contribute their ideas and observations. The facilitator undertakes to:

- make clear that they are not committed to a particular position on the questions introduced
- encourage the divergence of opinion and make clear that there is no pressure to agree or reach consensus
- ask open-ended questions
- actively ensure an equal opportunity for participation
- make use of probes and pauses to encourage participants to elaborate on initial comments
- summarise significant points made for clarification and agreement.

The six focus groups

Six focus groups were convened in the first half of 2004, and their compositions were as follows: Older people aged 65 and above (eight members), Māori adults (seven members), Pasifika adults (eight members), Pākehā adults (nine members), rural adults (nine members) and young people aged between 16 and 24 (eight members). The three ethnically specific groups were facilitated by people of the appropriate ethnicity. The groups comprising older people, rural adults and young people were not ethnically specific and were facilitated by a Pākehā researcher.

The focus group discussions were guided by facilitators who followed a semi-structured interview schedule that was designed to find out:

- where people obtain information about things, in general, and medical matters, in particular
- people's views about different information sources
- where people would like to be able to obtain information
- what format people would like the information to take.

The interview schedule was developed by the researchers in consultation with staff from the Ministry of Health. The interview schedule is attached as Appendix 2. To increase the specificity of responses, very short scenarios, or vignettes, were developed for the interview, questioning participants' likely behaviour in different circumstances. There are three main purposes in using vignettes of this kind: "to allow actions in context to be explored; to clarify people's judgements; and to provide a less personal ... way of exploring sensitive topics" (Barter and Renold 1999).

The focus group discussions were audio taped. The recordings were transcribed and analysed thematically. In the quotations that are included in this report, "F" precedes statements by the focus group facilitator, and "P" precedes statements made by a focus group member (participant).

Findings

Information is an important part of health services; there are many sources of information

- Many groups have an interest in information that forms a vital part of health services.
- Research indicates more needs to be understood about information for consumers.
- Doctors and pharmacists are the most frequently used sources of information.

There is official recognition in New Zealand that information for patients, including information about pharmaceuticals and related treatments, is an important component of health services. The New Zealand Health Strategy (Minister of Health 2000) and numerous other government strategies note the significance of good consumer information in promoting health and enabling citizens' appropriate self-care and participation in decision-making.

There are many stakeholders in consumer health information, representing a range of roles from users and recipients of information to providers and conduits of information. At times, stakeholders' interests compete or conflict (Canadian Medical Association Journal 2002; Hunter 2002; Herxheimer 2003). Stakeholders include:

- consumers
- central government – Ministry of Health and related agencies
- DHBs, hospitals
- not-for-profit community agencies
- health care provider organisations
- health professionals – both mainstream and alternative practitioners
- information professionals
- businesses:
 - pharmaceutical and treatment producers
 - community pharmacies
 - advertising companies
 - mass media companies.

In the focus group brainstorming sessions used to generate a list of information sources, participants listed 201 separate sources of information. Participants were invited to begin by naming any sources of information they used, whether these were for general information or for medical information. This was a warm-up exercise and was followed by a focus on sources of information about medicines and treatments specifically. In practice, the participants tended to focus on medical information from the beginning, and all of the sources discussed here were identified as being for medical information. Through coding, the 201 sources have been reduced to the following 19 broad categories under five broader headings: medical; complementary; personal contacts and other support; commercial; and media. The range of responses that has been collapsed into these categories is listed in full under the category headings in Appendix 1.

1 Medical

- Family doctor or GP
- Specialist
- GP practice nurse and other nurses
- Other health professionals
- Chemist or pharmacist

- Health services
- Information that comes with medicines
- Organisations like the Cancer Society and the National Heart Foundation

2 Complementary

- Traditional healers and remedies
- Alternative

3 Personal contacts and other support

- Family members
- Friends and associates
- Self-medication/treatment
- Other support groups

4 Commercial

- Information from retail and other commercial outlets (excludes pharmacies)

5 Media

- Internet
- Magazines etc
- Radio
- TV advertising and programmes

More needs to be understood about information for consumers

This report focuses on consumers, who, according to the literature, tend to see prescription drugs (Slovic et al 1991) and non-prescription medicines (Bissell et al 2000) as safe. They tend to think more about the benefits of medicines than any potential risks. This may lead consumers to underestimate the amount of information they need to make good decisions about medicines. Being informed about potential side effects of medicines, for example, may lead to better health outcomes. One United Kingdom case-control study found that patients who reported being better informed about the side-effects of non-steroidal anti-inflammatory treatment were less likely to suffer an acute gastrointestinal bleed, presumably because they were more likely to reduce their drug intake when they experienced symptoms (Wynne and Long 1996).

A more recent report from the United Kingdom (Dickinson and Raynor 2003) drew on earlier work with patients' information needs to show that consumers respond to "four essential aspects of a drug: side effects; what it does and what it's for; do's and don'ts; and how to take it" (Dickinson and Raynor 2003: 861). Trends in who is trusted as a source of information identified health professionals as "the most popular source of drug advice", with electronic sources becoming important, and friends and family "always popular". The authors described the aspects of an ideal source of drug information:

- "Accurate, up to date, reliable, and practically useful
- Accessible in language, format, and tone
- Capable of customisation or personalisation
- Available at different levels of detail at different times
- Informative about conditions as well as treatments
- Striking a balance between a treatment's beneficial and adverse effects
- Available at the time of a consultation and consistent with best advice

- Linked to other reliable and consistent sources of advice and information” (Dickinson and Raynor 2003: 861).

Focus group participants were asked what would be their ideal way of finding out about medicines and medical treatments. There was a widely shared preference for receiving information from a health professional of some kind, and for this information to be received verbally initially, and for the verbal information to be followed up with written information in the form of a pamphlet or booklet also provided by the health professional. Preferences were expressed for detailed and comprehensive information about the side effects, cost, reliability and content of medicines and treatments. It was important that information be accessible and understandable.

Over the past decade, there have been several calls for New Zealand to develop and improve consumer health information in terms of policy, practice and research (Bidwell 2001; Toop et al 2003; Harris 1996; Harris and Hutt 1996). The most recent call arose at the Independent Consumer Health Information Conference, Christchurch, 20–21 May 2004, where participants endorsed an end to direct-to-consumer advertising of pharmaceuticals and a national stocktake of consumer health information and sources. Some participants also expressed the need for existing information and services to be evaluated.

For the related area of health promotion, guidance is given in government and other publications on developing health promotion materials for different groups in New Zealand (Ministry of Health and Health Funding Authority 1995, 1997, 1996; Ministry of Health 1997; Health Promotion Forum – Runanga Whakapiki ake i te hauora o Aotearoa 2002). These prescriptive works are also likely to have a general application in the development of information resources for consumers. There is extensive advice available internationally on preparing, presenting and assessing consumer health information, for example, in a review by Barratt et al (2000) and through tools such as DISCERN (Charnock and Shepperd).

Doctors and pharmacists are the most frequently used sources of information

A key finding from the literature is that doctors and pharmacists are the most frequently used, and the most trusted, sources of information for health matters in general, and specifically for information about pharmaceuticals and related treatments. None of the literature we reviewed challenged this point of view.

In a 2003 telephone survey of 500 people by Colmar Brunton for the Christchurch School of Medicine, the researchers found that doctors and pharmacists were the chief sources of information about prescription medicines or other treatments (Colmar Brunton 2003). This result accords with findings elsewhere. A 2001 Australian study of the information-seeking behaviour of 786 randomly chosen adults explored information on medicine use, information seeking and satisfaction and the understanding of the information received. It found that overall doctors and pharmacists were the most frequently used sources of information (Newby et al 2001). The American National Pharmacy Consumer survey of the same year found that consumers ranked physicians and pharmacists as first and second respectively in terms of most important sources for drug information. Consumers were also more satisfied with information obtained from these sources than they were with information obtained from print or electronic information (Stergachis et al 2002), and this was considered to be directly associated with consumers’ actively seeking information from pharmacists.

In the focus groups, information from sources that can be described as being part of the medical mainstream comprised approximately half of the total discussion. The family general practitioner (GP) was generally regarded as the first place to go, but because of consultation cost the pharmacist was also considered a useful first port of call.

Doctors

- New Zealand consumers generally hold doctors in high regard.
- A high proportion of New Zealanders access doctors.

The opportunity to seek and receive information about pharmaceuticals and related treatments probably depends on treatment need and the frequency of contact with possible sources. In New Zealand as in other countries, the literature shows that GPs are consumers' prime choice as a source of health information, including information on pharmaceuticals.

Consumers in New Zealand generally hold doctors in high regard. The 2002 Commonwealth Fund International Health Policy Survey of Sicker Adults, a five-nation survey of 750 or more people in the United States, Canada, Australia, New Zealand and the United Kingdom (Blendon et al 2003), found that the New Zealanders gave their physicians high ratings compared with patients in the comparator countries. This was in spite of the New Zealanders' overall dissatisfaction with their health system as a whole.

In the large 2002/03 New Zealand Health Survey, with over 12,000 respondents (Ministry of Health 2003, 2004), 80% of people surveyed had visited a GP in the previous 12 months. There were variations in GP use according to demographic factors, for example, women were "significantly more likely than men to have visited their general practitioner in the previous year"; and Māori and Asian men were "less likely to visit their general practitioner than European/Other and Pacific men" (Ministry of Health 2003: 26).

New Zealand Health Survey respondents who had visited a GP in the previous year were asked: "Did the doctor write you a prescription on [respondent's latest] visit?" Provisional results showed an estimate of 69.2% (95% confidence interval (CI) 67.8%–70.5%) of those respondents who had visited a doctor had a prescription written at their latest visit (Ministry of Health 2004b). Variations in this result by age and ethnicity show Pacific and Asian people – who were less likely than others to have visited a GP – were more likely than others to have a prescription written: Pacific: 81.8% (95% CI 77.4%–86.1%); Asian: 74.9% (95% CI 70.2%–79.6%). People aged 55 and over were also more likely to receive prescriptions than younger adults. New Zealanders surveyed for the 2002/03 health survey who had not seen a GP when they needed to were asked why; the most common reason given (by nearly half this group) was that it cost too much (Ministry of Health 2004a).

In the Colmar Brunton survey conducted on behalf of the Christchurch School of Medicine (Colmar Brunton 2003), GPs were the most commonly used source of information about prescription medicines or other treatments and also the most trusted source. Sixty-nine percent of respondents had used a GP as a source for this type of information. For over half of respondents, their GP was the main source for this information (56%). Hospital doctors were also a source: 25% of the respondents had obtained prescription medicine or treatment information from such doctors. This is approximately the proportion to be expected: of the respondents to the 2002/03 New Zealand Health Survey, 26.3% of adults had used private or public hospital services in the previous year (Ministry of Health 2003: 25). In the Colmar Brunton survey (Colmar Brunton 2003), women and retired people were significantly more likely than other groups to use GPs as a source or main source of information.

People involved in providing health services and related information concurred that doctors are an appropriate source of information. Oliver and Bidwell (2001) undertook a survey to explore the provision of consumer information services by hospitals in New Zealand; 196 questionnaires were returned from a wide variety of people selected as representing a number of different sectors of the public and private hospital system. When asked who was the most appropriate source of comprehensive patient information, 72.4% named physicians as their first choice of appropriate source of patient information.

A telephone survey of 250 people over the age of 14 resident in Dunedin was carried out in 1996 (Solomon 1996) to assess what residents commonly think to utilise for health-related queries. The most likely source of health information named was the GP.

In 2004, a study reported on what a random sample of 450 Danish GPs tell their patients about side effects to common treatments (Krag et al 2004). The study found that the doctors were significantly more likely to spontaneously give side-effect information if they considered the side effects to be frequent than if they considered the side effects to be rare. Severity of side effects seemed to have no impact on the doctors' decision to give out information.

In the six focus groups, information from sources that can be described as being part of the medical mainstream comprised approximately half of the total discussion. The family doctor or GP was generally regarded as the first place to go for information (and treatment) about anything that seemed serious:

P: The doctor would be the essential one in the case of something of a serious nature, more serious – well of course straight hospital. (65+ group)

While the GP was regarded as a reliable source of information, the cost of consulting a GP was a disadvantage. This consideration led to the identification of the pharmacist as a second preferred port of call for information because the advice offered by a pharmacist will be free, while the person providing the advice is still a medical professional.

Views about hospital doctors were mixed and reflected people's personal experiences:

P: I could answer that in some degree, there is a specialist [?] at the [local] hospital where they deal with that, the asthmatic treatment and things like that, it is specialised to the use of the inhalers and tests and all sorts of things, they are very, very good. (65+ group)

Or, on the negative side:

P: I'm just saying that sometimes I have been given medication after surgery in hospital without a very adequate explanation of what the drug is. I think my worst experience was having a coronary; while I was actually having the coronary in the emergency section, having to sign a consent form for them to use a new kind of drug on me. It was three pages to read, and here was me trying to read it. That's true, you can ask my wife; she was there. I gave my consent, but I didn't have a clue what I was giving it to or for. (65+ group)

The information provided with medicines was regarded as potentially useful:

P: I find they are very good for information about what it does and if there are to be side effects, what you can expect and that sort of thing. More than trying to tell you this is a good drug, they tell you what it does and that sort of thing. (Rural group)

There were concerns, however, about its objectivity, in view of its purveyors, the drug companies and distributors, being perceived as having a vested interest in their product. There were also concerns about the difficulty of reading the material due to what was termed the "jargon" and being "blinded by science":

F: So sometimes they shower you with jargon?

