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DOCTOR OF PHILOSOPHY

ON..... 3 June 2003

.....
→ Sec. Research Graduate School Committee

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ERRATA

- p 5 line 2: "Australian Internet use varied" for "Australian Internet use varies"
- p 7 line 9: "preventive" for "preventative"
- p 9 line 14: "varied" for "varies"
- p 35 line 6: "questions" for "question"
- p 42 third reference: "outpatients" for "outpatients"
- p 51 line 3: "preventive" for "preventative"
- p 71 line 4: "consequently" for "subsequently"
- p 78 line 11: delete "," and read "although packaging contains some information, ..."
- p 83 line 2: "who" for "whom"
- p 85 line 10: delete "." and read "published on webpages ..."
- p 91 line 24: "Consumers" for "Consumer"
- p 98 line 10: "groups:" for "groups;"
- p 99 line 10: "less" for "lees"

ADDENDUM

- p 1 line 10: delete "and" and read "how, when, why and which ..."
- p 2 line 6: delete "a" and read "The Web is characterised by multimedia..."
- p 11 line 10: delete "and", insert "that had" and read "online information that had a positive experience...."
- p 12 line 14: delete "and implemented" and read "Guidelines for the clinical use of email between Australian doctors and consumers are yet to be developed."
- p 14 line 7: "was" for "is"
- p 14 line 10 "where" for "whereby"
- p 33 line 5: "but" for "and"
- p 21 line 4: delete "subsequently" and read "These online resources have ..."
- p 23 line 24 delete "subsequently" and read "duplicates were removed."
- p 23 line 25 delete "first" and insert "then" and read "The researcher then screened each citation ..."
- p 30 line 3 & 4: delete "meanwhile" and insert "users" and read "Jones compared Internet users versus outpatients ..."
- p 34 line 21: insert "the identification of" and read "did not result in the identification of any other studies"
- p 36 Add at the end of paragraph 1 sentence 1: The researcher conducted all further data analysis including the coding and stratification of de-identified primary Health Omnibus data provided by the Behavioral Epidemiology Unit of the South Australian Department of Health.
- p 36 Add a new paragraph after paragraph 4 and insert: Although 643 of the 3027 participants reported using online health information in the past twelve months only 82 percent of these online health seekers had internet access. Eighteen percent (17.5%, 95%CI 14.66, 20.54) gathered online health information via third parties such as family and friends.
- p 38 delete table 10 and insert table 10 below.
- p 38 Add at the end of paragraph 2 sentence 1: "The estimated maximum sampling error with a sample size of 643 participants is $\pm 3.86\%$ at the 95% confidence level. Thus the above estimates regarding the frequency of online health seekers who bought medicines online is subject to considerable sampling error and lacks robustness."
- p 39 line 8: insert "(table 9)" and read "more females are online health seekers"
- p 39 Add at the end of paragraph 2 sentence 1: Despite this observation, maleness is a predictive characteristic of online health seeking (table 10) because online health seeking is strongly associated with Internet access.
- p 39 line 18: insert "to have" and read "are more likely to have better health status"
- p 47 line 7&8: insert "In this case," and "generated by the researcher (TB)" and read "In this case, the drug information pharmacist who originally conducted the interviews reviewed the resultant themes generated by the researcher (TB)."
- p 48 line 2 & 3: delete "of" and insert "a" and read "comprising a product or disease name."
- p 67 line 4: insert "when informed of the research" and read "No e-pharmacies withdrew their results when informed of the research."
- p 71 line 20: delete "current" and read "total number of e-pharmacies ..."
- p 82 delete "determined to be" and read "services provided by websites selling medicines online in winter 2001 was highly variable"

p 83 delete "in 2002 were considered" and read "to gather qualitative data".
 p 83 line 22: replace "whereby people who" with "where people" and read "The participants of online newsgroups where people come together ..."
 p 84 line 4: delete "Media" and read "Monash University Media Fax Stream Service".
 p 100 line 4: delete "Although" and read "Evidence of discounted PBS listed pharmaceuticals ..."
 p 100 line 7: delete "Although" and read "This may change in the near future ..."
 p 101 line 3: Delete "," and read "If a two tier dispensing fee was implemented ..."
 p 108 line 10: "have" for "has"

Table 10: Logistic regression analysis to identify predictive characteristics of online health information seekers.*

Characteristic	Reference Variable	df	Sig.	Odds Ratio	95%CI for Odds ratio	
Age						
<34 years	55 years +	1	.000	2.3	1.6	3.3
34-54 years	55 years +	1	.000	2.2	1.6	3.0
Education						
Still at School	Left 15 years +	1	.002	2.8	1.4	5.3
Certificate/Degree	Left 15 years +	1	.000	1.8	1.4	2.3
Early Leaver /Trade	Left 15 years +	1	.023	0.7	0.5	1.0
Income						
Household Income \$40,000+	<\$40,000	1	.000	1.8	1.4	2.2
Gender						
Male	Female	1	.001	1.4	1.2	1.7
Employment						
Employed	Not employed	1	.098	1.3	1.0	1.6
Country of Birth						
Australia	Not Australia	1	.411	1.1	0.9	1.4
Residential Area						
Metropolitan	Not metropolitan	1	.585	1.1	0.9	1.3
Marital Status						
Married /Defacto	Never married	1	.445	1.1	0.8	1.5
Separated/Divorced/Widowed	Never Married	1	.719	0.9	0.6	1.4

* 78% of the variance was explained by the variables in the equation.

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THE INFLUENCE OF THE INTERNET ON THE QUALITY USE OF MEDICINES.

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Monash Institute of Health Services Research
January 2003

A thesis submitted for the degree of Doctor of Philosophy, Monash University.

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ABSTRACT

Many Australians have the capacity to access online health information and buy medicines via the Internet but does this cause more harm than good? This thesis explores how Australians seek and use online health resources, particularly information about medicines and whether consumers who buy medicines online can do so in a manner that supports their safe and appropriate use.

This thesis comprises several discrete studies including the first Australian population survey describing the online health information seeking behaviour of consumers and the first large study evaluating the quality of services and information published on global e-pharmacy websites. Furthermore, the results of these surveys are enriched by the personal insights of Australian consumers who bought medicines or sought information about medicines via the Internet.

Australians value online health information. Overall they view online health information and services as useful and complementary to existing healthcare resources. The Internet provides consumers access to information and a range of health care options that was once largely unavailable to them. It also permits consumers to have a greater degree of control and input into health care decision-making, although misinformed consumers are potentially at risk.

Consumers perceive the risks associated with buying medicines from either an Australian local or e-pharmacy to be not significantly different; nonetheless caution is well founded when importing medicines from overseas websites. The quality of services delivered by global e-pharmacies is variable, and many websites lack or publish poor quality information and thus do not support the safe, and appropriate use of medicines.

In 2002, only small but increasing numbers of Australians buy medicines via the Internet. Consumers buy medicines online for reasons of costs and convenience. However, the growth of e-pharmacies in Australia is likely to increase incrementally,

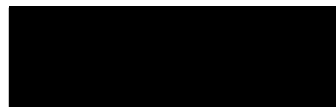
unless PBS policy reforms diminish universal access to medicines and consumers are forced to pay a greater share of the costs of medicines.

The Internet is an integral part of Australia's health care system. Public access to online healthy information and services including e-pharmacies can both positively and negatively influence the quality use of medicines. To support the achievement of QUM in an online environment will requires a systems based approach and potentially numerous interventions. However, the necessity to implement such interventions is tempered by a lack of evidence of harm to Australians resulting from online sales of medicines and the methodological challenges of studying the behaviour of consumers who use the Internet to meet their medication needs.

STATEMENT OF AUTHORSHIP

This thesis is original work and to the best of my knowledge it contains no material previously published or written by another person, except where due reference is made in the text.

This thesis contains no material, which has been accepted for the award of any other degree or diploma in any university or other institution.



31/1/03.

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"If I have seen further than others, it is by standing on the shoulders of giants."

Isaac Newton

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I first met Emeritus Professor Lloyd Sansom AO as a pharmacy undergraduate in the 1980s at what is now known as the University of South Australia. However, it was at one of many pharmacy dinners in 1996 that he told me about the Master of Public Health course offered at the University of Adelaide, and 'the rest is history.' Lloyd is a 'living treasure' of pharmaceutical and pharmacy knowledge. He is also a driver of health policy reform and practice, in particular the development of Australia's National Medicines Policy.

Professor Janet Hiller is the Chair of Public Health and the first woman to be appointed Professor in the Medical Faculty at the University of Adelaide. Janet is a great teacher who makes epidemiological concepts seem easy. She is also an inspiring role model who has a great passion for research. In 1999, when she asked me if I had considered undertaking PhD studies and I flippantly replied 'only if I can work with the best'; she introduced me to Professor Chris Silagy AO at Monash University.

Professor Chris Silagy AO was my primary supervisor and much has been written about his achievements and academic legacy, after his untimely death in December 2001 from non-Hodgkins lymphoma at age 41 years. Professor Nick Saunders said 'a month of Chris Silagy was worth a lifetime of some people.' Chris was a great mentor and visionary, who despite his illness was always positive, dynamic and exuberant. I still miss the buzz and excitement of bouncing ideas around and working alongside him.

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ACRONYMS

ABS	Australian Bureau of Statistics
APAC	Australian Pharmaceutical Advisory Council
CMI	Consumer Medicines Information
CRADE	Consumer Reporting of Adverse Drug Reactions
FDA	Food and Drug Administration
HIV	Human Immunodeficiency Virus
IP	Internet Protocol
ISP	Internet Service Provider
MIHSR	Monash Institute of Health Services Research
NHIAC	National Health Information Advisory Council
NMP	National Medicines Policy
PBAC	Pharmaceutical Benefits Advisory Committee
PBS	Pharmaceutical Benefits Scheme
PDA	Portable Digital Assistant
PHARM	Pharmaceutical Health and Rational Use of Medicines
QMH	Queensland Medication Helpline
QUM	Quality Use of Medicines
SSRI	selective serotonin reuptake inhibitors
TCP	Transmission Control Protocol
WAP	Wireless Application Protocol
WWW	World Wide Web

PUBLISHED PAPERS AND CONFERENCE ABSTRACTS*

Papers

Bessell TL, Anderson JN, Silagy CA, Sansom LN, Hiller JE. Surfing, Self-Medicating and Safety: Buying Non-Prescription and Complementary Medicines via the Internet. Quality, Safety and Health Care (in press, publication in February 2003).

Bessell TL, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Quality of Global E-pharmacies: Can we safeguard consumers? *European Journal of Clinical Pharmacology* 2002;58:567-572.

Bessell TL, Whitty JA, McGuire TM, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Medicines and the Internet: a qualitative study of the views and experiences of online medicines information seekers. *Australian Pharmacist* 2002;21:361-65.

Bessell TL, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Prevalence of South Australia's Online Health Seekers. *Australian New Zealand Journal of Public Health* 2002;26:75-77.

Bessell TL, McDonald S, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Do Internet interventions cause more harm than good? A systematic review. *Health Expectations* 2002;5:28-37.

*All published papers and conference abstracts were peer-reviewed. Copies of the papers are in Appendix 1.

Conference Abstracts

Oral Presentations

Bessell TL, Anderson JN, Hiller JE, Sansom LN. Can we regulate e-pharmacies? World Pharmacy Congress, Nice, August 2002.

Bessell TL, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Surfing, Self-Medicating and Safety. World Pharmacy Congress, Nice, August 2002.