P: Yes.

P: Should be simple; they blind you with science. (Rural group)

Medical specialists, while being identified as sources of information, were in the end discussed in the context of the treatment they provided. The need for a patient to be referred to them initially by another medical professional really ruled them out as people to go to for information in the first instance. Thus, unsurprisingly, specialists were not regarded as being very accessible:

P: I think my problem with specialists is that they are so inaccessible. You ring up for an appointment, you have to get it through your GP to start with, and sometimes when I have wanted to talk to my coronary specialist, oh, he is away, or you will have to wait.
(65+ group)

Pharmacists

- New Zealand consumers generally hold pharmacists in high regard.
- Many people use a pharmacist as their first stop for health information.

Studies of actual encounters between pharmacists and patients (in New Zealand and overseas) have found that a limited amount of information is actually exchanged in a pharmacy visit. Some of the studies describe interactions with real customers (Livingstone 1996), while others have used “mystery shoppers” (Anon 1996; Norris 2002). Norris’s research on pharmacists’ counselling of consumers when selling restricted medicines, for example, found that pharmacies varied widely in the amount of counselling they provided. In the United Kingdom, Morris et al (1997) found that while consumers understood the need for pharmacy staff to counsel patients about over-the-counter medicines, 62% had expected to make their last purchase without being questioned. In Counsell et al’s survey (1993), half (49%) of the 245 parents asked about information on prescribed medications did not recall receiving any information from the pharmacist. In some circumstances, such as for consumers filling repeat prescriptions, information and counselling may be redundant.

In Britain, a qualitative study found that customers use pharmacies for treatment of minor ailments, sometimes before going to the GP, and sometimes in preference to the GP. Reasons for this include availability and costs of obtaining a prescription through a GP (for example, for people without prescription exemption status) (Hassell 1997). The 2001 American National Pharmacy Consumer random survey of 1201 consumers who had filled a prescription in the previous six months found pharmacies were regarded as being convenient. Satisfaction with pharmacy services was high: 85% of respondents were satisfied when filling a new prescription. Respondents who had consistently asked the pharmacist questions were particularly satisfied with pharmacy services (Stergachis et al 2002).

By contrast, in Australia Whitehead et al (1999) compared consumer satisfaction with pharmacies that provided a higher amount of information to satisfaction with pharmacies that provided a lower amount of information. They found no difference in satisfaction levels, although about 40% of customers at the low information-provision pharmacies would have preferred higher levels of information, other things being equal.

In New Zealand, community pharmacists have long been seen as having an important and trusted role as advisors in self-medication and screening of minor illness, as shown in a review of all medicine sales during one trading day at 57 Wellington region pharmacies (Shaw and Trevean 1983). The high use of and trust in pharmacists continues, as much of the literature we reviewed illustrates: in a recent PHARMAC survey of 500 people, 69% of respondents over the age of 15 agreed that they trusted their chemist to give them the right medicine without them having to go to a doctor, for medicines relating to colds and flus (PHARMAC 2003). According to the 2002/03 New Zealand Health Survey, “most adults ... had been to a pharmacy or chemist for a health product or health information or advice in the last 12 months” (Ministry of Health 2004a: 127).

According to the Ministry of Health, over 44 million individual prescriptions were dispensed in 2002/03 (Director-General of Health 2003). It is not clear how many were repeat prescriptions. In terms of demographics: “On a per-person basis, pharmaceutical services are predominantly used by people over the age of 45, with the number of prescriptions increasing rapidly with age thereafter. Females obtain more prescriptions on average than males of the same age in all age groups except for children under five years” (Ibid: 75).

As in other areas, there are variations in the amount of use of this source of information. In the Colmar Brunton survey (2003), 43% of 500 respondents had used a pharmacist for information about prescription medicines or other treatments, but blue-collar workers were less likely than average to use pharmacists as a source of information.

In the focus groups, the pharmacist was considered to be a useful first port of call:

P: *For quite a number of things, I would tend to check with the pharmacist to decide, if it's a wart or something, should I go to the doctor with this or is it something that can be dealt with by some medication?* (Pākehā group)

Other health professionals

- Practice nurses have a significant role in health information.
- Treatment-based and community-based providers are useful sources.

It is likely that as Primary Health Organisations (PHOs) develop, the role of other primary health care professionals in information provision may expand. This is anticipated in the report of the Expert Advisory Group on Primary Health Care Nursing, which endorses primary health care nurses in “helping clients identify and use health resources”, and “acting as a source of health information for clients” (Expert Advisory Group on Primary Health Care Nursing 2003: 11).

New Zealand studies of practice nursing show the growing importance of this role. Practice nurses are increasingly educated about specific conditions such as asthma, diabetes and weight control and can advise on patient self-care. With this comes a growing dependence by consumers on practice nurses for advice about appropriate medication (Eagle et al 2002; Kenealy et al 2004).

In the focus groups, GPs' practice nurses were well regarded as sources of information, with the advantage of being more accessible than the GP:

P: *... I find that trying to get hold of [the doctor] sometimes is like trying to catch a fly on the wall, but if I talk to the practice nurse, she is as much help sometimes.*

P: *Practice nurses are good for information.*

P: [general agreement] (65+ group)

A number of other health professionals were also identified as sources of information: ambulance officers, dieticians, health educators, health professionals, nutritionists, optometrists, physiotherapists and therapists.

However, apart from those who were discussed in the context of providing treatment, such as the ambulance officers, focus group discussions concentrated on dieticians and nutritionists in the context of information about dealing with being overweight.

Other health services were further identified as sources of information: accident and emergency, Hauora clinics, health centres, health service providers, hospitals, Karitane, marae-based centres

(eg, Kōkiri), on-site medicals offered at work and union health. These were divided according to those associated primarily with treatment, such as the hospitals, and other more community-based providers that were considered to be useful alternatives to a GP because they were more accessible and also anonymous, for example, where issues associated with STDs and unwanted pregnancies were concerned.

Advertising

- New Zealand is unusual in allowing direct-to-consumer advertising (DTCA) of both non-prescription and prescription medicines.
- There is a lack of information about the effects of DTCA in New Zealand.

There is advertising of both non-prescription and prescription medicines in New Zealand, for example, on TV, radio, in the print media and on billboards. A recent New Zealand study found one advertisement for medicines of some kind was broadcast on average once in every 102 minutes on TV, with considerably more at certain times of the day (Norris et al 2004). New Zealand and the United States are the only OECD countries that allow direct-to-consumer advertising (DTCA) of prescription medicines, and such advertising has been much discussed in this country (Coney 2002; Ashton 2003; Norris et al 2004; Toop et al 2003). While some of these writers and some organisations seek increased constraints on or prohibition of DTCA, others strongly support it (Saunders 2003; Association of New Zealand Advertisers 2004).

In the United States, research on DTCA has identified significant public misconceptions about the regulatory framework for DTCA. In a survey of 329 adults (Bell, Kravitz and Wilkes 1999) many held erroneous beliefs about DTCA: 50% of respondents believed that DTCA had to be submitted to the government for prior approval; 43% thought that only completely safe prescription drugs could be advertised to consumers; 21% thought that only extremely effective drugs could be advertised to consumers and 22% thought the advertising of prescription drugs with serious side-effects was banned. People from minority ethnic groups were more misinformed than white Americans. Positive attitudes towards DTCA were positively correlated with these misconceptions. Other studies looked at different issues: for example, most respondents in an earlier survey of 440 people (Alperstein and Peyrot 1993) felt that DTCA could help educate consumers (70%), while a minority agreed with possible objections to DTCA. Twenty-eight percent felt it would confuse consumers; 21% believed that asking for an advertised product would upset a doctor and 12% felt that DTCA would weaken the doctor-patient relationship. The WHO/NGO database on drug promotion concludes that “Most of the available studies report mostly positive attitudes to DTCA amongst consumers”, but that this could be put down to methodological influences. However, “social and educational differences seem to influence acceptance of DTCA: the less educated may accept it more readily” (WHO 2002).

There is some overseas evidence that exposure to DTCA affects consumers’ behaviour, for example, in a substantial review from Canada (Mintzes 2001). Studies using hypothetical situations, for example Everett (1991), suggest that some consumers would ask their doctors for advertised drugs and may even change doctor if the drug was not prescribed. Studies of actual behaviour support this finding. In *Prevention* magazine’s survey of a representative sample of 1,222 adult consumers in the United States (*Prevention* magazine 2000/2001), 32% of consumers who had seen a DTC advertisement had talked to their doctor about an advertised medicine. Of these, 26% had asked for a prescription for the advertised medicine. Most of those who asked (71%) received a prescription for that medicine, and 10% received a prescription for another medicine. In a study of Sacramento adults (Bell Wilkes and Kravitz 1999), 19% reported having asked for a prescription and 35% reported having asked a doctor for more information, both as a result of a DTC advertisement. Asked how they would respond if their physician were to deny an “advertisement-motivated drug request”, 15% considered ending their relationship with the physician.

Mintzes et al (2002) analysed a sample of 1431 visits to primary health care physicians in one Canadian and one United States city. They found patients requested prescriptions in 12% of visits, and 42% of these requests were for products advertised to consumers. The authors found that patients who requested a prescription were more likely to receive one than those who did not (after controlling for health status, socio-economic status, demographics and doctor characteristics). Doctors were ambivalent about the choice of treatment in about 50% of cases where the patient requested an advertised drug. It is unclear exactly how many of the patient requests were prompted by advertising. Advertised drugs may be different in other ways from unadvertised drugs (eg, they may be for more common conditions or be newer drugs) and this could make them more likely to be requested by patients.

Economic studies examining the population-level impact of DTCA also suggest an effect on consumer behaviour and doctors' prescribing. Eichner and Maronick (2001) analysed correlations between sales, expenditure on DTCA and patient visits to doctors for four groups of drugs between 1996 and 1998. They concluded that DTCA campaigns had variable success but that DTCA did seem to increase patient visits to doctors for advertised conditions. Basara (1996) examined the impact of a DTCA campaign on sales of a new medicine and concluded that the campaign significantly increased the number of new prescriptions for the product.

Internationally, the quality of information in over-the-counter medicines advertising has been criticised by several writers. For example, Sansgiry et al (1999) arranged for five clinical pharmacists to evaluate print advertisements for over-the-counter products from three consumer magazines over a nine-month period. The researchers found misleading and inaccurate information in the advertisements and argued that consumers may not have the appropriate information to identify misleading advertisements. A survey of 150 randomly-selected participants in the United States showed that respondents who had seen DTCA of a drug and wanted further information had the strongest preference for seeking that information from a physician or pharmacist, ahead of other sources such as a family member, a reference book or a manufacturer (Doucette and Schommer 1998).

In New Zealand, the Association of New Zealand Advertisers and the Advertising Standards Authority Inc help advertisers, advertising agencies and the media when advertising medicines. Various self-regulatory codes are recommended, including the Advertising Standards Authority Code for Therapeutic Advertising. The Association of New Zealand Advertisers' Therapeutic Advertising Pre-vetting System (TAPS) (Advertising Standards Authority Inc.) provides pre-vetting of advertisements for compliance with the various legislative and voluntary industry requirements (Medsafe). However, drug advertisements do not always convey the full information to consumers, as shown in a case study of Diane-35®, an anti-androgen/oral contraceptive pill marketed as a skin treatment. "The contraceptive effects of Diane 35® were mentioned only in the small print and in even smaller print at the bottom of the page", and a survey by Colmar Brunton for PHARMAC in 2000 "showed only 20% of women surveyed after being shown the advertisement for Diane-35® realized it was also a contraceptive" (Toop et al 2003: 10).

Nearly all DTCA is for unfunded medicines (ie, those not listed on the New Zealand pharmaceutical schedule). In 2001, "at least 18 prescription products were advertised direct to consumers through television, radio, the press, at cinemas or in magazines" (AC Nielsen (NZ) Ltd, quoted in PHARMAC 2003: 10). PHARMAC, as well as managing the Pharmaceutical Schedule, is also charged with promoting the responsible use of pharmaceuticals (see Crown Entities on the Ministry of Health website at: www.moh.govt.nz). In a submission to Medsafe in August 2002, PHARMAC noted its concerns about DTCA's role, "that it creates fiscal risk on the limited government pharmaceutical budget ... in its current form does not meet accepted international standards of health promotion; and the current regulatory system of self-monitoring and compliance is not optimal" (PHARMAC 2003: 8).

In New Zealand, of 500 consumers surveyed by Colmar Brunton (2003), TV advertisements were used as a source of information by 23% and magazine and newspaper advertising by 22%. Students and young people were significantly more likely than average to report magazine/newspaper advertisements as their main source of information about prescription medicines or other treatments. Overall, 21% of students and 22% of 15- to 19-year-olds reported magazines or newspaper advertisements as their main source of information. In terms of attitudes, New Zealand consumers did not seem to share the misconceptions about DTCA that researchers such as Bell, Wilkes and Kravitz (1999) found amongst Americans: “the least trusted sources of information [by New Zealand respondents] include magazine or newspaper advertisements, with ... 59% [believing] it is untrustworthy to some extent (either 1 or 2 on a scale out of 5)” (Colmar Brunton 2003: 7).