Bessell TL, Anderson JN, Hiller JE, Sansom LN. Can we regulate online health services? A case study of global e-pharmacies. National Medicines Symposium, Canberra, March 2002

Bessell TL, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Surfing, Self-Medicating and Safety. National Medicines Symposium, Canberra, March 2002.

Bessell TL, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Surfing, Self-Medicating and Safety. Australian Pharmaceutical Sciences Association Conference, Melbourne, December 2001. (Awarded Best Student Presentation at this conference.)

Bessell TL, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Australia's online health seekers. Pharmacy Australia Congress, Melbourne, October 2001.

Bessell TL, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Australia's online health seekers. Royal Australian College of General Practitioners 11th Computer Conference, Melbourne, August 2001.

Posters

Bessell TL, Whitty J, McGuire T, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Online Medicine Information Seekers: A Qualitative Pilot Study of Australian Consumer Views and Experiences. National Medicines Symposium, Canberra, March 2002.

Bessell TL, Whitty J, McGuire T, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Online Medicine Information Seekers: A Qualitative Pilot Study of Australian Consumer Views and Experiences. Australian Pharmaceutical Sciences Association Conference, Melbourne, December 2001.

Bessell TL, Silagy CA, Anderson JN, Hiller JE, Sansom LN. E-Pharmacies and the Quality Use of Medicines: the good, the bad and the ugly. Australian Pharmaceutical Sciences Association Conference, Melbourne, December 2001.

Bessell TL, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Consulting Cyberspace. Australian Pharmaceutical Sciences Association Conference, Newcastle, December 2000.

Bessell TL, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Consulting Cyberspace. Monash University, Faculty of Medicine, Nursing & Health Sciences Postgraduate Research Symposium, Melbourne, October 2000.

Bessell TL, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Consulting Cyberspace. National Prescribing Service (NPS) & Pharmaceutical Rational Use of Medicines (PHARM) Conference, Melbourne, August 2000.

1 INTRODUCTION

"Four years ago it was unusual for a person to walk in with a recommended course of treatment in hand. But it is not unusual anymore. Forty million people visited health care sites in the first quarter of this year [2000]. By 2005, it is expected that 88 million will use the Internet for health care information. The health care industry is beginning to realise that we are rapidly running out of ignorant uniformed patients. This is going to have a profound impact on every aspect of the industry."¹

Whilst the Internet can provide consumers with access to innovative health care services, support and information, it lacks quality assurance and equity of access. Evidence about how, when, and why and which Australians use the Internet for health care is lacking. Furthermore, the development of legislation, regulations, policies, practice standards and guidelines designed to safeguard the public is piecemeal and often lags the implementation of technology driven by the consumers' demands.

Australians can now obtain medicines and health information via the Internet from almost anywhere in the world. It is unknown whether this behaviour enhances consumers' health care outcomes and experiences. As Australians increasingly access the Internet and buy medicines online, it is timely to examine whether effective medicines are supplied in a manner that optimises their safe and appropriate use.

1.1 THE INTERNET

The Internet has revolutionised communication. It provides global communication to homes, businesses and governments but is not controlled or administered by a single entity. It is a global network, comprising thousands of Wide Area Networks, Local Area Networks and individual computers, connected together by Transmission Control Protocol/Internet Protocol (TCP/IP),² the service that reassembles data sent over the Internet into a consistent stream.

1.1.1 HISTORY OF THE INTERNET

The Internet was initially developed in the US and has taken over 40 years to reach its current capabilities (table 1). Over time computer use has changed from data processing to providing interactive communication, information, commerce and entertainment delivered via the Internet.

The advent of the World Wide Web (WWW or the Web) was a milestone Internet event. The Web is characterised by multimedia (a combination of text, graphics, audio and video) with hypertext (links between documents) that allows information distributed from multiple locations to be retrieved in a non-sequential manner.³ It is also the collective term for all information available via the Internet. Public access to such information is now facilitated by public Internet Service Providers (ISPs) and search engines, which index huge amounts of information.

In 1997, a survey of 1010 Americans who accessed the Internet from home estimated that they spent 43 percent of their time researching or getting information from the Web and 34 percent of their time sending or receiving e-mail.⁴ Other uses included playing games (9%), reading magazines or newspapers online (5%), participating in online chat rooms (4%), online banking (2%), using two-way voice communications analogous to speaking on the telephone (1%) and online shopping (1%).⁵

In 2002, Internet access is still almost entirely via personal computers (PCs). Already, the nature of this access is changing as web-based appliances are being more commonly used, such as digital television, Wireless Application Protocol (WAP) enabled mobile telephones and portable digital assistants (eg Palm Pilots®). E-commerce, the electronic trading of goods or commodities via the Internet, is also predicted to further drive the uptake and application of Internet technologies by businesses and consumers.⁶ However, information gathering and communication are likely to remain the core reasons for Internet use.

Table 1: Summary History of the Internet

1940s	First computers developed during World War II.
1950s	IBM put the first commercially available general-purpose computer on the market in 1952. USSR launches Sputnik, the first artificial earth satellite. In response, the US forms the Advanced Research Projects Agency (ARPA), within the Department of Defence to establish US advancement in science and technology applicable to the military.
1960s	'Packet switching' the precursor to computer networking was developed. US Air Force asked Paul Baran to conduct research on a military research network that could withstand a nuclear strike.
1970s	First demonstration of APRANET (one network) First cross-country links established. Standard communication protocol- TCP/IP (Transmission Control Protocol/Internet protocol) developed and implemented over ten year period to create inter-networks needed for unlimited growth.
1980s	Entire networks can be connected.. Networks mushroomed and the term "Internet" born. Non-governmental use of the system began. Domain name system introduced. Moderated newsgroups introduced on USENET. Desk top work-stations available Commercial networks, such as CompuServe and America Online drew users. E-mail established Virus alerts issued.
1990s	Australian Academic Research Network established WWW developed and publishing on the Internet grew. Public Internet Service Providers (ISPs) provide public access. First search engine launched in 1995. Graphics, video and sound effects were added to the Internet
2000s	Internet access via mobile phones and digital television Cable and broad band internet connection for faster information downloads

Sources :

- 1 Zakon RH. Hobbes' Internet Timeline Copyright (c)1993-2000. Available online at <http://www.isoc.org/zakon/Internet/History/HIT.html> [Accessed 28 Apr 2000].
- 2 Gromov GR. History of the Internet and WWW: The Roads and Crossroads of Internet History. Available online at <http://www.internetvalley.com/intvalold.html> [Accessed 28 Apr 2000]

1.1.2 GLOBAL INTERNET USE

Internet use has rapidly increased in the past decade. Despite being based upon different methodologies and definitions, between March 2000 and September 2002, the estimated number of people with Internet access has grown from 333 to 605 million people worldwide (table 2).⁷ In 2002, the greatest growth is occurring in the Asia Pacific region.

Table 2: Estimated Global Internet Users in September 2002.

<u>World Total</u>	605.60 million
<u>Africa</u>	4.15 million
<u>Asia/Pacific*</u>	157.49 million
<u>Europe</u>	171.35 million
<u>Middle East</u>	4.65 million
<u>Canada & USA</u>	181.23 million
<u>South America</u>	25.33 million

*Australian estimates are part of those for the Asia/Pacific region.

Source: Scope Communications Group. NUA Surveys – How Many Online? Sep 2002

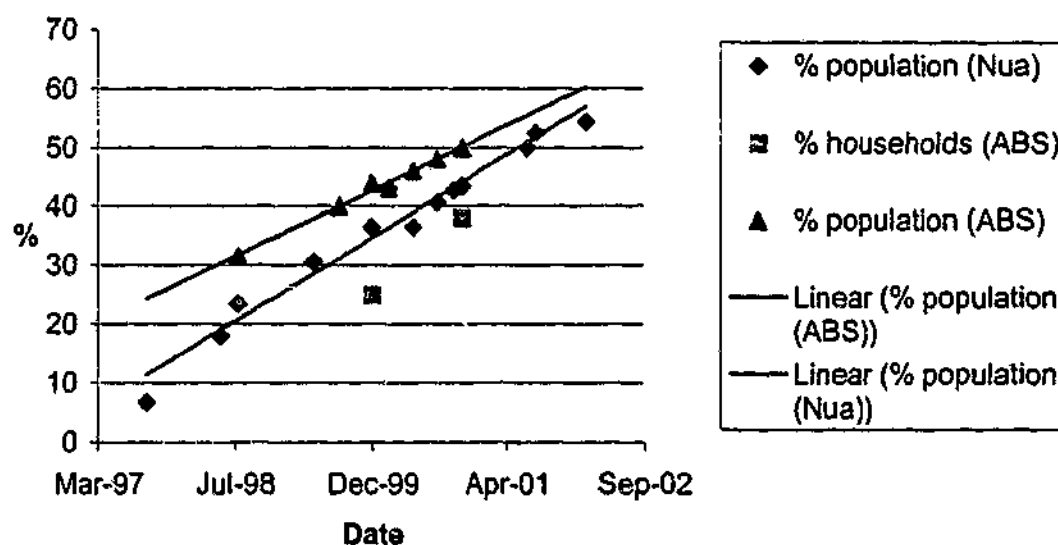
Available at: http://www.nua.ie/surveys/how_many_online/index.html Cited Dec 2, 2002.

From the table above it can be observed that Internet access however is not equal. The people of many developing nations remain largely unconnected to the Internet and are therefore unable to access online information and resources.

1.1.3 AUSTRALIAN INTERNET USE

Australians have rapidly adopted the use of Internet technologies (Figure 1). During the 12 months prior to November 2000, it was estimated that 6.9 million adults (50% of all Australian adults) had accessed the Internet, whilst 2.7 million (37%) of Australian households had home Internet access.⁸ Australians are amongst the highest users of the Internet technologies in the world.

Figure 1: Estimates of Australians and Australian households with Internet access between Sep 1997 to Feb 2002.



Sources:

1. % population data from Nua Surveys. How many online? [online] Available at: http://www.nua.ie/surveys/how_many_online/asia.html Cited Dec 2, 2002.

2. % ABS population and household data from Australian Bureau of Statistics.

Use of the Internet by Householders 8147.0, series of reports August 1998 to November 2000 [online]. Available at:

<http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/AE8E67619446DB22CA2568A9001393F8> Cited Dec 2, 2002.

Not only is Internet access distributed unequally across countries but also within nations. In 1999 Australian Internet use varies according to age, education, income and profession (tables 3, 4 & 5). Twenty-five to fifty-four year old adults are most likely to access the Internet at home or work. Older adults are more likely to access the Internet at home, whilst younger adults access the Internet from sites other than home or work. Internet use is higher in metropolitan than rural areas and also amongst households with children.

Of the Australian adults with Internet access, 84%, 79% and 30% used the Internet at least once a week at home, work or other sites (table 6).

Table 3: Proportion of Australian Households with Internet access in 1998 and 1999 categorised by family type, income, and location.

	Proportion(a) of households with home Internet access	
	1998 %	1999 %
Family type		
Married/defacto couple	13	18
Married/defacto couple with dependants	23	35
Single parent	11	15
Single person	7	8
Other	22	25
Children		
Without children under 18	13	17
With children under 18	22	31
Household income		
\$0-\$24,999	5	6
\$25,000-\$49,999	12	17
\$50,000-\$74,999	21	31
\$75,000-\$99,999	32	39
\$100,000 or more	44	52
Not stated/don't know	18	24
Location		
New South Wales	18	22
Victoria	15	23
Queensland	15	21
South Australia	13	20
Western Australia	15	23
Tasmania	10	18
Northern Territory	16	29
Australian Capital Territory	28	35
Region		
Metropolitan areas	19	26
Other areas	11	15
Total	16	22

Source: ABS Use of the Internet 8147.0 Feb 2000.

- (a) Proportions are of all adults in each category.
 (b) (b) Adults can nominate more than one site if applicable.
 n.a not available.* estimate has a relative standard error between 25% and 50%.

Table 4: Australian Adult Internet Access categorised by Occupation and Education 1999

	Site of Internet access(b)			
	Home %	Work %	Other sites %	Any site %
Occupation				
Manager and professional	35	51	29	69
Clerk, sales and personal services	20	29	30	55
Trades person, plant or machinery operator, labourer	15	10	25	38
Education				
Secondary	11	9	18	28
Trade certificate/apprenticeship	11	11	18	31
Other certificate	15	18	22	41
Assoc/undergrad diploma	31	34	28	59
Bachelor's degree	41	56	39	80
Total	18	20	23	41

Source: Household Use of Information Technology, Australia, 1999 (Cat. no. 8146.0).

Table 5: Australian Adult Internet Access by site in 1999.

	Site of Internet access(c)			
	Home %	Work %	Other %	Any site %
Age (in years)				
18-24	36	21	62	77
25-39	30	29	26	55
40-54	26	26	11	43
55 or over	9	6	3	13
Sex				
Males	28	24	21	46
Females	21	18	20	41
Employment status				
Employed	31	32	24	56
Not employed	13	n.a	15	23
Income				
\$0-\$39,999	19	12	21	37
\$40,000 or more	38	46	23	66
Region				
Metropolitan areas	28	22	22	47
Other areas	16	19	18	37
Total	24	21	20	43

Source: Household Use of Information Technology, Australia, 1999 (Cat. no. 8146.0).

Table 6: Frequency of Australian Adult Internet Access

Frequency of Internet Access*	Home	Work	Other sites
	%	%	%
Daily	32	41	5
2 – 6 times a week	41	24	16
Once a week	11	14	9
Once every 2 weeks	4	5	8
Once a month or less	11	16	63

*Adults can nominate more than one site if applicable

Source: Australian Bureau of Statistics Use of the Internet 8147.0 Feb 2000.

Thus increasing numbers of Australians are accessing the Internet as part of daily life. They use the Internet to communicate, seek information and support, bank, buy goods online and for entertainment. They probably also use the Internet for health care purposes.

1.2 HEALTHCARE AND THE INTERNET

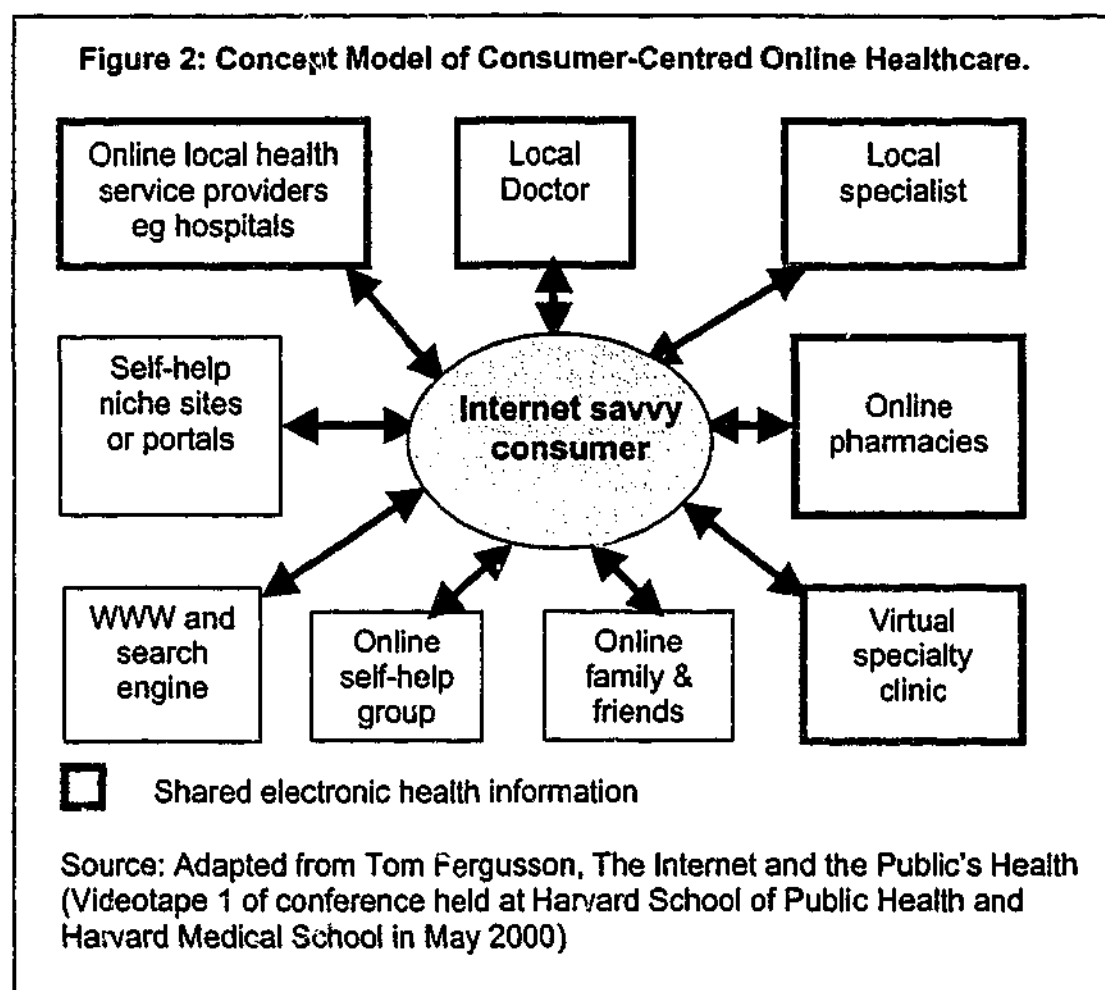
Commercial, accounting and record keeping needs have driven the introduction of Internet technologies in primary health care settings and only recently has the focus changed to utilising technology to improve health care outcomes and delivery.⁹ Current e-health initiatives include: e-prescribing, integrated data exchange, electronic health records, clinical and preventative web-based tools, and decision support systems.

1.2.1 DEFINITION OF E-HEALTH

“E-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterises not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology.”¹⁰

1.2.2 E-HEALTH MODELS AND THE HEALTH CARE SYSTEM

As societies increasingly access the Internet for health care, online services must become more consumer-focused and improve self-care. An example of a consumer centred e-health model is shown in figure 2.

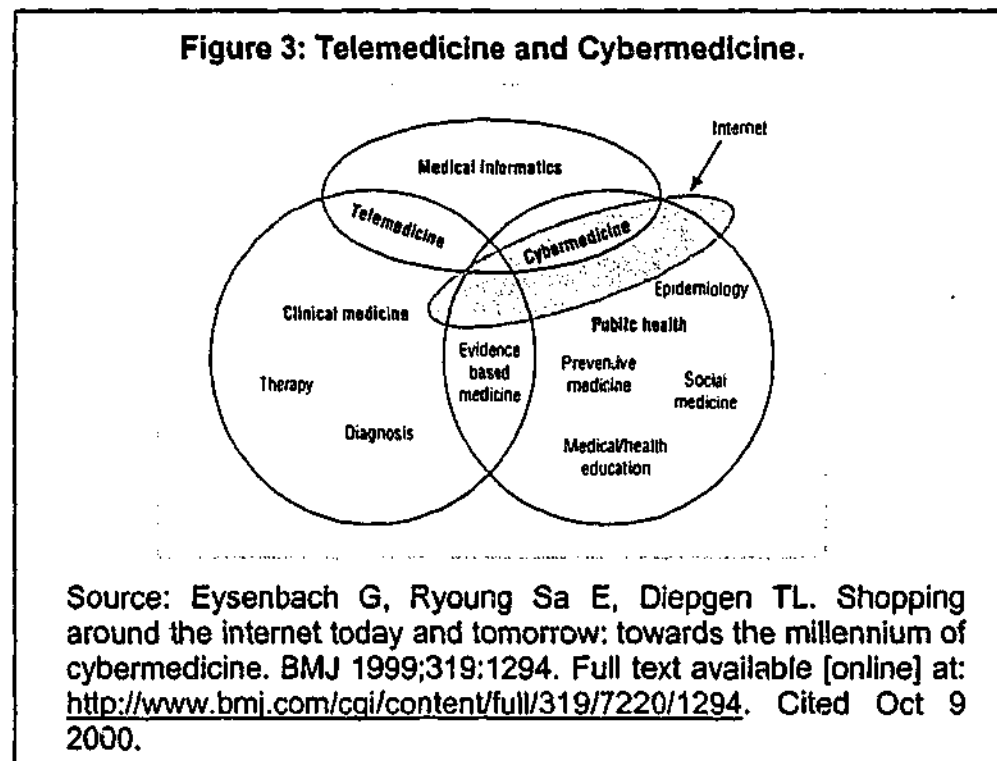


If the above or similar e-health models are realised by large numbers of consumers, the potential impact upon health professional workflows and practices, costs and outcomes could be dramatic. Thus it is timely to examine how health professionals and consumers use the Internet for health care and the effectiveness of e-health interventions.

1.2.3 CLINICIANS & HEALTH SERVICE PROVIDERS

Clinicians and health service providers use the Internet for education, information, communication, decision-support, record keeping and research purposes. Telemedicine focuses on the provision of clinical services delivered via the Internet between health care provider and patient whilst cybermedicine focuses on preventive medicine and self

care (figure 3). In 2002, some doctors are also providing online consultations and/or prescribing whilst some pharmacists provide online ordering and delivery of medicines.



Despite the potential of the Internet to deliver these innovative services, clinicians have largely resisted the use of Internet technologies in their daily practice, in particular to communicate with and educate consumers. The Internet challenges the balance of power between health care providers and consumers because it provides online consumers access to the same information as health professionals. The reduction in the disparity of information available to both health professionals and consumers combined with current political policies such as deregulation and competition are a potential threat to the power of professional organisations.¹¹ Professional power has been described as the control of knowledge and practice, which is subsequently protected by legislation and self-regulation.¹² Thus, health professionals may fear and resent consumer use of the Internet and act to protect the interests of their profession. In 2000, the attitude of doctors to consumer use of the Internet as a health care resource varies from actively encouraging to actively discouraging.¹³⁻¹⁴

The Internet may empower consumers. Empowerment is defined as the 'process through which people become more able to influence those people and organizations that affect their lives.'¹⁵ Thus, whilst technical knowledge resides with health care providers, and preferences and experiences reside with consumers, good communication

and a partnership approach are vital to achieving positive health outcomes. To date, a core issue that has been largely ignored by researchers is why consumers use the Internet for online consultations and information instead of traditional consultations with health professionals.

1.3 CONSUMERS, HEALTH AND THE INTERNET

"The Internet revolution in health care is largely driven by a massive consumer demand for online health services."¹⁶

Consumers use the Internet to seek health information, electronic discussion and support groups, online consultations and referrals, and to buy medicines and health related products online. Consumers can now enter their personal health information online using software to create and maintain a personal electronic health record. Software packages assist self-diagnosis and management by providing tools such as self-risk assessments, tracking of blood sugar levels and behaviour modification programs.

1.3.1 SEEKING ONLINE HEALTH INFORMATION

Both good and poor quality health information has always existed in society, and information available via the Internet is no exception. The difference between traditional and Internet information is the scale of information retrieval. When a person seeks information via the Internet using a general search engine they may be presented with thousands of Web site 'hits'. They then have to elect from which sites to gather information. The material may be outdated, no longer available or may not be relevant to the user. The quality of Web information is variable and the best method of quality information retrieval is unknown.¹⁷⁻¹⁸ The current technological challenge is to both reduce the amount and improve the quality of the information that is relevant to consumers' needs so that they may make well-informed, evidence-based health care decisions.