TV advertising and programmes were discussed by all the focus groups. All but the Pasifika group either expressed scepticism about TV’s value as a source of information or simply did not rely on it. A common view was that TV emphasised advertising rather than straight, unbiased information:

P: *I think, generally speaking, you look at these ads on TV and what they claim, this, that and the other thing, well, yes and no. Frankly I am highly suspicious.*

P: *They wouldn’t be advertising if there wasn’t something in it for them.*

P: [general agreement] (65+ group)

The Pasifika group, on the other hand, had a member who had learned about having sleep apnoea after seeing an advertisement on TV:

P: *Yes, if it wasn’t for the ad on TV, I wouldn’t know I had sleep apnoea.*

F: *Is that right?*

P: *And lucky I did, yeah.* (Pasifika group)

Focus group participants were asked specifically whether they had ever asked their GP to prescribe something that they had seen or heard advertised in a direct-to-consumer advertisement. The Young people aged between 16 and 24 group were vehemently opposed to doing something like that. In the Older people aged 65 and above group, one member had done so:

P: *Yes, I have. I am an asthmatic. Symbicort came up on the screen, and I was in seeing him, just getting my usual drugs and things, and I asked him about it, and we talked about the three asthma drugs I am now using, and it was very clear that that would offer me nothing which I wasn’t already receiving from the drugs I was on, but I did ask.* (65+ group)

But no other members of that group said that they had, and there was a general cynicism about advertising. None of the Pasifika group had ever asked their GP to prescribe something they had seen in an advertisement. The Māori, Rural and Pākehā groups did not discuss this issue.

Current information about precise expenditure in New Zealand on DTCA of prescription and over-the-counter medicinal items was difficult to locate. A Ministry of Health publication gave the following details for 2000: “expenditure in New Zealand on prescription and over-the-counter DTCA is estimated to be \$48 million during 2000, up 41.7% on 1999. DTCA on prescription drugs was up 23.6% in 2000 to around \$17.9 million” (Ministry of Health 2000:4).

The Association of New Zealand Advertisers’ annual report for 2003 (Association of New Zealand Advertisers 2003) gives the following table:

“Therapeutic Advertising Expenditure

2003 estimated expenditure for all categories in all media	\$80 million
2002 expenditure	\$74 million
Television comprises 56% of advertising expenditure.”	

The Internet

- Health consumers are increasing their use of the Internet, but the uptake is variable.
- The Internet is generally not seen as a reliable source of information.

Consumer use of the Internet for health information has been studied overseas and in New Zealand. A study of 3027 South Australians to gauge the proportion of consumers accessing online health care information found that Internet access decreases with age, while online health information seeking is constant (26% to 28%) among people aged between 15 and 54 years. The survey found that the most commonly sought information is the cause or description of disease (60%). Consumers use online health information as a second opinion (19%), discuss it with their doctor or pharmacist (16%) or change their health care management as a result of using it (11%) (Bessell et al 2002).

The 2001 American National Pharmacy Consumer random survey (of 1201 consumers who had filled a prescription in the previous six months) found that 31% of respondents had searched the Internet for information on prescription medications within the past year (Stergachis et al 2002). In another United States representative survey (Bundorf et al 2004), of 12,878 Internet users (response rate 69.4%) for an economic study, 34% had used the Internet in the last year to seek health information, but people with chronic conditions were more likely, and uninsured people were less likely, to use the Internet to retrieve health information.

The Internet is increasingly used by New Zealanders for finding health information in general, and this reflects the international trend. In the 2003 Colmar Brunton survey, 18% of 500 respondents had used the Internet as a source of information about prescription medicines and other treatments. For 5% of respondents, it was their main source. Low socioeconomic respondents (at 9%) and blue-collar workers (at 7%) were significantly less likely than others to have used the Internet to find this information, and high-income earners were more likely to report the Internet as their main source for the information. But the Internet was among the least trusted sources of information on prescription medicine or other treatment, with 36% of respondents deeming it untrustworthy to some extent and 18% deeming it “very untrustworthy” (Colmar Brunton 2003).

A non-random study of 183 people (Brenner et al N.d.) found 50% used the Internet to access health information. About half of these discussed the information with their health care provider. Seventy-one percent of 168 Otago/Southland GPs stated in a 1998 postal survey that they had had patients who had sought medical information from the Internet (Eberhart-Phillips et al 2000). The Internet was rated slightly higher than medical libraries as an appropriate source of patient information by 158 respondents in Oliver and Bidwell’s survey (2001).

Medsafe is New Zealand’s medicines and medical devices safety authority and provides an online Consumer Medicine Information (CMI) service, including pharmaceutical fact sheets for consumers. In the year to April 2004, the Medsafe website had nearly 950,000 users, of which just over 36,000 were requests for consumer medicine information (B Slyfield, personal communication, 2004). These could have been from either consumers or health professionals accessing information to give to patients. Recently made available in New Zealand is BestTreatments (*British Medical Journal*, available online at: <http://unified.bmj.com/btuk/home.html>), a website with clinical evidence in plain language for consumers, accessed by condition, with discussion of available treatments and drugs. Some health interest groups have noted that several drugs listed in BestTreatments are not funded or

not available in New Zealand (MacDonald 2004). The New Zealand Guidelines Group also provides a gateway to web-based consumer health information (available online at: www.nzgg.org.nz/index.cfm?fuseaction=fuseaction_12).

This website links to New Zealand Guidelines Group information for consumers, Informed Health Online, the Cochrane Collaboration's Consumer Network, Health*Insite*; MedlinePlus, DISCERN and CHIC. There are other sources of web-based information available, but not all are available generally, for example, the Consumers' Institute website is only available to registered members (see www.consumer.org.nz/category.asp?category=Health).

The Internet was mentioned by all focus groups in our study as a source of information about medicines and treatments. It was seen as having considerable potential as an information source because of the relative ease with which information about specific conditions could be accessed:

P: Yeah, with the Net you can just type in your symptoms as well, and it comes out with all these sort of services that people have. (16–24 group)

But concerns were expressed about the reliability of the information available and the difficulty of distinguishing the good from the bad because there was so much information:

P: Too much information.

P: That's true.

P: You can get confused. (16–24 group)

P: I also think it can be sometimes, especially the Internet, can be dangerous. You get an overload of information, you don't quite know where to start. (Pākehā group)

Concerns about Internet information overload and about judging quality of Internet information are discussed in the literature. A United States report on “health seekers” using the Internet showed 86% were “concerned about getting health information from an unreliable source online Compared to other Internet users, health seekers show greater vigilance in checking the source of online information. Health seekers are pretty evenly divided about whether the information they get online is credible” (Fox et al 2000). Currently research is underway that may report on young New Zealanders' approaches to assessing Internet information (H Darling, personal communication 2004), following a survey of 3,434 Year 10 and Year 12 New Zealand secondary school students in 2002 (Darling and Reeder 2004). That survey found that 31.6% of respondents had used the Internet for “general health information” and 16.7% for “a specific health issue”.

There is a continuing “digital divide” in access to and use of the Internet, which impacts on equity in terms of the Internet as a source of information on pharmaceuticals and related treatments, assuming that the accessible information is considered of value. New Zealand has one of the highest overall rates of Internet access in the world, according to Statistics New Zealand (2004), but those with low household income, those with lower levels of educational qualification, older people and one-person and single-parent households with dependent children are less likely to be connected to the Internet than others. Māori and Pacific people are concentrated in most of these groups. Māori and Pacific peoples “have significantly lower levels of access to, and use of, information and communication technologies than do others in the country” (Gibson 2002: 95).

Libraries

- Libraries have an important role to play in providing health information.
- They are seen as a reliable source of information.

In Oliver and Bidwell's survey of provision of consumer information services by hospitals (2001), the second choice for hospital patient information (after physicians) was a library or information centre located within a hospital and solely for patients. Public libraries were the third highest choice for health information (159 out of 196 respondents), although two-thirds of these respondents had some reservations about them. Solomon's study of 250 people (Solomon 1996) also identified libraries as sources of consumer health (including treatment) information.

Oliver and Bidwell (2001) found that 50 hospitals in New Zealand had library and information centres that were accessible to patients from all departments. Examples of such services are the Family Information Service at Starship Children's Health in Auckland (online at: www.starship.org.nz/Story?Action=View&Story_id=1204) and the Health Information Centre at Hutt Valley District Health Board. At these hospitals, staff referred patients to the information service "frequently" or "sometimes" in 42 of the 50 sites, and if patients required further information, then the library referred them to support groups, physicians, public libraries, special libraries, the Internet or medical libraries.

In the focus groups, participants expressed suspicion of older books that might contain out of date information, and they had greater confidence in contemporary books obtained from libraries:

P: It is just, she is 67 now, and there's nothing wrong with that, but she goes back to the books that were around when she was nursing and still pontificates, and I think they are dangerous actually, and I had another sister who was the same, she used to stand up and give the doctors the message about what they should and shouldn't be doing for her grandchildren and things. I mean they were old ... they were books that ... so I think that some of them can be dangerous, maybe some of them are good, but some can be quite dangerous. (Rural group)

Public libraries play a part in consumer health information. For example in the 2002/03 year, the Wellington City Library issued about 41,000 health related items from a stock of 11,611 (I McDonald, personal communication, 2004). Some public libraries, such as Canterbury City libraries, provide guidance on assessing Internet health information.

Self-help groups, non-government providers, family and friends

- There is a lack of New Zealand research about the use of self-help groups.

In Solomon's telephone survey, the second most likely source of health information (after GPs) was self-help groups (Solomon 1996). Organisations supporting people with arthritis, cancer, asthma and other conditions provide information about treatments, including pharmaceuticals, and information and support are often among the key objectives of such groups (cf. National Heart Foundation or Cancer Society). There are few publicly available evaluations of the information services of self-help non-government organisations. Research about Cancer Society services suggests that Māori are less likely to use the information and support services than Pākehā (Olsen et al 1999).

A systematic review of the effects of online electronic support (peer-to-peer) groups (Eysenbach et al 2004) found that there are thousands of such groups, and that while they appear to do no harm, there is no robust evidence (from randomised control trials) about positive effects. This result was suggested to be related to the design of the studies reviewed, "... most peer to peer communities have been evaluated only in conjunction with more complex interventions ..." (Ibid: 1166). The reviewers note considerable qualitative evidence that "... self-helping ... virtual communities are in fact the single most important aspect of the web with the biggest impact on health outcomes" (Ibid: 1170). A recent survey of five United States support groups found members are likely to attend groups to gain information about diagnosis, treatment options and coping strategies (Purk 2004).

There is some concern that pharmaceutical manufacturer sponsorship of support groups is likely to affect the kind of information provided by these groups and their lobbying activities (Moynihan et al 2002; Herxheimer 2003). Herxheimer gives examples from the United Kingdom and the United States. For example, in the United States, the National Alliance for the Mentally Ill is supported by Eli Lilly and 17 other companies. Mintzes (1998: Chapter 1) also gives examples of sponsorship by pharmaceutical companies of patient groups, institutes and foundations, stating that: “industry links are often unclear and sponsorship may or may not be disclosed”, which is contrary to the World Health Organization’s ethical criteria for medicinal drug promotion (WHO 1985).

An alternative in the United Kingdom, which provides consumers with information about illnesses and treatments, is DIPEX, a database of patients’ experiences. “The site covers cancers, heart disease, epilepsy and screening programmes as well as plans for new areas on depression, pregnancy, teenage health, chronic illnesses and many others” (available online at: www.dipex.org). Users can watch, listen to or read interviews with patients. The multimedia site links patients’ experiences with evidence-based information and gives leads to other information and support (Herxheimer et al 2000).

The focus groups identified organisations such as the Cancer Society, and others that are strongly linked to the mainstream medical system, as important sources of information. Participants mentioned organisations, foundations and sufferer support groups associated with arthritis, asthma, diabetes, epilepsy, cancer, heart disease, kidney disease, neurological conditions and family planning, health research and general health promotion. Participants’ views about these organisations and support groups were generally positive. The information such organisations provided about specific conditions was regarded as being reliable and had the advantage of being free:

P: I’m a diabetic. Diabetes New Zealand is very helpful. (65+ group)

P: They are usually helpful, any foundations that we’ve had anything to do with, they are always helpful, and they do have the information. (Rural group)

All groups identified family members as sources of information, but confidence in this source was qualified, with doubts expressed about how detached a lay person, such as a family member, might be from their own concerns and problems. Family members were most likely to be a source of information about something if they themselves had first-hand experience of it. Friends and associates were discussed less frequently than family members and were not more valued as sources of information. In common with family members, friends and associates were most likely to be sources of information about things that they had had first-hand experience with:

P: I would ask friends if they had used it or not. Have you heard about that thing, have you used it, what’s it like? (Māori group)

However, concerns were raised about the accuracy of information from these sources:

P: One of the problems with local knowledge of course, is that people elaborate and distort the information; it is not always as accurate as it might be. (Pākehā group)

In making the comparison with health professionals:

P: I think if I was asking for information, I wouldn’t exactly go to the whānau or friends, or community workers; I would go to the pharmacist (Māori group)

Self-medication and treatment are included in this category. They were discussed in the context of people trying things out to see what worked. As such, this was not a discussion of a source

of information, although, of course, the results of trying something out would constitute information for the person concerned.