Public interest in health information is fuelled by social, political and economic changes such as the consumers' rights and women's health movements.¹⁹ Searching for health information is reported to be one of the most popular reasons for using the Internet.²⁰ Health and medical web sites are reported as being the second most widely visited sites on the Internet – second to 'adult only' sites.²¹⁻²²

Public access to online health information potentially improves consumer awareness of health conditions, management and treatment options, costs, benefits and risks. Consumers are using the Internet to obtain information about their illnesses and treatments and interpreting such information to shape treatment preferences.²³ An example of consumers seeking online health information and a positive impact on health outcomes is shown in box 1.

Box 1: A positive health outcome²⁴

In 1998, an ultrasound test performed on a New Jersey woman showed that the child she was carrying, her fourth, would have the birth defect known as spina bifida. The baby girl would be born paralysed below the waist and probably brain-damaged. Their doctor told the women and her husband that the only alternative was an abortion. They rejected that option and settled in to wait apprehensively for the life they would have to live after the baby was born. To help prepare the couple, a cousin researched the condition on a number of consumer health sites. At one of the sites, the expectant father read a news article about Vanderbilt University in Nashville experimenting with foetal surgery to repair spina bifida. The couple contacted doctors at Vanderbilt and were accepted into the program. The foetus underwent the pioneering surgery in her mother's womb. The surgery was successful. The girl is now able to stand and walk.

1.3.2 ONLINE DISCUSSION AND SUPPORT GROUPS

Electronic discussion and support groups allow consumers to exchange health information and experiences amongst people with similar health conditions that may subsequently influence their health care decisions in a different manner.

Support groups are member run and composed of peers that share a common problem or experience, providing a powerful sense of community. Support groups enable people to share experiences, pool knowledge, multiply options, reinforce hopes and join efforts as

members strive to help one another.²⁵ However, initial research conducted on one particular discussion group found that the majority of information exchanged was unconventional, based on limited evidence, and/or inappropriate.²⁶

1.3.3 E-MAIL TO HEALTH CARE PROVIDERS

Communications within discussion groups and support groups have no contractual arrangement for health care provision and advice. In contrast, e-mails communicated directly between health care providers and consumers, are within the context of a professional health care relationship where professional ethics, practice standards and a duty of care exist.

In 2000, it was estimated that 3.7 million US adults had e-mailed their doctor's office and that 33.6 million more were interested in doing so.²⁷ Whether e-mail communication is better than the telephone or facsimile is unknown and issues such as privacy, security, workflow and costs must be adequately addressed. Guidelines for clinical use of e-mail between Australian doctors and consumers are yet to be developed and implemented.

1.3.4 ONLINE CONSULTATIONS

Websites offering consultations with health professionals may require a consumer to complete an online medical history questionnaire, state the reason for the consultation and provide credit card details for payment of services. Responses may be e-mailed directly to the consumer, or consumers may access responses by logging on to a password-protected website.

Online consultations may be convenient, reduce travel and waiting times and avoid consumer embarrassment. However, the disadvantages of online consultations include difficulty detecting unregistered and unqualified health care providers, and deliberate deception by consumers to obtain inappropriate health care. It has been argued that remote dialogue via the Internet is no substitute for 'face-to-face communication.' Lack of privacy and security are also important issues.

An example of a typical and ethical online doctor-patient consultation and website agreement can be found at www.americasdoctor.com. A second type of online consultation also exists where doctors and other health professionals act more as 'coaches'.²⁸ These doctors typically answer questions informally with numerous options, recommend Web sites, referrals, journal articles, offer informal second opinions and often suggest questions for consumers to ask their local doctor. There is usually no charge or sometimes a modest monthly subscription fee.

Peer review of the appropriateness of online consultations used to procure prescription for Viagra® (sildenafil) indicated for the treatment of erectile dysfunction and Xenical® (orlistat) indicated for weight loss found that overall the quality of care and advice was variable and not optimal.²⁹ Although these results are limited due to the small sample size of online consultations, it was not clear whether the sample was random or purposely selected. Thus these results may not be representative of all online consultations.

In November 2000, Australia's first online medical consulting service eMedical Consulting Online®, (www.emedical.com.au) was launched. Consumers could send an e-mail request for personal medical advice and receive an email within 72 hours from a general practitioner or specialist. At that time, it was reported that a doctor would spend an average of 10 to 15 minutes to answer a question for \$15 fee.³⁰ By December 2002, that fee has increased to \$45 for an online consultation and the reply will be delivered within 48 hours. This service does not provide written or electronic prescriptions.

1.3.5 BUYING MEDICINES ONLINE

Traditionally, Australians have obtained prescription and non-prescription medicines from local community pharmacies and complementary medicines from a variety of retail outlets. However, Internet use is changing the supply of medicines, information and related services.

The first online pharmacy opened in the USA in 1995 and since that time online pharmacies have experienced huge market growth in the United States. The US Internet

pharmacy market is expected to grow from US\$11 million in 1998 to US\$890 million in 2002.³¹ In the US, large online pharmacies are often aligned with health insurance/managed care providers. Smaller online pharmacies operate using 'clicks and mortar' business models whereby the fulfilment of online pharmacy orders is an extension of their traditional service to local consumers, analogous to the introduction of the fax machine or telephone. The first UK online pharmacy, Pharmacy2U (www.pharmacy2u.co.uk) opened in late 1999 whilst PharmacyDirect (www.pharmacydirect.com.au) became Australia's first online pharmacy in 2000.

The potential advantages of buying medicines via the Internet include lower prices, convenience and privacy (only if using a secure electronic lodgement facility) and quality personalised interactive information. Disadvantages include a lack of quality assurance of drug quality and efficacy, no face-to-face consultation or examination, breaches of storage conditions during delivery, security, confidentiality of medical information, inappropriate drug promotion and delivery costs.³² For example, the availability of sildenafil (Viagra®) over the Internet has resulted in sales of counterfeit medicines and resulted in post marketing surveillance problems.³² Furthermore, information about sildenafil on the Internet varies from responsible information posted by the US Food and Drug Administration (FDA) to message boards linked to pornographic material.³³ The FDA website provides information about sildenafil for the treatment of erectile dysfunction while the message board promotes sildenafil as a recreational drug.

1.4 QUALITY USE OF MEDICINES

1.4.1 AUSTRALIA'S NATIONAL MEDICINES POLICY

The prevention and treatment of disease is of prime concern to governments throughout the world. Pharmaceuticals play a major role in the provision of adequate health care for communities; however they must be available, of satisfactory quality, accessible, affordable and properly used. The World Health Organisation (WHO) believes that both developed and developing nations should address these issues by developing a National Medicinal Drug Policy, which needs to integrate both the public and private

sectors and should make the best use of the limited resources available to the health care sector.³⁴ WHO emphasises that governments are not the only entities involved in any national drug policy and that there needs to be partnerships between the governments, those people who prescribe, dispense and consume medicines, and those people who make, market, distribute or sell medicines.

In 1991, the Australian Pharmaceutical Advisory Council (APAC) oversaw the development of a comprehensive national drug policy. In December 1999, the National Medicines Policy 2000 (NMP) was launched.³⁵ The NMP encompasses prescription, non-prescription and complementary medicines. The overall aim of the NMP is to address Australia's medication and related service needs, so that both optimal health outcomes and economic objectives are achieved for all Australians.

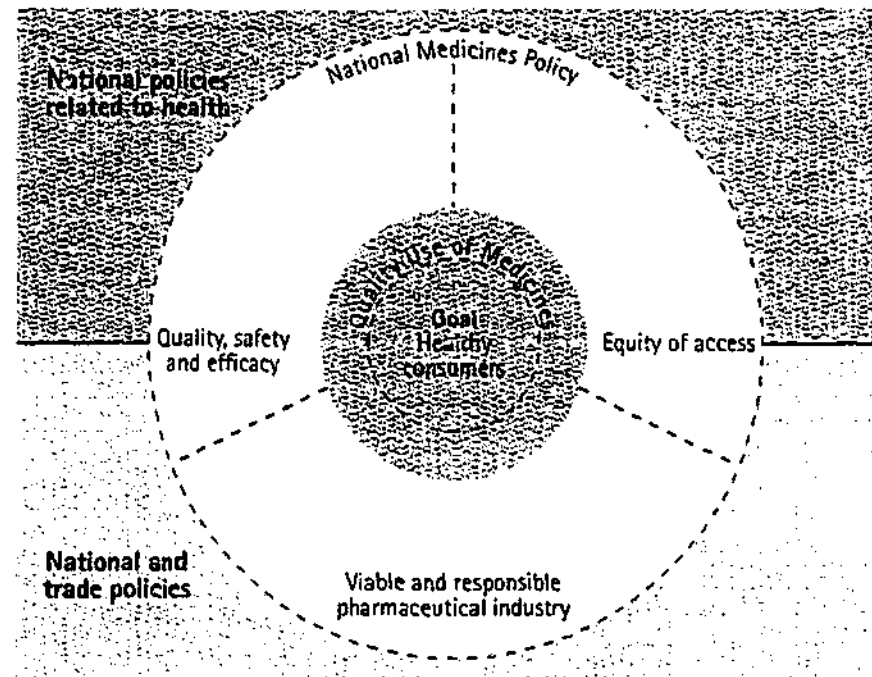
When viewed from outside Australia, the NMP may appear as a coherent whole. In reality, the different sections of the policy have evolved at different rates and in response to different pressures and opportunities. The evolution of the drug registration system and the Pharmaceutical Benefits Scheme (PBS) began in the 1950s, while the emphasis on the viability of the pharmaceutical industry occurred much later (1970s and 1980s). In the early 1990s, a multi-disciplinary working party on the Pharmaceutical Health and Rational Use of Medicines (PHARM) began looking at ways to improve the quality use of medicines, leading to the formation of the Quality Use of Medicines (QUM) policy in 1992.³⁶ This policy linked the other three arms of what was later to become the NMP to health outcomes. QUM is an integral part of Australia's National Medicines Policy (figure 4).

The four interdependent objectives of the NMP are:

- timely access to the medicines that Australians need, at a cost individuals and the community can afford;
- appropriate standards of quality, safety, and efficacy in medicines;
- quality use of medicines; and
- maintaining a responsible and viable medicines industry.

APAC seeks to maintain a balance between the four key objectives of the policy using a partnership approach including consumers.

Figure 4: QUM and the National Medicines Policy



Source: Commonwealth Department of Health & Ageing. The National Strategy for Quality Use of Medicines 2002. Canberra, Publications Production Unit.

1.4.2 DEFINING THE QUALITY USE OF MEDICINES

QUM is the:

- judicious selection of management options (including non-drug therapies);
- appropriate choice of medicines, where a medicine is considered necessary; and
- safe and effective use of medicines.³⁷

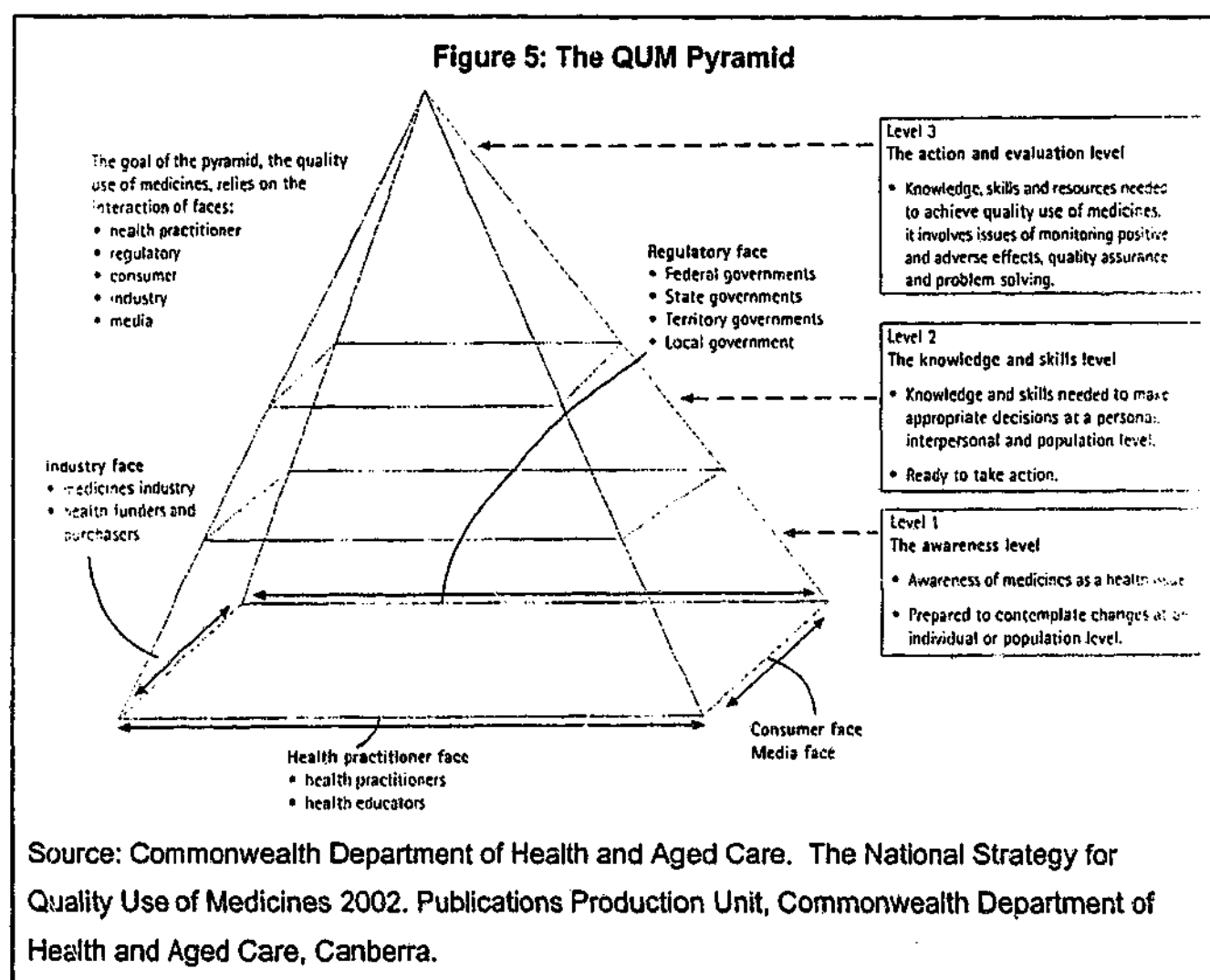
QUM is concerned with optimising the benefits of medicines whilst reducing the inherent risks. This term applies to decisions about medicines at both an individuals and population level. QUM is sometimes referred to as 'rational drug use' in other countries.³⁸

1.4.3 AUSTRALIA'S NATIONAL STRATEGY FOR THE QUALITY USE OF MEDICINES.

QUM policy was updated in 2002 and is now known, as the National Strategy for the Quality use of Medicines.³⁷ The goal of Australia's QUM strategy is to 'optimise the use of medicines to improve health outcomes for all Australians.' This strategy focuses on the primacy of consumers; achieving active, respectful, multidisciplinary,

collaborative partnerships; and using systems based approaches that develop behaviours to optimise the use of medicines.

The principles necessary to achieve QUM in Australia are outlined in the National Strategy for Quality Use of Medicines and the QUM pyramid (figure 5) represents the conceptual framework's multi-strategic, multi-level, systems approach.



"Each face of the pyramid represents a key partner and taken together the pyramid illustrates the need to bring consumers, health practitioners, health educators, health facilities, medicines industries, media, health purchasers and funders, and Governments together in partnership. The necessity of partnership can be seen within this representation. If one group is not included in the process, the inter-relationships suffer and outcomes may be compromised. The faces of the pyramid also illustrate that strategies need to be developed for individual groups or partners, but taken as a whole the pyramid also represents the need for multidisciplinary approaches to achieve and maintain QUM."³⁷

Many people, including consumers, clinicians, industry, media policymakers and regulators, all contribute and have responsibilities with respect to achieving QUM. The Strategy utilises a systems based approach whereby all stakeholders have the collective responsibility to 'improve medication use by recognising when and where problems exists, identifying factors that contribute to these problems, subsequently initiating interventions to improve medication use and evaluating outcomes.'³⁷

1.5 RESEARCH OUTLINE

1.5.1 AIM

This thesis aims to examine the influence of the Internet on the Quality Use of Medicines.

1.5.2 OBJECTIVES

The first part of this thesis addresses the research question:

What are Australians' views and experiences of obtaining medicines and related information via the Internet?

The objectives of the first part of the thesis are to:

- describe the epidemiology of Australians using the Internet to seek medicines and related health information and advice;
- identify the reasons consumers choose to use the Internet to obtain medicines and related information;
- identify the methods consumers use to search and access information about the use of medicines on the Internet; and
- understand how consumers use the information obtained from the Internet in informing their health care decisions.

The second part of the thesis addresses the research question:

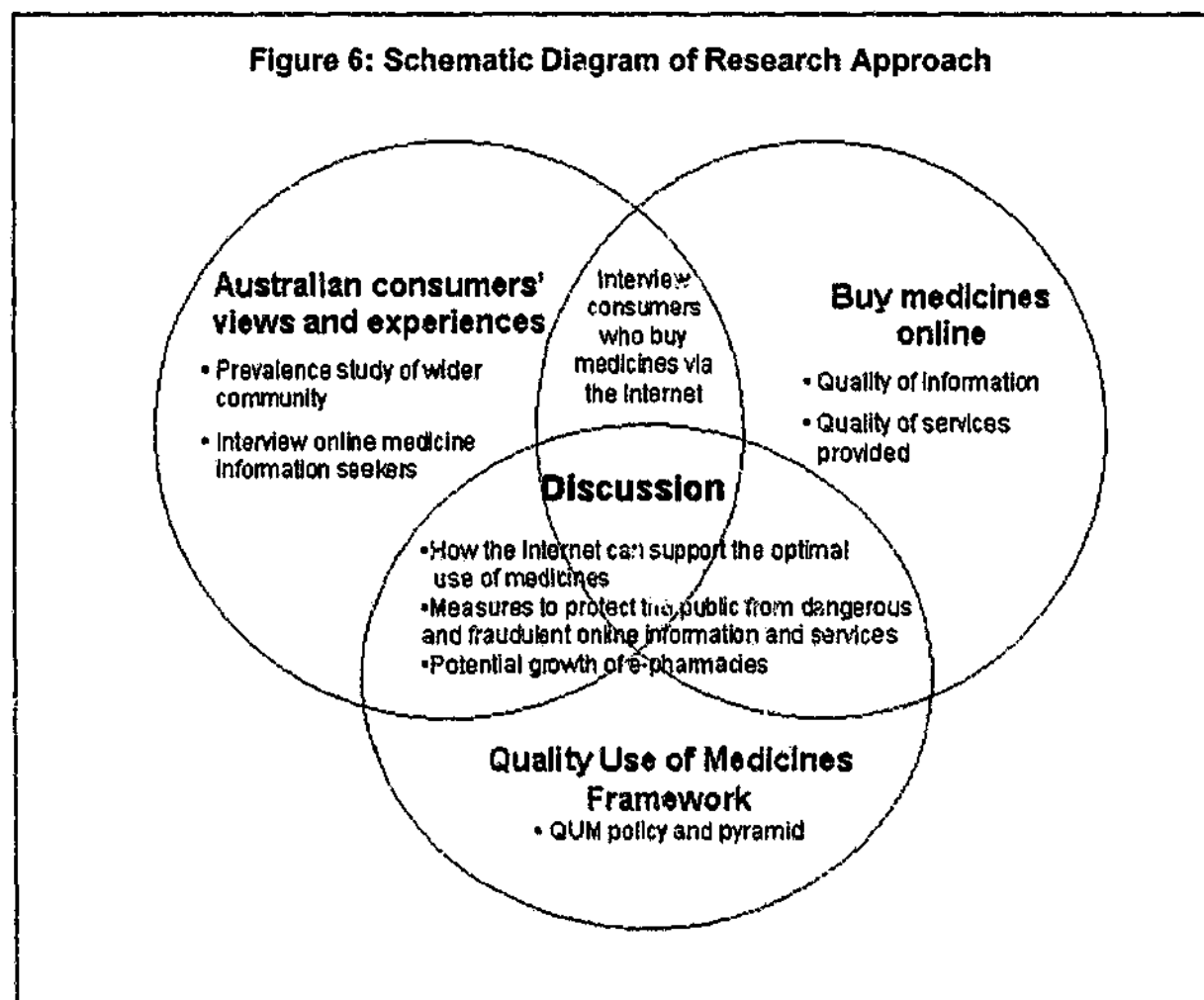
Can consumers buy medicines via the Internet in a manner that supports their safe and effective use?

The objectives of this second part of the thesis are to:

- identify the characteristics of websites supplying medicines online;
- identify the public health benefits and risks of obtaining medicines via the Internet from an Australian perspective;
- identify legislative and policy 'loopholes' that result in medicines being used outside of the goals of QUM policy;
- compare the structural and process indicators of obtaining medicines via the Internet with traditional community pharmacy practice; and
- compare the standards of pharmacy practice in Australian community pharmacies and global online suppliers of medicines.

1.5.3 APPROACH

This research was conducted in defined stages, each addressing a specific research question and objectives (figure 6).



Both quantitative and qualitative research methods were employed and details of the methodologies used in each stage are described in the relevant chapters. Chapter two is a literature review regarding whether interventions delivered via the Internet cause consumers more harm than good. Chapters three, four and five, each report the methods, results and discussion of individual studies. While, chapter six integrates the research findings and discusses the future strategies and studies needed to support the quality use of medicines in an online environment. Chapter seven, the conclusion describes the significant contribution of this project to knowledge about the influence of the Internet on the Quality Use of Medicines.

1.5.4 SIGNIFICANCE

Qualitative inquiry that encourages the discovery of new behaviours and perceptions, and quantitative research that statistically describes the online population of interest makes a significant and original contribution to knowledge about the influence of the Internet on the Quality Use of Medicines.

This thesis:

- includes the first large-scale population survey of Australians and Internet use for health care;
- includes the first large-scale survey of global websites selling scheduled medicines;
- compares traditional and online pharmacy practices within a QUM framework; and
- informs and contributes to the development of future policies designed to safeguard the public from inadvertent medication misadventures.

From a consumer perspective, buying medicines and seeking related information via the Internet are now part of Australia's health care system. However, the nature of online information resources and changing distribution of medicines has important public health implications including safety and quality of health care, impact on the doctor-pharmacist-consumer relationship, costs and morbidity. These are global health issues.

2 DOES CONSUMER USE OF THE INTERNET CAUSE MORE HARM THAN GOOD?

2.1 INTRODUCTION

In chapter one, it was established that the Internet is a social and technological revolution that has become an integral part of many people's daily lives. People who use the Internet have access to vast amounts of online health information and global health services of potentially variable quality. These online resources subsequently have the potential to cause both harm and good, but is this potential realised and what evidence exists about the effects of consumer Internet use on health outcomes?