Other support groups included in this category cover people, organisations and facilities from which people may obtain medical and health related information in an informal manner through their non-medically related associations with them. Included in this category were: church ministers and priests, citizens advice bureaux, community health workers, the Community Law Office, dreams, the education system, gyms, information centres, the Law Centre, noticeboards, polytechnics, schools and school newsletters, social workers, sports clubs, teachers and universities.

While some of these sources were of potential value, they did not figure very strongly in the overall focus group discussions. Of those suggested, schools and church ministers seemed to be the most useful:

P: Frequently, teachers in schools know quite a bit, because they have had to deal with youngsters who are sick, sent to the office to get their inhaler and that sort of thing.
(Pākehā group)

Other media: magazines and radio

- Little evaluative research has been done in New Zealand.

In a study in the Netherlands in 1995, Van Trigt et al found that family magazines can play an important role in diffusing medical information and information on drugs to consumers, and they found that patients had questions about drugs in response to material they found in family magazines (Van Trigt et al 1995). In New Zealand, a health magazine, *Healthy Options*, publishes 18,000 copies per issue and has 47% to 50% of its advertising from alternative medicine companies (J Priest, personal communication, 2004).

Health issues and treatments are discussed on public, access and commercial radio, and DTCA of pharmaceuticals and alternative medicines is broadcast on commercial radio as well. Investigations found no New Zealand research about radio sources. Community public radio is recognised internationally, however, as a significant health information source for the “poor, geographically dispersed, and illiterate portions of the [Third World] population to gain access to the information and knowledge that is stored on the Internet and in the host of other resources enabled by ICTs” (The Communication Initiative 2003). It is unclear how much community or iwi stations in New Zealand broadcast health information other than advertisements and “advertorials”.

Research into the role played by the mass media in general in communicating science to the public found that treatment of some science issues, including medical science, was superficial. One of the cases studied was about Lyprinol, a treatment for cancer (MediaWatch 2004). A finding was that many journalists appear to be uncomfortable with the “technical nature of science claims”. A senior journalism teacher in New Zealand has said that “scientists and journalists are working to different agendas ... Science stories too often linked medicine with miracles” (Gee whiz Martha! 2003).

A telephone survey sample of 801 New Zealanders for the Ministry of Research Science and Technology found that politicians, lobby groups and journalists were the “least trusted sources of information about science issues” (Hipkins et al 2002: 3). In terms of scientific information in a health-related context, respondents indicated high levels of confidence in medical practitioners (83%) to give trustworthy information (Ibid: 42).

Printed media including pamphlets, magazines, books and encyclopaedias was widely discussed in the focus groups. The following sources were identified during the discussions: archives, booklets, books, bookstores, brochures, *Consumer* magazine, dictionaries, Doctor Turbott's book on medical information, encyclopaedias, *MIMS New Ethicals* (a drug book held by chemists), flyers, leaflets, libraries, *Listener* magazine, other magazines (such as *Woman's Day* or different *Woman's Weekly* magazines), Medsafe leaflets (MoH/Internet), media, medical dictionaries, *The Merck Manual of Diagnosis and Therapy*, newspapers (news and advertisements), pamphlets, the *Pears Cyclopaedia*, Plunket library, reference books, telephone books, the old Red Cross handbook and *Yellow Pages* (see Appendix 1 for a full list of all sources identified by focus groups).

Participants distinguished between popular magazines such as *Woman's Day*, specialist magazines such as *Consumer* and investigative magazines such as *Time*. The specialist and investigative magazines were regarded as more reliable sources of information about medicines and treatments than the popular magazines:

P: *I think really investigative magazines are the ones we are talking about, Consumer, the Listener.*

F: *So, the popular ones you wouldn't trust the stuff, say it was in the [women's magazine], you be less inclined to hear about it or listen to it?*

P: *Twenty years ago, I might have. The [women's magazine] now, no. (65+ group)*

Only the Pākehā group discussed the radio in any depth, although all other groups, except the Pasifika group, did refer to it. The Pākehā group revealed mixed feelings about radio's value as a source of information. On the one hand, it was compared unfavourably with written media because it was not possible to remember everything that was broadcast:

P: *Well sometimes you forget exactly what it was you heard, you know. You think, now I'm sure that's what ... or was that what they said?*

P: *As soon as they've said it, I forget.*

P: *When you go to write it down, they don't repeat it. (Rural group)*

On the other hand, it was felt that concise information conveyed in plain language, as offered in radio broadcasts, could be very effective as an alternative to wading through lots of written material. This was considered to be particularly the case for people of limited literacy.

Information leaflets

- Health consumers like written information.
- Information provided in leaflets is of varying quality and use for consumers.
- Evaluative research is required about information leaflets in New Zealand.

Information leaflets appear easy to prepare and produce, but little is known about details of their use in New Zealand. Koo et al (2002) reviewed the literature in English since the late 1970s on the factors that influence the use of written drug information. They found that the subject has not been widely investigated and concluded that much more research is needed in this area.

Some systematic reviews of written information have been reported, for example, one review of written and verbal information versus verbal information only found that a combination of verbal and written information was recommended for communication about care issues on discharge from hospital to home (Johnson et al 2003). A British survey of 95,000 inpatients in 2003 showed that only 28% felt they had been "completely informed about the drugs they would be taking after discharge" (Eaton 2003: 180). Another systematic review (by Haynes et al 1996) considered interventions aimed at increasing medication adherence, of which written

information was one of numerous complex interventions. The reviewers found most of the studies did not separate the impacts of the different components of complex interventions, thus making it difficult to assess any impacts of written information; but in any case, none of the interventions had delivered substantial improvements in prescription adherence.

Drug patient information leaflets in anaesthesia were assessed for their impact on patient anxiety and satisfaction in 85 patients randomly assigned either a standard leaflet about anaesthesia or a standard leaflet plus a drug manufacturer's leaflet. While there was no significant difference between the two groups in anxiety, significantly more in the latter group felt they had received too much information. However, a minority wished to have the drug leaflet information (Oldman et al 2004). Drug information leaflets accompanying different brands of the same generic drug were found to differ in the information they provided in a Danish study, and this caused confusion among consumers (Bjerrum and Foged 2003).

Vander Stichele et al (1991) designed a questionnaire to determine the attitude of the Belgian public toward package inserts for medication information, written in technical language and intended for health professionals, within an original drug-dispensing distribution system. There were 398 respondents to this general public survey. Most respondents considered the package insert information useful and complete but difficult to read. A study in Norway in 1990 of 500 patients found most patients liked to receive prescription information pamphlets and found them useful and that physicians informed the patients more about the effects than about the side-effects of drugs (Strom 1990). British studies of the effect of prescription information pamphlets found that they were effective and of benefit to patients of both sexes, all age groups and all social classes (George et al 1983; Gibbs et al 1990; Mottram and Reed 1997). A Canadian study of 635 adults over the age of 18 also found that personal counselling and printed information materials were commonly preferred options when making health decisions commonly related to medical or surgical treatments or birth control (O'Connor et al 2003).

An Australian study used focus groups to explore consumers' use of consumer medicine information (CMI). In Australia, pharmaceutical companies write this information, but the content is defined in regulations. Patients with severe disease, information-oriented coping strategies and an internal locus of control were more likely to use CMI. Patients who had difficulty reading and understanding CMI, who had more confidence in health professionals or who viewed their treatment as "problem-free" were less likely to use CMI (Koo et al 2002). However an Australian survey of the comprehensibility of pamphlets on asthma found that a substantial number of pamphlets on asthma were beyond the reading and comprehension abilities of many of their target population (Sarma et al 1995). Similar findings have been made in other studies examining whether the general population understand information in patient information leaflets. For example, Kirk et al (2000) found both literacy levels and eyesight to be issues for people reading package inserts about a non-prescription medicine.

Analysing "published discourses about the use of patient information leaflets", Dixon-Woods (2001) identified two discourses. The first reflected traditional biomedical concerns in a "patient education" approach, and gave priority to the interests of health professionals, such as patient compliance with treatment regimes. The second discourse drew on "patient empowerment" values.

Clinicians have often found it challenging to explain risk to consumers, and they can manipulate things to "present information so [consumers] select the treatment you want them to" (Say and Thomson 2003: 543). Edwards et al. (2002) note that patients often want more information than they get and that medical professionals can support patient choice by turning raw data about risk into information that can be discussed with the patient. Straightforward graphic displays are recommended. A study by Trewby et al (2002) found nearly three-quarters of 307 patients in varying stages of health would not take a preventive drug offering a 5% or less absolute risk reduction over five years. They reported that most subjects had a very unrealistic notion of the

benefit of preventive drugs and that both “patients’ and doctors’ numeracy skills may not allow full understanding of the implications of accepting or refusing treatment” (Trewby et al 2002: 532).

Information leaflets are a source of information about pharmaceuticals and related treatments in New Zealand. Those available from Medsafe have been noted above. They are written by pharmaceutical companies, using guidelines set by Medsafe, but Medsafe takes no responsibility for the content of the information. Availability of CMI for any drug depends on the manufacturer supplying it to Medsafe. Pharmacies may also pass on manufacturers’ information leaflets with prescription medicines and treatments. This usually comes in the form of inserts with the pharmaceuticals.

In the focus groups, the reliability of information contained in pamphlets and booklets was related to where the pamphlets and booklets came from. Something provided by a doctor or other medical professional was considered more reliable than junk mail through the letterbox:

P: Yes, it may be totally alright for it to go in the letter box, but what happens to it after its ... it could be thrown away. Whereas if it comes from the pharmacy, and pharmacists do have these brochures that are factual, and they give you references and sometimes even studies that have been done, that is a good way, but then of course, not everyone visits (Pākehā group)

The focus group discussion also led to an analysis of “commercial” material. This category covered retailers and marketers of various sorts and included the following areas: direct marketing, health food and other health products shops, Jenny Craig, a petrol station, retailers, general retail and supermarkets. The information available from retailers was primarily via the health-related products they sold and the information that was packaged with them. Weight-loss businesses such as Jenny Craig were identified as useful sources of information about weight loss, specifically. This category was not identified as a significant source of information.

Overall, the literature and the current study suggest that consumers like to have access to written information about their prescription medicines but that attention needs to be paid to the quality and comprehensibility of the information.

Help lines

- Help lines provide easy-to-understand interactive health information.
- New Zealand’s Healthline is popular.

Telephone help lines provide the hearing general public with an easy-to-understand information source about health issues, including pharmaceuticals. In the United Kingdom, hospital pharmacy-based medicine help lines for consumers have proliferated since 1992. Raynor et al (2000) found that the increasing use of the telephone to provide services directly to consumers in general is reflected in the growth of these help lines there and that the telephone route is likely to become more important.

Grymonpre and Steele (1998) described the use of a medication phone line for the elderly in the eight years to 1992 in Canada and concluded that many older consumers had medication information needs that were not already being met and that they were not aware that pharmacists can provide drug information.

The NHS Direct nurse-led telephone help line in the United Kingdom was started in 1998. An evaluation of the first sites set up found NHS Direct to be “well-used and rapidly-developing [and] appreciated by callers” (Munro et al 2001: 2). The Internet extension of NHS Direct is NHS Direct Online. A pilot of the NHS Direct Online’s Clinical Enquiry Service, involving

web chat, found the sessions where patients chatted online with triage nurses were too long and expensive to be sustainable but that such a service has potential for specific groups such as deaf or socially isolated people (Eminovic et al 2004).

In New Zealand, Healthline was set up as a pilot in 2000. It is “a free telephone health information service that assesses a caller’s health needs and gives information and advice to help a caller decide on the type of health care they need. The Healthline service will incorporate PlunketLine, which provides information, advice and support on child health and parenting” (available online at: <http://www.moh.govt.nz/healthline>). In 2002, the final report of an evaluation of the New Zealand Healthline looked at many aspects of the service. Of the 87% of calls that were health-related, most were “symptomatic” calls. “During a symptomatic call, Healthline nurses question callers to determine the nature of their symptoms, an algorithm is accessed and a triage completed. The call ends with a recommendation to the caller as to the action they should take” (Kalafatelis et al 2002: 24). The other types of calls included requests for general information, and the example given by the evaluators is: “callers asking whether aspirin is better than panadol” (Ibid). Of the 453 people questioned about Healthline as part of the evaluation, 63% agreed or strongly agreed that they would use the Healthline service if they “wanted to check up on advice or medicine they had been given”. Calls from Māori were roughly in proportion to the number of Māori in the population, and calls from Māori and non-Māori covered similar topics, except that Māori were more likely than non-Māori to seek triage of symptoms (St George et al 2003). The number of calls received by Healthline in June 2004 totalled to 4117 (Stephen Lungley, Ministry of Health, personal communication, August 2004). The focus groups did not discuss telephone help lines as sources of information.

Information about complementary, alternative and traditional treatments

- There is growing demand for information about complementary and alternative medicine.
- The Ministry of Health’s new Complementary and Alternative Medicine (CAM) website is popular.

Recent developments in New Zealand on information about complementary and alternative medicines (CAM) and treatments include the report of the Ministerial Advisory Committee on Complementary and Alternative Health (MACCAH) (MACCAH 2004a). The Committee, which was set up in 2001, had received 315 submissions on a discussion document; about one-third from organisations and the remainder from individuals, many of whom were health care providers both mainstream and complementary or alternative. The Committee’s report on consumer information needs noted “the lack of information available on what New Zealand consumers themselves want to know about ... complementary and alternative therapies (including their preferred style and content of information, where they would like the information to be located and how that information might be made available ...)” (MACCAH 2004a: 19). The report drew on a Canadian discussion which identified that “users of complementary and alternative health care typically ask several basic questions about a therapy or product: What is it? Will it work? Where can I get it? How much will it cost? and Who will pay for it?” (de Bruyn 2001b).

MACCAH made two recommendations on consumer information about complementary and alternative health:

- “Consumers should have ongoing access to evidence-based information on the efficacy and safety of CAM therapies. As one way of achieving this, MACCAH recommends that the Ministry of Health continue to fund research summaries from the Complementary and Alternative Medicine Database (CAM Database).” (See details for the CAM website below.)
- “The Ministry of Health should fund research on the needs of consumers for CAM information” (MACCAH 2004a: 20).

In relation to the CAM database, the CAM website (www.cam.org.nz/) was launched on 1 April 2004. As at 21 June 2004, the total number of visitors to the site was 11,179. Most of these visits (nearly 7,000) occurred in April, possibly in response to publicity about the website. The pages most frequently looked at in April were the General modality page (over 25%), the Home page (25%) and the Evidence summary page (19%). This pattern was reflected in May and June statistics (New Zealand Clearing House for Health Outcomes and Health Technology Assessment 2004). The CAM website was praised by the Informed Health Online organisation when it was rated “website of the month” for August 2004 (online at: www.informedhealthonline.org).

Interest in complementary and alternative medicine is an international phenomenon. Estimates from the United States’ National Health Interview Survey of 2002 indicate 36% of adults used some form of CAM therapy in the previous 12 months. If prayer specifically for health reasons is included, the figure becomes 62% (Barnes et al 2004). In New Zealand, the national health survey 2002/03 showed that one-quarter of adults surveyed had seen a complementary or alternative health care worker in the last 12 months, most commonly massage therapists, chiropractors and osteopaths (Ministry of Health 2004a). The use of traditional healers by Māori and Pacific peoples was not traced by the 2002/03 New Zealand Health Survey, and the 2001 Disability Survey results do not provide details, although the survey asked “traditional healer” questions.

In the focus groups, traditional and alternative practitioners and bodies of information as information sources received very little discussion in comparison with the mainstream sources. Included in this category were the following areas of alternative or complementary medicine and treatment: acupuncture, alternative medicines and remedies, chiropractic care, herbal remedies, homoeopathy, natural health, “natural things”, naturopathy, osteopathy and reflexology.

Traditional healers and remedies were discussed a little by the Māori adults group and the Young people aged between 16 and 24 group (many of whom were Māori). The Māori and 16–24 groups indicated that traditional healers were more accessible than doctors. The Pasifika and Rural groups identified these sources but did not discuss them further.

Alternative sources received more discussion than “traditional” sources, mainly in the context of information and treatments for arthritis and indigestion. Alternative sources were recognised as being more expensive to access than mainstream medical services. A generational divide was identified by the Pasifika group, which suggested that while older Pacific people were likely to access traditional Pacific treatments, younger Pacific people in New Zealand were more likely to use “new age” alternative sources.

Different types of consumers

Some of the diversity in consumers’ information source use and preference relates to demographic variation and has been noted in some of the sections above. For example, the Colmar Brunton survey of 500 people (2003) showed that men, students and single people were significantly more likely than average to have used no sources of information about prescription medicines or other treatments in the last 12 months. Demographic categories are of interest in the present research project, as reflected in the make-up of the focus groups. Issues relating to some of the groups are discussed below.

Ethnicity

- More evaluative research is needed to address issues of health literacy, ethnicity and culture.

As far as we know, reasons underlying variations in health information preferences by ethnicity in New Zealand have not been addressed by primary research. It has been suggested that Māori and Pacific cultures are essentially oral, and Māori and Pacific peoples may prefer to receive health information personally and face-to-face, verbally and visually, rather than from written resources (Ministry of Health and Health Funding Authority 1996; Public Health Commission, 1995). We also note data on literacy levels. The 1996 International Literacy Survey showed: “the majority of Māori, Pacific Islands people and those from other ethnic minority groups are functioning below the level of competence in literacy required to effectively meet the demands of everyday life” (Ministry of Education 2001: 21). There are issues of access: Māori and Pacific people are less likely than others to live in households with good telecommunications. At the 2001 Census, one in nine Māori and one in eight Pacific people lived in a household without telephone, fax or Internet access (Statistics New Zealand Census Snapshot 2). Research has not yet addressed whether educational/literacy levels or ethnicity in itself more strongly predict people’s health information behaviour.

It is possible, too, that different cultural understandings are relevant here. The understanding of health and illness, how the body works and concepts of health and wellbeing are likely to affect people’s information behaviour. People whose cultural concepts of health differ from western, scientific approaches may well have information needs and preferences that differ from those comprehended in mainstream “health literacy”.¹ Tse and Soergel (2003) consider terminology and understanding of medical concepts as a serious issue in communication between health professionals and patients. “Non-specialists often do not understand technical terms and explanations or interpret them differently ... [and professionals] may have difficulty in correctly interpreting lay health expressions and associated conceptualizations” (Ibid: 1). Such challenges may be increased where there are differences in cultural background and in first language.

A New Zealand study of 244 adults found low levels of understanding of medicine-related words, particularly amongst Māori and Tokelauan respondents (Norris et al 2001). Understanding varied significantly by ethnicity, gender, age and level of education. Only 37.1% of answers to questions asking about the meaning of nine pharmacy-related terms were correct. “The average number of correct answers (out of nine) was 5.30 for Pākehā, 3.06 for Māori, and 1.69 for Tokelauans. Overall, 23.2 per cent of words were defined incorrectly” (Norris et al 2001: 269). The researchers conclude, “Pharmacists and other health professionals cannot assume knowledge of medicine-related terms by consumers. Even when consumers themselves believe that they understand a term their understanding of it may differ from that of health professionals” (Norris et al 2001: 269).

Some of the focus groups were cautious about and distrusted information sources where there appeared to be a vested interest in the provision of information about pharmaceuticals and treatments. All respondents except those in the Pasifika group expressed skepticism about television advertising and programmes as sources of information. The degree of awareness of Internet sources was high in the groups, but concerns were expressed about the reliability of Internet information, information overload and distinguishing good information from bad.

Other differences according to age and ethnicity appeared in some aspects of information about pharmaceuticals; for example, in attitudes to CAM and the identification of younger Pacific people as more likely than their elders to seek “new age” alternative information. Some Māori reported traditional healers as being more accessible than doctors. However, complementary and alternative approaches received a lot less attention in the groups than did mainstream medical sources.

¹ Health literacy definition: “The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” (Health Literacy Studies. Department of Health and Social Behaviour, Harvard School of Public Health).

Rural residents

- There is a lack of data about access to health information for rural people.

The literature review found little data about health information sources used by New Zealand rural dwellers. The 2003 Colmar Brunton survey, for example, sought respondents almost entirely from urban zones of 15 main centres. The 2001 Census showed access to the Internet in rural centres and “other rural” areas was 26% and 37% of households respectively (cf 40% in main urban centres) (Statistics New Zealand). The citizens advice bureau provides health-related information leaflets and contacts. A review by the New Zealand Association of Citizens Advice Bureaux in 1997 showed inquiries for health, mental health and disability support groups had increased more at rural bureaux than in other areas (New Zealand Association of Citizens Advice Bureaux 1997).

An Australian study of rural residents’ perceptions of health issues used census data and surveyed 499 rural residents. Rural consumers indicated that they would like to access information through a variety of sources, but local media was the most preferred source of information (Bourke 2001).

One of the focus groups was composed of rural adults, but there did not appear to be any difference between the data given by this group and the other groups.

Summary

Literature review

The literature review selected relevant, available New Zealand information and overseas material that might shed light on the research topic. The Ministry of Health's support in providing useful materials is acknowledged. This was not a systematic review of literature, and some relevant information may have been missed, particularly in terms of unpublished and grey literature. The following points emerged:

The literature has a broad scope

There have been several quantitative research reports on consumers' sources and preferences for information about pharmaceuticals and treatments. The field is multidisciplinary, and we note as much interest in research from information professionals as from those in medical disciplines. Certain aspects have received more attention and emphasis in the literature than others, for example, DTCA and its impacts have been of particular interest in the United States and recent New Zealand literature.

The context is changing

The research takes place in the context of expanding sources of information, especially through the Internet, advertising by pharmaceutical companies and the development of complementary and alternative treatments. There are also major changes occurring in the way health services are delivered, as the health reforms foreshadowed in the New Zealand Public Health and Disability Act 2000 are implemented. The establishment of DHBs and, more recently, PHOs, has introduced a new range of stakeholders. The consumer health information scene has been changing rapidly, and there have been consistent calls over the past decade from researchers, information providers and others (for example Harris 1996; Harris and Hutt 1996) for government policy interventions and further research into consumer health information in New Zealand.

Doctors and pharmacists remain trusted sources of information

In the context of change and expanding information sources, the literature shows that the traditional providers – doctors and pharmacists – generally remain the most used and trusted sources of information. They are responsible for prescribing and dispensing prescription and non-prescription medicines. However, there are demographic variations in the use of these primary health providers, and it is evident that some groups have more contact with health providers and with health information than others. The international literature is in accord with New Zealand studies in reporting higher use of and trust in doctors and pharmacists than other sources of information.

Existing health and socioeconomic inequalities carry over in health information

Variations in access to and use of health services extend to sources of information as well. Existing inequalities based on ethnicity, income and literacy are of concern. The New Zealand literature shows that those who are missing out in the area of health in general are also less well served in terms of information sources about pharmaceuticals and related treatments.

Focus groups

While the focus groups identified an extremely wide range and large number of sources of information, there was a clear preference for information to be provided by medical and health professionals, of one sort or another. This preference, which came through in the overall discussion, was reinforced when people were asked specifically about how they would prefer to receive information. The responses to this question revealed a widely-shared preference for receiving information from a health professional of some kind and for this information to be received verbally initially and for the verbal information to be followed up with written information in the form of a pamphlet or booklet that was also provided by the health professional. Preferences were expressed for detailed and comprehensive information about the side effects, cost, reliability and content of medicines and treatments. It was important to people that information about medicines and treatments be accessible and understandable and, where necessary, available in different languages.

The preference for information to be provided by medical and health professionals (in some cases through health-related organisations such as the Cancer Society) was associated with the view that there needed to be some assurance that the information would be accurate and reliable. The concerns expressed about other sources of information, such as the popular media, the Internet, friends and family, were really based on uncertainty about the accuracy, reliability and potential bias of the information and the motives of those providing it.

The diverse and sometimes surprising range of sources of information about pharmaceuticals and related treatments named by participants in the focus groups reinforces the value of qualitative research in the area of consumer health information. These kinds of sources would be unlikely to emerge even in the open-ended question sometimes included at the end of quantitative surveys. They are a reminder that people often have very individual experiences in relation to obtaining information.

Conclusions

Themes

Several clear themes became evident from the focus group results that are generally in close accord with the literature (mostly from overseas) reviewed for the project.

The central role of the traditional medical providers: doctors (GPs) and community pharmacists, was emphasised in the research findings and in the New Zealand and international literature. These two key providers have a position of trust. Both the literature review and the focus groups also showed some recognition of the role of practice nurses as key information providers. The barriers to using GP services included cost and embarrassment, but the range of alternatives was well recognised in the groups. Such alternatives were well known and well regarded and included pharmacists and the non-government “condition” organisations, such as the Cancer Society, whose information was valued as being free and reliable. Family and friends, considered “always popular” as a source of information in recent British research, were used as an information source by the focus groups if they also had first-hand experience of the relevant health issue or treatment.

Five of the eight points set out by Dickinson and Raynor (2003) as ideal for information were touched on by the focus groups. These were: currency of information; accessible language, format and tone; striking a balance between a treatment’s beneficial and adverse effects; different levels of detail at different times; and personally delivered information that is linked to other sources. The information queries arising for participants when contemplating pharmaceuticals and treatments were to do with side effects, cost, reliability and content of medicines/treatments. These are fairly close to the “four essential aspects of a drug: side effects; what it does and what it’s for; do’s and don’ts; and how to take it” discussed in

Dickinson and Raynor (2003). The preferred means of receiving information, as described by the focus groups, is identical to that noted as preferable in the systematic reviews: verbal information followed up by written information handed over by the same provider.