2.1.1 AIM AND OBJECTIVES

The aim of this chapter is to review the literature regarding consumer use of online health services and information and its effects on decision-making, attitudes, knowledge, satisfaction and health outcomes and utilisation. Consideration is also given to whether the discrete communication features of the Internet also affect these outcomes.

2.2 METHODS

This systematic review considered all post-1995 to March 2001, comparative studies of consumer use of online health information and services. Internet users versus non-users, Internet users versus other communications mediums and Internet users using discrete characteristics of the Internet are examined. For example, studies that compare consumers who use online smoking cessation programs versus face-to-face counselling and consumers who communicate with doctors via e-mail versus the telephone would

be of interest. Seminal papers published between March 2001 and November 2002 were also considered prior to the publication of this thesis.

2.2.1 INCLUSION CRITERIA

All comparative studies of consumers using the Internet to access healthcare information and services were included. Controlled studies, before and after studies, and interrupted time series analyses of Internet users versus non-Internet users, Internet versus other communications mediums and specific Internet characteristics such as email versus other communication mediums were also included. Outcomes of interest included consumer decision-making, attitudes, knowledge, satisfaction and measurable changes in health status or health utilisation.

2.2.2 EXCLUSION CRITERIA

Non-Internet computer-based consumer information systems eg information kiosks Intranets and CD-ROMs were excluded. Whilst these might be good quality resources their access is restricted and evaluating their use does not inform us about the risks and benefits of public access to the variable quality of information and services on the Internet. A suitable analogy is that studying the effects of access to a library is not the same as studying the effects of access to four specifically chosen books. Studies of Internet use by health professionals were excluded because clinicians have skills and training that may enable them to interpret the quality of health information in a manner different to the general public. Studies pre 1995 were excluded because at that time the Internet was not widely used by the general public. In 1995, there were less than 10 million computers with registered Internet service provider addresses compared with more than 100 million at the end of the year 2000.³⁹ The history of the Internet outlined in chapter one illustrated that the World Wide Web was only developed in 1991 and that the first commercial search engines only became available in 1995.⁴⁰

2.2.3 IDENTIFICATION OF STUDIES

Studies were identified from the following databases:

- Cochrane Controlled Trials Register (Cochrane Library Issue 1, 2001)
- MEDLINE (1966 – December, week 4, 2000)
- PREMEDLINE (March 14, 2001)
- CINAHL (February 2001)
- Australian Medical Index (Feb 2001)
- Health and Society (January 2001)
- National Institutes of Health Clinical Trials Database (March 14 2001, available at www.clinicaltrials.gov)
- CenterWatch Clinical Trials Listing Services (March 14 2001, available at www.centerwatch.com/patient/trials.html).

The MEDLINE search terms included internet, online, world wide web, web, email or e-mail or electronic mail, mail list, discussion list, chat room and newsgroup textwords. These terms were combined with study terms including evaluation studies, intervention studies, cohort studies, controlled studies or study, comparative study, before and after study, clinical trial and pilot project textwords. The combined results were restricted to years 1995 to the March 14, 2001. Searching was not restricted by language. After scanning the first 500 citations, the terms Internet, online, world wide web and web were subsequently limited to those appearing in the title or abstract. This reduced the number of MEDLINE citations from approximately 2500 to 397 without the loss of relevant studies. The strategy designed for MEDLINE was adapted and used to search all other databases. A copy of the MEDLINE search strategy is shown in table 7.

2.2.4 STUDY SELECTION AND DATA EXTRACTION

The citations retrieved by each search were downloaded via bibliographic software (EndNote 4.0) to form a single library from which duplicates were subsequently removed. The researcher first screened each citation for possible inclusion according to the selection criteria and only those studies that did not meet the selection criteria were discarded. Full texts of the remaining citations were sought and independently

appraised by two researchers (TB and SM). Discrepancies were resolved by discussion with CS.

Table 7: Medline search strategy.

#	Search history	Results
1.	internet.ti	1674
2.	online.ti	622
3.	world wide web.ti	328
4.	web.ti	1641
5.	(email or e-mail or electronic mail).ti	168
6.	mail list.ti	2
7.	discussion list.ti	5
8.	chatroom.ti	1
9.	newsgroup.ti	3
10.	or/1-9	3977
11.	exp evaluation studies/	329005
12.	exp intervention studies/	1694
13.	exp cohort studies/	372855
14.	controlled study.tw	12267
15.	controlled studies.tw	4641
16.	comparative study.tw	28437
17.	"before and after study".tw	1472455
18.	exp pilot projects/	22773
19.	or/11-18	1923663
20.	10 and 19	392
21.	clinical trial.pt	289135
22.	(controlled adj5 trial).tw	20268
23.	controlled trial.tw	13671
24.	(controlled adj5 study).tw	24117
25.	or/21-24	299337
26.	10 and 25	43
27.	limit 26 to yr=1995-2001	29
28.	limit 20 to yr=1995-2001	392
29.	or/27-28	397

2.2.5 STATISTICAL ANALYSIS

It was intended to assess the relative contribution of included studies to determine the current state of knowledge so as to generate hypotheses for future research using a random effects model. However, the nature of the studies did not allow data pooling or further statistical analysis.⁴¹⁻⁴²

2.2.6 DESCRIPTION OF STUDIES

The initial search identified 599 citations of which 10 comparative studies were identified.⁴³⁻⁵² Forty-four descriptive studies (appendix 2) and two case reports were also identified.⁵³⁻⁵⁴ The majority of citations were excluded because they were concerned with 'web's of a non-Internet nature or clinicians. A further comparative study was also identified, but in November 2002 it is not yet completed.⁵⁵

2.3 RESULTS

From the literature search only ten comparative studies were identified. All were concerned with evaluating the effectiveness of specific health interventions that had been delivered online rather than a comparison of consumer online behaviour with another information channel (table 8).

Of the 10 studies identified, there is limited evidence that Internet-based materials may provide consumers with necessary information and support in a timely manner to achieve positive health outcomes. Only the studies conducted by Takahashi Cellio, Winzelberg, Winett and Scherrer-Bannermann and Tate demonstrated that the Internet is an effective medium that can deliver clinical interventions to the broader public and achieve limited positive health outcomes.

Table 8: Characteristics of included studies

Author	Study design & number of participants	Comparison Groups	Intervention	Outcome	Absolute Change	Relative Change	Quality
Celio 2000	Controlled trial n=76	Internet (n=24) versus classroom (n=15) versus no intervention (n=19) for young women at a US private university	Education program for reducing risk factors for eating disorders	At 6 months: Relative effect sizes and absolute mean differences for: Body image score Bulimia Drive for thinness Weight /Shape concerns Eating concerns Restraint Social support	Net vs no intervention 17.1 points 1.9 points 7.9 points 0.9 points 0.6 points 1.0 point NS (net and classroom)	Classroom vs no intervention NS NS NS NS NS NS NS	Drop out rate in classroom group (40%) was higher than the Internet group (11%). 30% 3% 19% 14% -8% 34%
Jones 2000	Retrospective quantitative analysis of patient records n = 346	Patients from an online health clinic (n=310) versus a US inner-city hospital clinic (n=36)	Seeking repeat requests for Viagra®	Sex life satisfaction Patient complaints	Not reported Nil reported		Recruitment bias and poor choice of control group.

Table 8: Characteristics of included studies contd.

Mackinnon 1995	Randomised controlled trial n=16	E-mail (n=7) Versus normal service (n=9)	Clinical and technical assistance to physically disabled persons from an augmentative communica- tion service.	Mean Satisfaction Number of contacts to clinicians and staff over 6 month period	0.2 points 36 contacts	4% 500%	Small sample size Randomisation method not stated.
Scherrer- Bannerman 2000	Controlled trial n=72	Patients with Internet access versus no Internet access, waiting for cardiac surgery in Vancouver	Website versus written manual	Social support Anxiety Lifestyle changes Attitude to surgery	Not reported	Not reported	Bias- Internet group provided training. Numbers of participants in each group not reported. Convenience sample – only those with Internet access assigned to intervention group and all others to control group.

Table 8: Characteristics of included studies contd.

Strom 2000	Controlled trial n=102	E-mail/internet (n=20) and no intervention (n=25) for chronic headache sufferers in Sweden	Applied relaxation and problem solving in the treatment of recurrent headache	Mean difference for:		Drop-out rate56%
				Headache Index improvement	0.5 points	
				Frequency (days/week)	NS	
				Peak intensity	NS	
Takahashi 1999	Before and after study (n=224)	Japanese smokers	Web page info Daily email reminders e-mail support.	Smoking cessation		
				>30 per day	53	52%
				<30 per day	53	43%
Tate 2001	Randomised controlled trial (n=91)	Internet behaviour therapy (n=33) versus Internet education (n=32) in healthy, overweight US hospital employees.	Weekly email lessons, monitoring tool, individual feedback, and bulletin board.	At 6 months:		71% of participants had complete data.
				Mean body weight loss	2.5kg	
				Mean decreased waist circumference	3.3cm	
				Achievement of 5% body weight loss	15 people	

Table 8: Characteristics of included studies contd.

Wagner 2001	Comparative survey (n=8)	Internet (n=4) versus traditional US pharmacy services (n=4)	Supply of medication and information from pharmacies.	Costs Delivery times Response times to questions Quality of information provided	NS NS NS NS		Small sample size
Winzelberg 2000	Randomised controlled trial n=60	Internet (n=24) versus no intervention (n=20) in young women at a public US university	Education program for reducing risk factors for eating disorders	Mean difference at 3 months (high risk participants): Body image score Bulimia Drive for thinness Weight concerns Shape concerns	22 (20)points 3.1 (4)points 5.3 (4.8)points 1.6 (0.8)points 0.8 (0.6)points		73% of participants had complete data. Method of randomisation not stated. Compliance with program 64%.
Winett 1999	Controlled trial n= 180	Internet and classroom (n=103) versus classroom (n=77) in a poor US high school.	Five educational modules for school health classes	Regular meals Fruits & vegetables Breads and cereals Regular sodas High fat snacks High fat dairy Fast food (calories)** Fast food fat (g)** Aerobic exercise (days /week)	0.3 points 1.1 points 1.0 Point 0.4 points NS NS 261 14.2 0.8	F=14.09 F=15.11 F=18.53 F=5.25 r= 3.98 r=4.28 F=4.27	Not randomised or blinded due to logistical restraints. Internet access was not always reliable.

• NS = not statistically significant ($p > 0.05$).

• ** n=39.

The methodological quality of the remaining four studies was poor and the results of these four studies are not reliable. The small sample size in the MacKinnon and Wagner studies does not allow robust conclusions to be drawn. Meanwhile Jones compared Internet versus outpatients seeking Viagra® repeats, however the control group of inner-city outpatients is likely to have lower health, social and educational status than Internet users. Furthermore consumers who experienced an adverse event are unlikely to request a repeat prescription. The controlled trial for self-help treatment conducted by Strom had 56% of participants drop out of the study.

2.4 UPDATE OF THE LITERATURE

Between March 2001 and October 2002 no seminal papers of comparative studies were identified.

2.5 DISCUSSION

The strongest finding to emerge from this systematic review is the lack of rigorous research regarding the effects of consumer Internet use on health outcomes. Given the widespread use of the Internet and the claims that are frequently made about its benefits as a tool for communicating health information and empowering consumers in health care decision-making, the lack of research evidence is disturbing and the issue remains unresolved. This lack of evidence underpins the need for original research to contribute to our knowledge about the delivery of online health information and services.