Implications

There are clear implications from this research for those seeking to improve consumer health information. Effort may need to focus on enhancing the capacity of providers to provide quality verbal and written material, as these are consumers' strong first and second preferences. This may involve:

- enhancing the training for GPs, community pharmacists and practice nurses in conveying information to patients of varying demographic groups
- identifying, developing and testing written information, ensuring it is of good quality and that written and verbal information are in accord
- researching with GPs, community pharmacists and practice nurses to establish their views on information availability, quality and other issues. Qualitative research to identify key topics could be followed by national survey research to assist with targeting support where it is needed
- studying clinical specialists and other groups of providers, including complementary and alternative providers, to determine information issues about the specific conditions they treat
- in the interests of equity, conducting further research with consumers that reflects the burden of disease and concentrates on the population groups with worst health and least access to mainstream information
- developing an evaluation culture in the information-provision sector. Government, non-government and professional groups put considerable effort into providing information services and materials, but there appears to be little evaluation of these services. At present little is known about exactly what patient information support is available and if or how patients and professionals use it
- increasing consumer education through educational institutions and mass media.

Researchers and others have begun to pay attention to consumer health information issues. Examples of recent initiatives include the following events.

- University of Otago Christchurch School of Medicine and Health Sciences hosted an Independent Consumer Health Information Conference in May 2004.
- Victoria University of Wellington has funded a pilot stocktake of information sources and resources available for patients in the Wellington region starting in late 2004.
- Qualitative research into the information experiences of Māori affected by cancer was started in late 2004 (Victoria University of Wellington, funded by the Cancer Society of New Zealand Inc).

These and other research projects are expected to contribute to a greater understanding of consumer health information issues in the coming years.

References

- Advertising Standards Authority Inc. Available online: www.asa.co.nz
- Alperstein NM, Peyrot M. 1993. Consumer awareness of prescription drug advertising. *Journal of Advertising Research* 33(4): 50–56.
- Anon. 1996. Can you rely on your pharmacist? *Consumer* 346: 6–9.
- Ashton J. 2003. Drug plugs. *Consumer* (429): 12–15.
- Association of New Zealand Advertisers (ANZA). 2003. Annual Report. Auckland: ANZA. Available online: www.anza.co.nz/
- Association of New Zealand Advertisers (ANZA). 2004. *Direct to Consumer Advertising of Prescription Medicines – Part of a well functioning democracy and economy*. Auckland: ANZA. Available online: www.anza.co.nz/
- Barnes PM, Powell-Griner E, McFann K, Nahin R. 2004. Complementary and Alternative Medicine use among adults: United States, 2002. *Advance Data Report* #343. Available online: <http://nccam.nih.gov/news/report.pdf>
- Barratt A, Ragg M, Cockburn J, Irwig L, Swinburne L, Chapman S. 2000. *How to Prepare and Present Evidence-based Information for Consumers of Health Services: A literature review (1999)*. Canberra: Commonwealth of Australia.
- Barter C, Renold E. 1999. *Social Research Update: The use of vignettes in qualitative research: University of Surrey, 1999*. Available online: www.soc.surrey.ac.uk/sru/SRU25.html
- Basara L. 1996. The impact of a direct-to-consumer prescription medication advertising campaign on new prescription volume. *Drug Information Journal* 30: 715–29.
- Bell R, Kravitz R, Wilkes M. 1999. Direct-to-consumer prescription drug advertising and the public. *J Gen Intern Med* 14(11): 651–57.
- Bell R, Wilkes M, Kravitz R. 1999. Advertisement-induced prescription drug requests: patients' anticipated reactions to a physician who refuses. *Journal of Family Practice* 48: 446–52.
- Benson J, Britten N. 2002. Patients' decisions about whether or not to take antihypertensive drugs: qualitative study. *British Medical Journal* 325: 873.
- Bessell T, Silagy C, Anderson J, Hiller J, Sansom L. 2002. Prevalence of South Australia's online health seekers. *Australian and New Zealand Journal of Public Health* 26(2): 170–3.
- Bidwell P. 2001. Needing to know: public access to health information, 1970–2000. *New Zealand Libraries* 49(4): 127–35.
- Bissell P, Ward PR, Noyce PR. 2000. Mapping the contours of risk: consumer perceptions of non-prescription medicines. *Journal of Social and Administrative Pharmacy* 17: 136–42.
- Bjerrum L, Foged A. 2003. Patient information leaflets – helpful guidance or a source of confusion? *Pharmacoepidemiology and Drug Safety* 12: 55–59.
- Blendon RJ, Schoen C, DesRoches C, Osnorn R, Zapert K. 2003. Common concerns amid diverse systems: health care experiences in five countries. *Health Affairs* 22(3): 106–21.
- Bonaccorso SN, Sturchio JL. 2002. Direct to consumer advertising is medicalising normal human experience: against. *British Medical Journal* 324: 910–11.
- Bourke L. 2001. Australian rural consumers' perceptions of health issues. *Australian Journal of Rural Health* 9(1): 1–6.

- Brenner B, Browne R, Guphtar M, Krisjanous J, McHugh P, van Lill S, Abernethy D. N.d. Consumer utilization of internet-based health resources: University of Otago, Health Informatics. Available online: <http://hein.otago.ac.nz/wwwHealth/InternetforHealthUse.ppt>
- British Medical Journal*. Best treatments: clinical evidence for patients. Available online: <http://unified.bmj.com/btuk/home.html>
- Bundorf MK, Baker L, Singer S, Wagner T. 2004. *Consumer demand for health information on the Internet*. Cambridge, MA: National Bureau of Economic Research.
- Burton B. 2004. Drug industry to fight New Zealand's move to ban direct to consumer advertising. *British Medical Journal* 328(1036): 68–70.
- CAM. Available online: www.cam.org.nz/
- Canadian Medical Association Journal. 2002. The invisible hand of the marketing department. Editorial. *Canadian Medical Association Journal* 167(1): 5.
- Cancer Society of New Zealand. Available online: www.cancernz.org.nz
- Canterbury City Libraries. Evaluating health web sites. Available online: <http://library.christchurch.org.nz/Resources/Health/EvaluatingHealthWebS/index.asp>.
- Charnock D, Shepperd S. DISCERN: quality criteria for consumer health information. Available online: www.discern.org.uk/
- Colmar Brunton. 2003. Colmar Brunton Survey. Christchurch: School of Medicine. 13.
- Coney S. 2002. Direct-to-consumer advertising of prescription pharmaceuticals: a consumer perspective from New Zealand. *Journal of Public Policy & Marketing* 21(2): 213–23.
- Consumers Institute. Consumer online: health: Consumers Institute. Available online: www.consumer.org.nz/category.asp?category=Health
- Counsell AM, Geddis DC, Smith AR. 1993. Parental perceptions of information about medication prescribed for their children. *New Zealand Medical Journal* 106(962): 369.
- Darling H, Reeder T. 2004. Use of the Internet for health information by New Zealand secondary school students, preliminary results (Youth Lifestyle Study). PHA conference. Christchurch.
- de Bruyn T. 2001a. *Information and Informed Choice in the use of Complementary and Alternative Health Care and Natural Health Products: An invitational roundtable*. Vancouver: Health Canada.
- de Bruyn T. 2001b. *Invitational Seminar on Information and Informed Choice in the Use of Complementary and Alternative Health Care with Respect to Practitioners, Users, and the Health System: Seminar report*. Vancouver: Health Canada.
- Dickinson D, Raynor DT. 2003. Ask the patients – they may want to know more than you think. *British Medical Journal* 327: 861.
- Director-General of Health. 2003. *Health and Independence Report 2003*. Wellington: Ministry of Health.
- Dixon-Woods M. 2001. Writing wrongs? An analysis of published discourses about the use of patient information leaflets. *Social Science & Medicine* 52: 1417–32.
- Doucette W, Schommer J. 1998. Consumer preferences for drug information after direct-to-consumer advertising. *Drug Information Journal* 32(4): 1081–88.
- Eagle LC, Chamberlain K, Zou L. 2002. Practice nurses – practically neglected in the DTC promotion of drugs debate. *Massey University, Department of Commerce Working Paper Series 02.15*.

- Eaton L. 2003. Hospital patients say they are not fully informed about drugs. *British Medical Journal* 327: 180.
- Eberhart-Phillips J, Hall K, Herbison GP, Jenkins S, Lambert J, Ng R, et al 2000. Internet use amongst New Zealand practitioners. *New Zealand Medical Journal* 113: 135–37.
- Edwards A, Elwyn G, Mulley A. 2002. Explaining risks: turning numerical data into meaningful pictures. *British Medical Journal* 324: 827–30.
- Eichner R, Maronick T. 2001. A review of direct-to-consumer (DTC) advertising and sales of prescription drugs: does DTC advertising increase sales and market share? *Journal of Pharmaceutical Marketing and Management* 13(4): 19–42.
- Eminovic N, Wyatt J, Tarpey AM, Murray G, Ingrams GJ. 2004. First evaluation of the NHS direct online clinical enquiry service: a nurse-led web chat triage service for the public. *Journal of Medical Internet Research* 6(2): e17. Available online: www.jmir.org/2004/2/e17/
- Everett S. 1991. Lay audience response to prescription drug advertising. *Journal of Advertising Research* 31: 43–49.
- Expert Advisory Group on Primary Health Care Nursing. 2003. *Investing in Health: Whakatohutia te Oranga Tangata: A framework for activating primary health care nursing in New Zealand*. Ministry of Health.
- Eysenbach G, Powell J, Englesakis M, Rizo C, Stern A. 2004. Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *British Medical Journal* 328: 1166.
- Fitzmaurice D, Adams J. 2000. A systematic review of patient information leaflets for hypertension. *J Hum Hypertens* 14(4): 259–62.
- Fox S, Rainie L, Horrigan J, Lenhart A, Spooner T, Burke M, et al. 2000. *The Online Health Care Revolution: How the web helps Americans take better care of themselves*. Washington: The Pew Internet & American Life Project.
- Gee whiz Martha! Unravelling the mysteries of science reporting. 2003. *Dialogue* (Liggins Institute). 6 July: 6.
- George CF, Waters WE, Nicholas JA. 1983. Prescription information leaflets: a pilot study in general practice. *British Medical Journal* 287(6400): 1193–96.
- Gibbs S, Waters WE, George CF. 1990. Prescription information leaflets: a national survey. *Journal of the Royal Society of Medicine* 83(5): 290–97.
- Gibson J. 2002. The digital divide in New Zealand: the position of Māori and Pacific peoples. *Journal of Māori and Pacific Development* 3(2): 90–96.
- Grymonpre R, Steele J. 1998. The medication information line for the elderly: an 8-year cumulative analysis. *Annals of Pharmacotherapy* 32(7–8): 742–48.
- Harris J. 1996. *Providing Consumer Health Information: Key issues: a report of the focus group on Consumer Health Information*. Wellington: New Zealand Health Information Service.
- Harris J, Hutt M. 1996. *Providing Consumer Health Information: The second report of the focus group on consumer health information*. Wellington: New Zealand Health Information Service.
- Hassell K, Noyce PR, Rogers A, Harris J, Wilkinson J. 1997. A pathway to the GP: the pharmaceutical ‘consultation’ as a first port of call in primary health care. *Family Practice* 17(6): 498–502.

- Haynes R, McKibbin K, Kanani R. 1996. Systematic review of randomised trials of interventions to assist patients to follow prescriptions for medications. *The Lancet* 348(9024): 383–6.
- Health Literacy Studies. Department of Health and Social Behavior, Harvard School of Public Health. Available online: www.hsph.harvard.edu/healthliteracy/
- Health on the Net Foundation. HON code of conduct (HONcode) for medical and health web sites. Available online: www.hon.ch/HONcode/Conduct.html
- Health Promotion Forum – Runanga Whakapiki ake i te hauora o Aotearoa. 2002. *TUHA-NZ: A treaty understanding of hauora in Aotearoa-New Zealand*. Health Promotion Forum.
- Herxheimer A. 2003. Relationships between the pharmaceutical industry and patients' organisations. *British Medical Journal* (326): 1208–10.
- Herxheimer A, McPherson A, Miller R, Shepperd S, Yaphe J, Ziebland S. 2000. Database of patients' experiences (DIPEX): a multi-media approach to sharing experiences and information. *The Lancet* 355: 1540–3.
- Hipkins R, Stockwell W, Bolstad R, Baker R. 2002. *Commonsense, Trust and Science: How patterns of beliefs and attitudes to science pose challenges for effective communication*. Research carried out for the Ministry of Research Science and Technology by the New Zealand Council for Educational Research in association with A C Nielsen. Wellington: Ministry of Research Science and Technology.
- Hunter M. 2002. UK consumers reject direct advertising to patients by drug industry. *British Medical Journal* (324): 1416.
- Informed Health Online. Available online at: www.informedhealthonline.org
- Johnson A, Sandford J, Tyndall J. 2003. Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home. *Cochrane Database of Systematic Reviews* 4(CD003716).
- Kalafatellis E, Fryer K, Harsant M, Cunningham C, Taite S. 2002. *The Evaluation of the Healthline Service: Final evaluative report*. Wellington: BRC Marketing & Social Research, for Ministry of Health.
- Kenealy T, Arroll B, Kenealy H, Docherty B, Scott D, Scragg D, et al. 2004. Diabetes care: practice nurse roles, attitudes and concerns. *Journal of Advanced Nursing* 48(1): 68–75.
- Kirk JK, Krick S, Futrell D, Devora T, Caiola SM, Mason E, Sawyer WT, Gal P. 2000. Connecting pharmacy and literacy: the North Carolina Medication Information Literacy Project. *American Journal of Pharmaceutical Education* 64(Fall): 272–82.
- Koo M, Krass I, Aslani P. 2002. Consumer opinions on medicines information and factors affecting its use: an Australian experience. *International Journal of Pharmacy Practice* 10(2): 107–14.
- Krag A, Nielsen HS, Norup M, Madsen SM, Rossel P. 2004. Research report: do GPs tell their patients about side effects to common treatments? *Social Science & Medicine* 59: 1677–83.
- Krueger R. 1988. *Focus Groups: A practical guide for applied research*. Newbury Park: Sage.
- Livingstone C. 1996. Verbal interactions between elderly people and community pharmacists about prescription medicines. *International Journal of Pharmacy Practice* 4: 12–18.
- MACCAH. 2004a. *Complementary and Alternative Health Care in New Zealand: Advice to the Minister of Health*. Wellington: Ministerial Advisory Committee on Complementary and Alternative Health (MACCAH).
- MACCAH. 2004b. *Summary of Submissions in Response to the Discussion Document: Complementary and alternative medicine: current policies and policy issues in New*

Zealand and selected countries. Wellington: Ministerial Advisory Committee on Complementary and Alternative Health (MACCAH).

- MacDonald N. 2004. Website medicines hard to get in NZ. *The Dominion Post*. August 7: A9.
- Mahony C. 2003. Interviews with patients better than surveys for generating change. *British Medical Journal* 326: 618.
- McLennan R. 1992. *The OD Focus Group: A versatile tool for planned change*. Wellington: Victoria University of Wellington.
- McMahon T, Clark CM, Bailie GR. 1987. Who provides patients with drug information? *British Medical Journal*. 294(6568): 355–6.
- MediaWatch. 2004. Laura Sessions on science reporting: Radio New Zealand. Available online: www.mediawatch.co.nz/default,440.sm
- Medsafe. Available online: www.medsafe.govt.nz/
- Minister of Health. 2000. *The New Zealand Health Strategy*. Wellington: Ministry of Health.
- Ministry of Education. 2001. *More Than Words: The New Zealand adult literacy strategy: Kei Tua Atu i te Kupu : Te mahere rautaki whiringa ako o Aotearoa*. Wellington: Office of the Minister of Education.
- Ministry of Health. 1997. *Do We Really Need This Resource? A manual for health educators and health promoters, to assist in the planning, development and production of more effective health education resources*. Wellington: Ministry of Health.
- Ministry of Health. 2000. *Direct-to-Consumer Advertising of Prescription Medicines in New Zealand. A discussion paper*. Wellington: Ministry of Health.
- Ministry of Health. 2003. *A Snapshot of Health: Provisional results of the 2002/03 New Zealand Health Survey*. Wellington: Ministry of Health.
- Ministry of Health. 2004a. *A Portrait of Health: Key results of the 2002/03 New Zealand Health Survey*. Wellington: Ministry of Health.
- Ministry of Health. 2004b. NRB Health Survey Questionnaire. Available online at: [http://www.moh.govt.nz/moh.nsf/0/3D15E13BFE803073CC256EEB0073CFE6/\\$File/questionnaire.pdf](http://www.moh.govt.nz/moh.nsf/0/3D15E13BFE803073CC256EEB0073CFE6/$File/questionnaire.pdf).
- Ministry of Health and Health Funding Authority. 1995, 1997. *Pacific People's Health Education Guidelines: Guidelines for developing Pacific People's health education resources*. Wellington: Ministry of Health and Health Funding Authority.
- Ministry of Health and Health Funding Authority. 1996. *He Tatai i te Ara: Guidelines for developing Māori health education resources. Determining the path*. Wellington: Ministry of Health and Health Funding Authority.
- Mintzes B. 1998. *Blurring the Boundaries: New trends in drug promotion*. HAI-Europe. Available online: www.haiweb.org/pubs/blurring/blurring.intro.html
- Mintzes B. 2001. *An Assessment of the Health System Impacts of Direct-to-Consumer Advertising of Prescription Medicines (DTCA) Vol 2: Literature review*. British Columbia: Health Policy Research Unit Research Reports, Center for Health Services and Policy Research, University of British Columbia.
- Mintzes B. 2002. For and against: direct to consumer advertising is medicalising normal human experience. *British Medical Journal* 324: 908–9.
- Mintzes B, Barer ML, Kravitz RL, Kazanjian A, Bassett K, Lexchin J, Evans R, Pan R, Marion SL. 2002. Influence of direct to consumer pharmaceutical advertising and patient's requests on prescribing decisions: two site cross sectional survey. *British Medical Journal* 324: 278–9.

- Morgan D. 1989. *Focus Groups as Qualitative Research*. Newbury Park: Sage.
- Morris C, Cantrill J, et al 1997. "One simple question should be enough": consumers' perceptions of pharmacy protocols. *International Journal of Pharmacy Practice* 5: 64–71.
- Mottram DR, Reed C. 1997. Comparative evaluation of patient information leaflets by pharmacists, doctors and the general public. *Journal of Clinical Pharmaceutical Theory* 22(2): 127–34.
- Moynihan R, Heath I, Henry D. 2002. Selling sickness: the pharmaceutical industry and disease mongering. *British Medical Journal* 324(7342): 886–91.
- Munro J, Nicholl J, O’Cathain A, Knowles E, Morgan A, Dagnall A. 2001. *Evaluation of NHS Direct First Wave Sites: Final report of the phase 1 research*. Sheffield: Medical Care Research Unit, University of Sheffield. Available online: www.shef.ac.uk/scharr/mcru/reports/nhsd3.pdf
- National Heart Foundation. Available online: www.nhf.org.nz
- New Zealand Association of Citizens Advice Bureaux. 1997. *Citizens Advice Bureaux and Rural Service Needs*. MAF Policy Technical Paper 97/18. Wellington: Ministry of Agriculture.
- New Zealand Clearing House for Health Outcomes and Health Technology Assessment. 2004. CAM website stats. Christchurch: University of Otago and NZHTA.
- New Zealand Guidelines Group. *Evidence for Consumers*. Available online: www.nzgg.org.nz/index.cfm?fuseaction=fuseaction_12
- Newby DA, Hill SR, Barker BJ, Drew AK, Henry DA. 2001. Drug information for consumers: should it be disease or medication specific? Results of a community survey. *Australian and New Zealand Journal of Public Health* 25(6): 564–70.
- Norris P. 2002. Purchasing restricted medicines in New Zealand pharmacies: results from a "mystery shopper" study. *Pharmacy, World and Science* 24(4): 149–53.
- Norris P, Nelson L, et al. 2004. Advertising of medicines on New Zealand television. Submitted to *Australasian and New Zealand Journal of Public Health*.
- Norris P, Simpson T, Bird K, Kirifi J. 2001. Understanding of pharmacy-related terms among three ethnic groups in New Zealand. *International Journal of Pharmacy Practice* 9: 269–74.
- O’Connor AM, Drake ER, Wells GA, Tugwell P, Laupacis A, Elmslie T. 2003. A survey of the decision-making needs of Canadians faced with complex health decisions. *Health Expectations* 6(2): 97–109.
- Oldman M, Moore D, SC. 2004. Drug patient information leaflets in anaesthesia: effect on anxiety and patient satisfaction. *British Journal of Anaesthesia* 92(6): 854–8.
- Oliver G, Bidwell P. 2001. Hospitals and consumer health information in New Zealand: the role of the library. *Health Information and Libraries Journal* 18: 83–90.
- Olsen T, Davies C, Pouwhare T. 1999. *Ko To Rourou, Ko Taku Rourou, Ka Ora Te Iwi: The needs of Māori affected by cancer*. Wellington: Kokiri Seaview Marae for the Wellington Division (Inc) of the Cancer Society of New Zealand.
- PHARMAC. 2003. *Fiscal Impact of Direct to Consumer Advertising*. Wellington: PHARMAC.
- PHARMAC. 2003. *Monitoring the "Wise Use of Antibiotics" 2003 Campaign – Wave 8 Results*. Wellington: PHARMAC.
- Prevention Magazine. 2000/2001. *Prevention's International Survey on Wellness and Consumer Reaction to DTC Advertising of Rx Drugs*. Emmaus: Pennsylvania.

- Public Health Commission (PHC). 1995. *Pacific Islands Health Information*. Wellington: PHC.
- Purk J. 2004. Support groups: why do people attend. *Rehabil Nursing* 29(2): 62–7.
- Raynor DK, Sharp JA, Rattenbury H, Towler RJ. 2000. Medicine information help lines: a survey of hospital pharmacy-based services in the UK and their conformity with guidelines. *The Annals of Pharmacotherapy* 34(1): 106–11.
- Rural Expert Advisory Group to the Ministry of Health. 2002. *Implementing the Primary Health Care Strategy in Rural New Zealand*. Wellington: Rural Expert Advisory Group to the Ministry of Health.
- Sansgiry S, Sharp W, et al. 1999. Consumer understanding and interpretation of printed over the counter advertisements. *Journal of Pharmaceutical Marketing & Management* 13(1): 15–26.
- Sansgiry S, Sharp W, Sansgiry SS. 1999. Accuracy of information on printed over-the-counter drug advertisements. *Health Marketing Quarterly* 17(2): 7–18.
- Sarma M, Alpers JH, Prideaux DJ, Kroemer DJ. 1995. The comprehensibility of Australian educational literature for patients with asthma. *Medical Journal of Australia* 162(7): 360–3.
- Saunders B. 2003. *Direct to Consumer Advertising of Prescription Drugs in New Zealand: Professors' "protest to Government" placed under the microscope*. Wellington: Saunders Unsworth Limited.
- Say RE, Thomson R. 2003. The importance of patient preferences in treatment decisions – challenges for doctors. *British Medical Journal* 327: 542–5.
- Shaw JP, Trevean MA. 1983. The advisory role of the community pharmacist in self-medication. *New Zealand Medical Journal* 96(727): 171–3.
- Slovic P, Kraus N, et al. 1991. Risk perception of prescription drugs: report on a survey in Canada. *Canadian Journal of Public Health* 82(May/June).
- Solomon H. 1996. Seeking consumer health information in New Zealand: a closer look. *New Zealand Libraries* 48(5): 82–8.
- St George I, Branney M, Horo-Gregory W, Duncan L, Cullen M. 2003. Māori callers to a telephone triage service. *New Zealand Family Physician* 30(4): 261–3.
- St George IM, Cullen MJ. 2001. The Healthline pilot: call centre triage in New Zealand. *New Zealand Medical Journal* 1140(1140): 429–30.
- Starship Children's Health. Family Information Service. Available online: www.starship.org.nz/Story?Action=View&Story_id=1204
- Statistics New Zealand. *Census Snapshot 2: Who has access to the Internet?* Available online: www.stats.govt.nz
- Statistics New Zealand. 2004. *The Digital Divide: Statistics New Zealand*. Available online: www.stats.govt.nz
- Stergachis A, Maine LL, Brown L. 2002. The 2001 National Pharmacy Consumer Survey. *Journal of the American Pharmaceutical Association* 42(4).
- Stewart D, Shamdasani P. 1990. *Focus Groups: Theory and practice*. Newbury Park: Sage.
- Strom S. 1990. Pharmacies' information pamphlets – what use are they to the patients? *Tidsskr Nor Laegeforen* 110(6): 729–31.
- The Communication Initiative. 2003. *The Digital Pulse: The current and future applications of information and communication technologies for developmental health priorities*. A

report published by The Communication Initiative. Available online:
www.comminit.com/pdf/TheDigitalPulse.pdf

- Toop L, Richards D, Dowell T, Tilyard M, Fraser T, Arroll B. 2003. *Direct to Consumer Advertising of Prescription Drugs in New Zealand: For health or for profit?* Report to the Minister of Health supporting the case for a ban on DTCA. Dunedin: University of Otago for New Zealand Departments of General Practice; Christchurch, Dunedin, Wellington and Auckland Schools of Medicine.
- Trewby PN, Reddy AV, Trewby CS, Ashton VJ, Brennan G, Inglis J. 2002. Are preventive drugs preventive enough? A study of patients' expectation of benefit from preventive drugs. *Clinical Medicine* 2(6): 527–33.
- Tse T, Soergel D. 2003. *Exploring Medical Expressions Used by Consumers and the Media: An emerging view of consumer health vocabularies*. American Medical Informatics Association Annual Symposium: AMIA.
- Van Trigt AM, de Jong-van den Berg LT, Pasma M, Haaijer-Ruskamp FM, Willems J, Tromp TF. 1995. Information about drugs in family magazines. *Pharmacy World Science* 17(2): 48–53.
- Vander Stichele R, Van Haecht C, Braem M, MG B. 1991. Attitude of the public toward technical package inserts for medication information in Belgium. *DICP* 25(9): 1002–6.
- WAVE Advisory Board. 2001. *From Strategy to Reality: The WAVE project*. Wellington: Ministry of Health.
- Whitehead P, Atken P, et al. 1999. Patient drug information and consumer choice of pharmacy. *International Journal of Pharmacy Practice* 7(2): 71–9.
- World Health Organization (WHO). 1985. *Criteria for Medicinal Drug Promotion*. World Health Organization. Available online: <http://www.who.int/medicines/library/dap/ethical-criteria/criteriamedicinal.pdf>.
- World Health Organization (WHO). 2002. *Drug Promotion Database: What's known and what is missing*. WHO Department of Essential Drugs & Medicines Policy. Available online: <http://www.drugpromo.info>.
- Wynne H, Long A. 1996. Patient awareness of the adverse effects of non-steroidal anti-inflammatory drugs (NSAIDs). *British Journal of Clinical Pharmacology* 42: 253–6.