3 AUSTRALIANS, ONLINE HEALTH INFORMATION & MEDICINES

3.1 INTRODUCTION

Consumers seeking a range of online health services and information are driving the Internet revolution in healthcare.⁵⁶ Consumers can access information, medical records, home monitoring, clinical consultations and buy medicines via the Internet.⁵⁷

In chapter one, it was estimated that 50% of all Australian adults and 37% of households had Internet access in the twelve months prior to November 2000.⁵⁸ These people can potentially access much of the same information as health professionals and use it to make informed health care decisions. Despite this potential to inform and empower consumers there are concerns regarding the effects of online information of variable quality on health outcomes. Nonetheless, chapter two reported a lack of evidence about whether consumer use of the Internet for health and health care purposes causes harm or good.

Online health information and services lack quality assurance and issues of security, privacy and practice standards are not always addressed. Consumer use of online health information and resources can potentially impact safety, health provider-consumer relationships, costs and outcomes. But how do consumers view online health information and services and what are the impacts of online health seeking behaviour upon health care experiences and outcomes?

3.1.1 AIMS AND OBJECTIVES

The aim of this chapter is to examine Australians' views and experiences of obtaining online health information, particularly with regard to medicines.

The primary objectives of this chapter are to:

- determine the proportion of South Australians who use the Internet to access health care information;
- identify the types of online health information sought by consumers;
- identify the subsequent actions taken by consumers using such information; and
- determine the predictive characteristics of online health information seekers.

Whilst the secondary objectives of this chapter are to examine:

- what prompts consumers to look for online information about medicines;
- how consumers search for online health information;
- how consumers assess the quality of the information they find; and
- how consumers use such information in the context of their own healthcare management.

3.1.2 SIGNIFICANCE

Although Australians are increasingly using the Internet, there is a clear lack of information and knowledge regarding whom, how and why Australians use the Internet for health care and medicines. Such information is vital if policymakers and clinicians are to harness the potential of the Internet to deliver preventive, clinical and public health information to consumers, particularly those with the greatest health needs. Furthermore, without this knowledge it cannot be established whether there is a need to develop and implement public health strategies and interventions to safeguard consumers from fraudulent and misleading online health information.

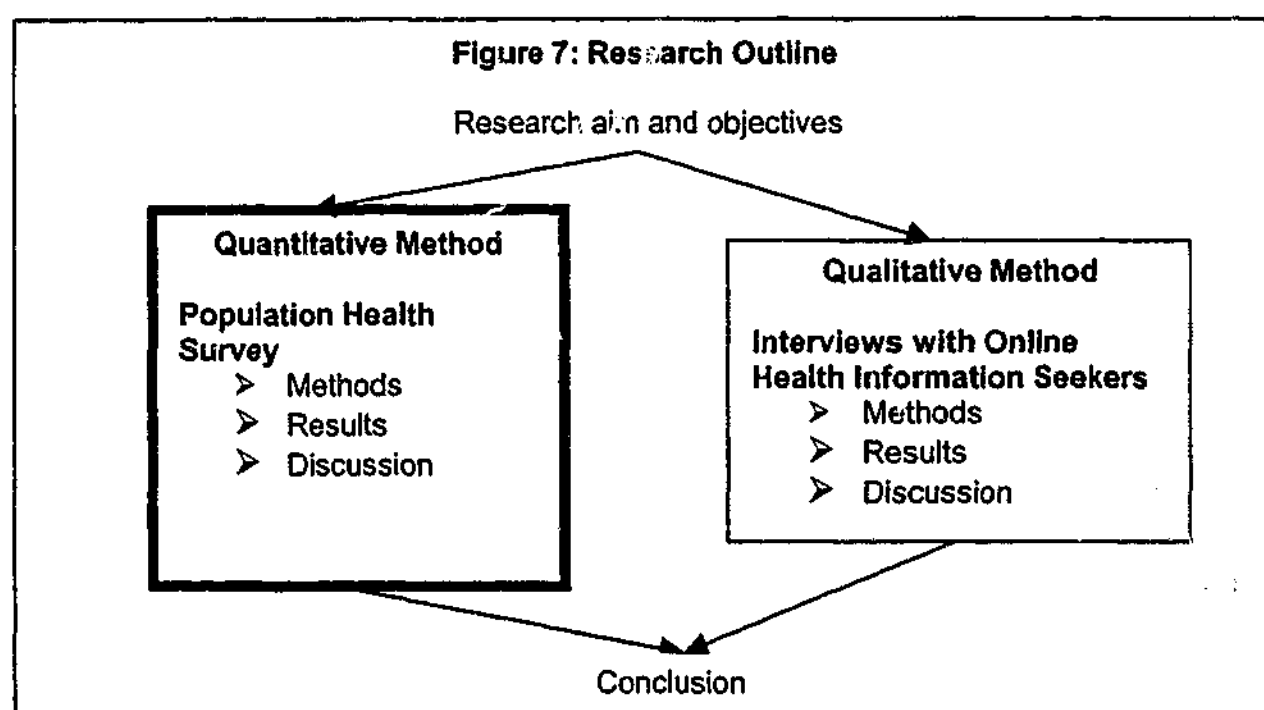
3.2 METHODS

3.2.1 RESEARCH APPROACH

An inductive research strategy was used to collect data about the online experience of Australian consumers seeking medicines and information. Both quantitative and qualitative methods of data collection were employed to maximise the amount of information gained and to strengthen the evaluation of this previously unexplored

research problem. This mixed-methods approach is referred to as triangulation. Triangulation uses data collected from different sources to corroborate, elaborate or illuminate the research in question.⁴

Qualitative and quantitative methods may be implemented either simultaneously or sequentially to address the same issue. These methods are employed in a separate and complementary manner in this research (figure 7). The researcher chose to conduct the larger quantitative study prior to a smaller qualitative study and the greater weight of importance was given to the larger quantitative study whilst the smaller qualitative study was used to 'tease out' the findings from the larger study.



3.3 POPULATION HEALTH SURVEY

3.3.1 METHODS

Quantitative Research

Quantitative research is often conducted using sample surveys where data are collected in a standardised format usually from a probability sample of the population at a single point in time. It employs cross-sectional measurements and explains statistical variability of certain features within a population. Survey research is an appropriate mode of inquiry for making inferences about a large group of people from data drawn

from a relatively small number of people within that group. Adequacy of the sample is statistically determined by the sample size and appropriateness is determined by the representativeness of the sample to the total population of interest. The assumption is that the characteristic can be described or measured accurately through self-report.

The strengths of using survey methodologies include accuracy, generalisability of the findings and administrative convenience. The weakness of survey methodologies is that they are of little value for examining contexts, processes, complex relationships and interactions. Population surveys are also expensive thus the amount of data collected is restricted by the amount of funding available.

The quantitative data for this part of the thesis were collected as part of a South Australian population survey.

Data collection

Data representative of the wider population were required to determine the prevalence of online health seekers. Furthermore, the sample size of the survey needed to be relatively large because only half of the population were likely to have used the Internet in the twelve months prior to Spring 2000 (see chapter one, figure 1, page 5) and of those only an unknown proportion would be online health seekers. The South Australian Health Omnibus was chosen, as the most appropriate survey in which to include our questions because it had a large sample size, was rigorously designed and affordable, and had been conducted for the past ten years.⁵⁹ Enquiries to the Australian Bureau of Statistics (ABS) and State Government Public Health Units did not result in any other suitable population health surveys being identified.

The data were collected in the 2000 South Australian Health Omnibus (September 2000 to January 2001), a representative survey of people aged 15 years or older (n=3027, response 70%). The survey was a multistage, systematic, clustered area sample of people who live in metropolitan Adelaide and major country centres in South Australia with a population of over 1000. The survey districts were selected from a random sample of Australian Bureau of Statistics collector districts. Within each collector's district a random starting point was selected and from this point 10 households were selected using a fixed skip interval. Hotels, motels, hospitals, nursing homes and other

institutions were excluded. The person whose birthday was next in each selected household was 'face-to-face' interviewed in their home by trained health interviewers. There was no replacement for non-respondents. Up to five call-backs were made in an attempt to interview the selected person. The data were weighted by age, sex, and geographic region to the estimated resident population data so that the analysis would be representative of the wider South Australian population. Four questions concerning use of the Internet for health information were asked as part of this survey (Box 2). Demographic data including age, gender, country of birth, marital status, education, employment, annual household income and postcode were also collected.

Box 2: SA Health Omnibus Questions

- 1 **How often do you use the Internet including e-mail?**
 - Daily
 - 2-6 times a week
 - Once a week
 - Once every 2 weeks
 - Once a month or less
 - Never → go to Q3
- 2 **In the past 12 months where have you accessed the Internet from?**
(More than one answer may be recorded.)
 - Home
 - Work
 - Friend or neighbour's house
 - Tertiary Institutions/TAFE
 - Public library
 - Shop / store / telecafe
 - Schools
 - Government agencies or departments
 - Other
- 3 **In the past 12 months have you (or someone else on your behalf) used the Internet to search for health information on any of these topics?**
(More than one answer may be recorded.)
 - I have not searched for any health information go to next section
 - Cause or description of a disease or health condition
 - Management or treatment of a disease or health condition
 - Prescription or over-the-counter medicine
 - Complementary medicine (includes vitamins, herbal treatments & alternative medicines).
 - Support group
 - Health appliance e.g. nebuliser
 - I have searched for other health information
- 4 **As a result of this information, did you?**
(More than one answer may be recorded.)
 - Find the information useful
 - Use it as a second opinion
 - Discuss it with your doctor or pharmacist
 - Buy a medicine online
 - Buy a medicine from a pharmacy or other shop
 - Change the way you manage your health care
 - Use it to choose a health care provider e.g. doctor, naturopath, specialist
 - None of these.

Data analysis

Data were weighted by household size, age, sex and geographical region to benchmarks derived from the 1999 Estimated Resident Population figures for South Australia.⁶⁰ The Health Omnibus data were subsequently adjusted for age and gender to make predictions about the national prevalence of online health seeking behaviour. Comparing the observed and expected rates of Internet use with the Australian Bureau of Statistics Internet Household Use November 2000 data validated these estimates.⁸

The demographic data for Internet users and non-users, online health seekers and non-health seekers were analysed using SPSS for Windows Release 10.0.5.9. Frequency tables were produced. The association between online health seeking behaviour and demographic variables were examined using chi-squared tests. Subsequently variables associated with online health seeking behaviour were evaluated using logistic regression to identify independent predictive characteristics of online health seekers. The direct entry method was used for the logistic regression calculations because the contribution of each variable is evaluated after removal of the effects of all other variables.

3.3.2 RESULTS

The prevalence of South Australian online health seekers was 21% (n=643, 95%CI 20-22%) and the results are presented in table 9. These results also demonstrate that Internet access decreases with age, whilst the prevalence of seeking online health information is relatively constant (26 to 28%) amongst people aged between 15 and 54 years.

Of the 3027 respondents 46% (n=1380; 95%CI, 44%-48%) had used the Internet, 31% were frequent users (twice a week to daily) whilst 15% were infrequent users (a few times a year to fortnightly). The 1307 Internet users accessed the Internet at home (70%) work (40%), family or neighbours (10%), school (9%), tertiary institution (8%), public library (7%) and shop or telecafe (2%). About half (46%) of the Internet users accessed the Internet from both home and another site.