Appendix 1: **Information sources identified by focus group participants**

1 Medical

Family doctor or GP

After-hours doctor
Doctor
Doctor (to get referral for dietician)
GP
Hospital doctor

Specialist

Cardiologist (to get referral for dietician)
Endocrinologist
Psychiatrist
Specialist
Specialist (referred by hospital nurse)

GP practice nurse and other nurses

District health nurse
Midwife
Nurse
Nurses
Plunket nurse
Practice nurse

Other health professionals

Ambulance officer
Dietician
Health educator
Health professional
Nutritionist
Optometrist
Physiotherapist
Therapists

Chemist or pharmacist

Chemist
Pharmacist
Pharmacy

Health services

A&E
Accident and emergency
Emergency room
Hauora clinic
Health centre
Health service provider
Health services
Health worker
Hospital

Hospital emergency
Karitane
Marae based centre (eg, Kokiri)
On-site medical at work
Union health

Information that comes with medicines

0800 phone number on medicine box
Health products
Insert (with the medicine)
Pharmaceutical firm
Product information
Read the bottle
Read the box

Organisations like the Cancer Society and the National Heart Foundation

Arthritis Foundation
Asthma Foundation
Asthma Society
Cancer society
Charitable research organisations
Choice health (apparently under the Ministry of Health)
Diabetes New Zealand
Diabetes organisation
Epilepsy organisation
Family Planning Centre
Health 2000
Health research organisations
Heart Foundation
Heart organisation
Heart Society
Kidney organisation
Neurological Society or Foundation
Organisations working with specific conditions (arthritis, Parkinsons, etc)
Radius Health
Research organisations
Rhesus Organisation
Sufferers groups
Support groups: Weight Watchers

2 Complementary

Traditional healers and remedies

Fofu (traditional healer)
Māori rongoa
Old remedies
Tohunga

Traditional healer

Alternative

Acupuncture
Alternative medicines and remedies
Chiropractor
Herbalist
Homeopath
Natural health
Natural things
Naturopath
Osteopath
Reflexologist
Special interest

3 Personal contacts and other support

Family members

Whānau
Ask my wife
Daughter
Family
Family history
Family knowledge
Mother
Mum
Parents
Wife
Wife (who has worked in med labs)

Friends and associates

Friend
Grapevine
Local knowledge
Mate
Older people
Other patients
Other people
People
People we live with
Take neighbour's word for it
Word of mouth

Self-medication/treatment

Trial and error
Try it out
Use it and find out
Yourself

Other support groups

CAB

Church minister
Citizen's advice bureaux
Community health workers
Community Law Office
Community workers
Dreams
Education system
Gym
Information centre
Law centre
Noticeboards
Polytechnics
Priest
School newsletter
Schools
Social workers
Sports club
Teachers
Universities

4 Commercial

Information from retail and other commercial outlets

Direct marketing
Health food place
Health food shop
Health shops
Herbal shops
Jenny Craig
Natural health stores
Petrol station
Retailers
Rush off and buy it
Shop
Shop assistant
Supermarket
Supplier
Write Price

5 Media

Internet
Computer
Internet
Search engine like Google
The Net

Magazines, etc.

Archives
Booklet
Books
Bookstore
Brochures

Consumer magazine
Dictionary
Doctor Turbott's book on medical
information
The Dominion Post
Encyclopaedia
New Ethicals (drug book held by chemists)
Flyers
Leaflet
Libraries
Library
Library (book in zone diet)
Listener magazine
Magazine
Magazines
Med Safe leaflet (Ministry of
Health/Internet)
Media
Medical dictionary
The Merck Manual of Diagnosis and
Therapy
Newspaper
Newspaper (news and ads)
Newspapers
Pamphlet
Pears Cyclopaedia

Plunket library
Reference book
Telephone book
The old Red Cross handbook
Woman's Day
Woman's Weekly
Yellow Pages
Radio
National Radio
Radio
Radio (local)
Radio Pacific Talkback
Radio Rhema
Talkback

TV advertising and programmes

Actor
Advertising
Celebrity
Documentaries
Television
TV
TV (ads suspicious)
TV news

Appendix 2: Semi-structured interview schedule for focus groups

Preamble

Thank you for coming along today.

One thing I need to stress is that we need to know about *where you and people you know get information, NOT about anybody's personal medical history.*

Before we get onto the main topic, I need to say that we do have a lot of questions to work through, so let's concentrate on where we go to for information. We're not interested in why people might need this information.

So, we want to concentrate on where you get information from; and where people you know get information from.

Okay. First – to get us warmed up – we'd like to do a bit of brainstorming about information in general.

So, to get us started, where do you personally generally go to get information about things in general?

We are thinking here about the whole range of places that people get information – from word of mouth to professional advice, for example.

Who'd like to go first?

Note: Responses may indicate participants' reading level, etc. Responses will allow us to compare general information sources with specifically pharmaceutical/treatment information sources.

*Prompt to make sure that a full range of sources are covered:
Radio, books, TV, magazines, friends, word of mouth, professional sources, etc.*

Okay, thanks. That's great. Thanks very much.

Now let's think about where you and people like you get information about medicines and other treatments.

Where do you get information about medicines and treatments for health problems?

There are many different health problems that people can have, and there are many different treatments for them.

You probably know other people who have health problems and needs that are different from your own.

Note: As sources of information are mentioned, please note them down on the whiteboard so that they can be referred to during the brainstorming that follows the scenarios.

Prompts: (Brainstorming a list)

Add to the list on a whiteboard, but remember that not everyone in the group will necessarily be able to read what is there either because of literacy or vision restrictions.

The purpose of this brainstorming is to record a list of sources that the participants know of and prefer.

If the brainstorm finished without some of the following being mentioned, prompt for them to find out whether participants did not think of them, but they do use them, or whether they do not use them at all.

Prompt specifically for:

- *Family doctor or GP*
- *GP practice nurse*
- *Chemist or pharmacist*
- *TV ads*
- *Magazines, etc.*
- *Drug companies – through direct advertising*
- *The information that comes with medicines, either on the packet/bottle or from the pharmacist*
- *Traditional healers*
- *Alternative (complementary) practitioners*
- *Family members*
- *Friends and associates*
- *Organisations like the Cancer Society and Heart Foundation*
- *Other support groups.*

Okay, great!

Now that we have this list of sources, let's work through it to discuss which of them are ones that you and/or people you know would be likely to go to first if:

- it were for you
- it were for a child
- it seemed to be a serious illness
- you didn't need to worry about cost
- you *did* need to worry about cost.

For each one that people identify as their first point of information ask the following question.

Thanks, now what would be your next choice of place to go for information if this one didn't work out very well for you?

Okay, thanks. Now which one would you go to next?

Responses will probably depend on the health problem – probe as necessary for first choice, second choice and third choice of information source.

Now we've got a list of these different sources of information. Could we take a closer look at them and talk about the good points and bad points of using each of them as a source of information about medicines or other forms of treatment?

For each listed source of information please ask the group to discuss the following questions.

What are the good points about getting information from [name of source]?

What are the bad points?

Prompts: Cost, availability, ease of use, feeling comfortable.

Now, one of the sources we have listed is direct advertising to consumers. We are interested to know whether any of you have asked your doctor/GP to prescribe a medicine that you have seen advertised and that you think would relieve some symptoms that you have?

Have you asked your doctor/GP to prescribe a medicine that you have heard about from any other source of information apart from your doctor/GP?

With direct advertising of medicines and treatments on TV, it is done through short advertisements and through longer infomercials. If you watch any of these, which do you prefer?

Would you tend to trust something that was being presented by a celebrity rather than by a normal actor?

Thanks, that's great!

The next lot of questions are based around situations or scenarios where people might want information about a medicine or treatment.

When you're discussing these, we'd like you to think about yourself or about people you know, it could be family or friends. You don't need to say their names.

Scenarios

Okay, so here we go.

- The doctor has prescribed an inhaler or puffer for asthma, and the person wants to know more about it, isn't sure about it, or maybe has heard people complaining about this medicine.
 - How would you find out about this medicine?
 - Would you want very detailed information or more general information (what sort/level of information)?
 - What would be the most worthwhile source of information?
- Say you have a medicine that seems to cause side effects, like diarrhoea, stomach ache or headache. You want to know if it might be the medicine that is causing the problem and what to do about it.
 - How would you find out about that?
 - What would be the most worthwhile source of information?
- Say you hear about a new medicine you can buy at the chemist for indigestion and wind/stomach gas (which they say can be serious), and you get indigestion a lot.
 - Would you want to find out anything more about the medicine?
 - Why? How would you find out?
 - Would you want very detailed information or more general information (what sort/level of information)?
 - What would be the most worthwhile source of information?

Prompt: Might the suggestion that this could be serious prompt a person to seek professional advice? Note: The problem might be embarrassing – having to have a bowel investigation etc, or even talking to chemist in shop about such a condition – public place.

- You've got a family member struggling with overweight. He's worried about his health, but he has trouble losing weight.
 - How would you get information about how to lose weight safely?
 - How would an overweight person prefer to get information?
 - Would you want very detailed information or more general information (what sort/level of information)?
 - What would be the most worthwhile source of information?
- You have arthritis. You see an advertisement on TV about a new medicine for arthritis. It shows people being really active on the new drug. The ad says to see your doctor about the medicine.
 - Would you want to find out anything more about this new medicine?
 - Why?
 - How?
 - Would you want very detailed information or more general information (what sort/level of information)?
 - What would be the most worthwhile source of information?

Prompt: Would you suggest a different way of finding out if it were not a drug but some other treatment, such as a copper bracelet?
- Your mother/sister/brother/husband has cancer of the bowel. S/he has had surgery at the hospital and is now at home with you and feeling well again. S/he has lots of pills of different kinds to take every day and is fed up with having to take so many.
 - Would you want to know more about the pills?
 - How would you find out?
 - Would you want very detailed information or more general information (what sort/level of information)?
 - What would be the most worthwhile source of information?
- You seem to be getting colds and flus a lot, and a neighbour suggests a supplement (vitamins? herbs?) that you can buy in the supermarket. Your neighbour swears by this supplement and says she hasn't been sick once since starting on it a few years ago.
 - Would you want to know more about this supplement?
 - Why?
 - How?
 - Would you want very detailed information or more general information (what sort/level of information)?
 - What would be the most worthwhile source of information?

That's great. Thanks very much.

Stage Two

Note to the facilitator: It is possible that the following issues will have already been covered in people's responses to earlier questions. At this point, to avoid needless repetition, use your judgement about whether or not to pursue any particular issue.

Okay, that's good. Now looking back at our list of sources of information, could you talk about how reliable or trustworthy AND how useful you think each source is.

Which of those sources of information do you think is the most reliable and trustworthy AND which is the most useful? How can you tell?

Which sources are less reliable or trustworthy? Less useful?

How can you tell?

Prompt: Because it is: from a “professional” source; from someone you know and trust; was on TV; was on the Internet; was in a magazine article.

Some of the sources you have suggested are health professionals, some are informal and some are commercial, such as TV and Internet advertising.

Would you go to a different source on different occasions?

Why?

What about other people you know?

What makes people decide?

Prompt: Cost, availability, accessibility, feeling comfortable.

If you could get information some other ways, what would you prefer?

This is the dreams question. Prompts: People, places, formats, situations, language, etc.

We've nearly finished now.

How do you like to receive information about medicines or treatments?

Are you more comfortable getting it straight from a person? Who?

Or by reading about it? Where?

Or from radio or TV? Which stations/channels?

Or from the Internet? Where?

What is most comfortable for you?

What level of information do you like to receive?

What are the most important things – from your personal point of view – for you to know about a medicine or treatment?

Prompt: Side effects, what the alternatives are, etc.

And finally – and this might be a bit tricky, but let's see how we go ...

When you think about what would be your ideal way of finding out about medicines and medical treatments, what sorts of words or ideas come into your thoughts or mind?

What words would you use to describe it?

Let's have a brainstorm.

Try not to prompt, but if you really need to get things going, try something like:

For example, “understandable”, “accessible”, “free”.

Well, we’ve reached the end.

Well done, and thank you all very much for your contributions.

You’ve worked really hard.