Table 9: Prevalence of Internet use and online health information seekers* (n=3027)

	Internet users*			Health seekers*		
	n	%	95%CI	n	%	95%CI
Age						
15-24	379	75	(71,79)	140	28	(24,32)
25-34	287	53	(49,57)	142	26	(22,30)
35-44	332	58	(54,62)	149	26	(22,30)
45-54	257	50	(46,54)	138	27	(23,31)
55-64	84	24	(20,28)	47	14	(10,18)
65+	42	8	(6,10)	26	5	(3,7)
Gender						
Male	759	51	(48,54)	287	19	(17,21)
Female	621	40	(38,42)	357	23	(21,25)
Region						
Metro	981	47	(45,49)	447	22	(20,24)
Non-metro	400	42	(39,45)	196	21	(18,24)
Income**						
\$0-\$39,999	344	26	(24,28)	173	13	(11,15)
\$40,000+	801	64	(61,67)	379	31	(28,34)
Education						
Left before 15 years/trade qual	186	21	(18,24)	99	11	(9,13)
At school	139	91	(86,96)	56	37	(29,45)
Left at /after 15	425	43	(40,46)	176	18	(16,20)
Cert/Diploma/Degree	631	65	(62,68)	313	32	(29,35)
Employment						
Employed	954	59	(57,61)	430	27	(25,29)
Not employed	427	30	((28,32)	213	15	(13,17)
Country of Birth						
Australia	1108	48	(46,50)	515	22	(20,24)
Other	272	39	(35,43)	128	18	(15,21)
Marital Status						
Married/defacto	780	43	(41,45)	401	22	(20,24)
Separated/widowed/divorced	106	23	(19,27)	59	13	(10,16)
Never married	494	67	(64,70)	183	25	(22,28)
Total	1380	46	(44,48)	643	21	(20,22)

* Proportions are of all participants in each category.

** 472 participants did not state their income.

The types of health information sought by the 643 online health seekers include cause or description of disease or health conditions (60%), management or treatment of a diseases or health conditions (45%), complementary medicines (including vitamins, herbal treatments and alternative medicines) (18%), prescription or over-the-counter medicines (10%), support groups (9%) and health appliances (3%). Participants could

select more than one type of health information. Furthermore, 486 (76%) of online health information seekers reported that the information they found was useful.

Consumers subsequently either used this information as a second opinion (19%), discussed it with their doctor or pharmacist (16%), changed the way they managed their health care (11%), bought a medicine from a pharmacy or other shop (4%), used it to choose a health care provider (3%) or bought a medicine online (1%).

All demographic variables were associated with online health seeking behaviour as demonstrated by the results of the chi-square calculations in Appendix 3. Variables that best predicted being an online health seeker were identified using logistic regression. These variables included being male, aged between 15 and 55 years, still at school or having a higher education certificate or degree, and household income greater than \$40,000 (table 10). Variables that were not predictive of online health seeking included employment status, residence in a non-metropolitan location, marital status and country of birth. Internet use was not included in the logistic regression analysis as it is closely associated with being an online health seeker (82% of online health seekers are Internet users).

Table 10: Logistic regression analysis to identify predictive characteristics of online health information seekers.* **

Variable	Reference Variable	Sig	Odds ratio	95%CI for odds ratio	
At school	Left school 15+	.002	2.8	1.5	5.4
Under 34	55+ years	.000	2.3	1.6	3.3
Aged 35-54	55+ years	.000	2.2	1.6	3.1
Degree/Cert	Left school 15+	.000	1.8	1.4	2.3
Total Household Income \$40,000+	THI>\$40,000	.000	1.8	1.4	2.3
Gender	Female	.001	1.4	1.2	1.7
Employed	Not employed	.09	1.3	1.0	1.6
Married/Defacto	Never married	.46	1.1	0.8	1.5
Non-metropolitan	Metropolitan	.54	0.9	0.7	1.2
Separated/Divorced/Separated	Never married	.73	0.9	0.6	1.4
Early Leaver/Trade	Left school 15+	.21	0.7	0.5	0.9

*78% of the variance was explained by the variables in the equation.

** df =1.

Although the results reflect the prevalence of Internet use and online health seeking in South Australia it may also indicate that the national prevalence is slightly higher than that observed in South Australia as illustrated by the ratios of observed to expected Internet users according to age in table 11, which varied between 0.75 (for 55 years and over) and 1 (40 to 54 years) and the association between internet access and online health information seeking behaviour.

Table 11: Observed versus expected number of Internet users

Age	ABS Internet Use* %	Health Omnibus n	Expected n	Observed n	Ratio Expected/ Observed
18-24	74	342	253	234	0.92
25-39	64	833	533	459	0.86
40-54	52	798	415	417	1.00
55+	19	890	169	126	0.75
Total	50	2863	1431	1236	0.86

Source: Australian Bureau of Statistics. Use of the Internet by Householders 8147.0, November 2000.

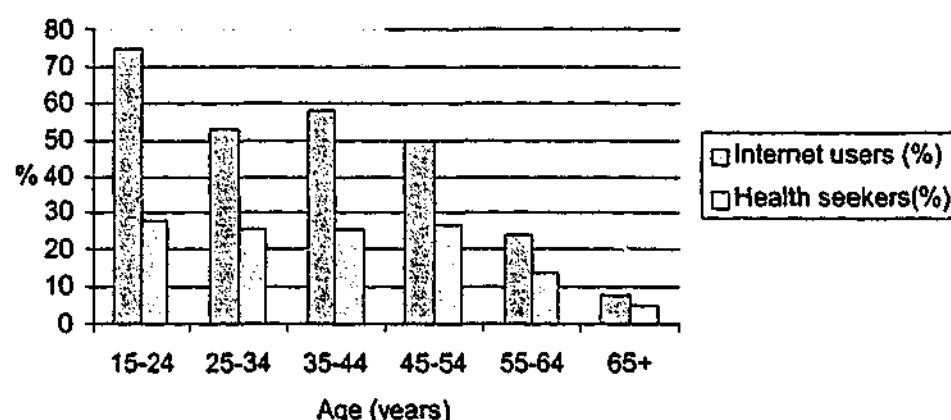
3.3.3 DISCUSSION

Major findings

More Australian males access the Internet, yet slightly more females are online health seekers, perhaps because females are the predominant health care decision-makers and carers in our society. In 2001, the prevalence of South Australians seeking online health information is relatively constant (26 to 28%) amongst people aged between 15 and 54 years (figure 8). This South Australian estimate of the prevalence of online health seeking behaviour was likely to be slightly lower than the wider Australian population, based on comparisons with Australian Bureau of Statistics data. Although Internet access is highly correlated with online health seeking, this study also determined that 18% of online health seekers used a third party to access such information. Australians who are young, affluent and highly educated are more likely better health status and Internet access, thus people with the poorest health status are less likely to have access to online health information. However, as Web-based television and mobile hand held

devices gain popularity, Internet service provider and computer package costs decrease, and as schoolchildren (all of whom have some Internet access and resources) age, the Australian 'digital divide' may potentially narrow, albeit at different rates amongst population sub-groups.

Figure 8: Prevalence of Internet Use and Online Health Seekers by Age (n=3027)



Limitations of the study

The South Australian Health Omnibus employs a rigorous sampling methodology that delivers results applicable to the wider South Australian population. However, the ability to collect national data would be advantageous. Additionally, it would have been preferable to include more survey questions but this was outside the project budget. In particular, questions regarding the self-reported health status of participants and their perceptions about the impact of online health information on the clinician consumer relationship were of interest.

Comparisons with other studies

Australian studies

Despite the variable quality of online health information, 76% of online health seekers perceived it to be useful and many used it to make health care decisions, yet only 16% discussed this information with their doctor or pharmacist. Our findings support those of a 1999 study of Western Australian radiology patients (n=174 consecutive patients, 97% response rate) that found one third of participants sought online health information related to their illness, and of those 47% reported that such information was at variance with their care plan but only half of these patients discussed such information with their doctor.⁶¹ The reasons consumers choose not to discuss online health information with

their doctor, particularly when this information conflicts with advice, and the subsequent impact on healthcare provider-consumer relationships and outcomes requires further research.

This study determined that 26% to 28% of 15 to 54 year olds accessed online health information in the 12 months prior to Spring 2000. This result appears to be consistent with the results published in the abstract of a recent Australian study (not publicly available) that reported "27% of the 5.2 million regular Internet users in Australia in the second half of 2002 use the Internet for health or medicines information on medical conditions." However this abstract also reports that three quarters of online health seekers discuss the information they found with their doctors.⁶²

Population studies

"More Americans research health information online on an average day than visit health professionals."⁶³

In 2000, 49 % of US adults had Internet access.⁶⁴ Studies conducted in 1999 and 2000 found that 31% (aged less than 60 years, n=1237) and 27% (n=12751) respectively of all American adults sought health information via the Internet.⁶⁵⁻⁶⁶ Whilst in 2002, it was estimated that 73 million (26%) people in the USA, representing 62% of Internet users, had gone online in search of health information including 72% of women and 51% of men with Internet access.⁶³ Although, the prevalence of online health seeking and Internet access in Australia and the USA is similar, public health messages may reach different target audiences in their respective countries. These US studies found that the Internet was an effective means of delivering health information to minority Americans and those people with lower incomes, less education, and fair or poor health status (except low-income black Americans, the uninsured and the elderly).^{63,65-66} In contrast, this Australian study determined that both income and education were predictive of online health seeking behaviour.

Clinic or disease state studies

Although there is only one existing Australian study concerned with Internet use amongst a defined clinical population there have been at least 15 such studies conducted overseas between 1999 and 2002 (table 12).

Table 12: Prevalence of online health seekers in clinical populations.

Reference	Time of data collection	Location	Population of interest	Survey data collection method	N surveys	Response rate (%)	Results
Carlsson ⁶⁷	2000	Sweden	Oncology inpatients		192	74	➤ OHS 6%
Cawdron ⁶⁸	Jan 2002	Ontario, Canada	8-18 year olds with inflammatory bowel disease (IBD)	Postal	63	39	➤ IA 98% ➤ OHS for IBD 52.4 %
Chen ⁶⁹	Apr 2000	Canada	Oncology outpatients	Self-completed	191		➤ OHS 56/111 (51%) 31/56 (56%) searched themselves, 25/56 (44%) searched with the help of family and friends ➤ Primary source of medical information 11/159 (7%)
Christian ⁷⁰					200		➤ IA 153/200 (77%) ➤ OHS 44/153 (29%) for genetic info 33/41 (80%) of OHS found information useful
Diaz ⁷¹	Dec 1999 to Mar 2000	Rhode Island, USA	Primary care internal medicine private practice patients	Postal	512	56	➤ OHS 274/512 (54%)
Gupte ⁷²	2001	London, England	Orthopaedic outpatients		398	93	➤ OHS 29%
Ikemba ⁷³	Mar 2000 to Aug 2000	Texas, USA	Families of children requiring cardiac surgery for congenital heart disease		275	100	➤ IA 160/275 (58%) ➤ OHS 93/160 (58%) related to child's cardiac diagnosis 88/93 information helpful or very helpful.

IA = Internet access, OHS = online health seekers

Table 12: Prevalence of online health seekers in clinical populations contd.

Kalichman ⁷⁴			HIV/AIDS patients at community AIDS and infectious disease clinics	259 (175 M, 84 F)		➤ IA 116 (48%) ➤ OHS 68 (26%)
Murero ⁷⁵		New York State, USA	Patients who had undergone off-pump coronary-artery bypass grafts, hospital	telephone		➤ IA 35/82 (43%) ➤ OHS 18/35 15/18 searched with the help of family and friends
Norum ⁷⁶	Jan 2001	Tromso, Norway	Oncology patients	31		➤ OHS 4 (13%)
O'Connor ⁷⁷	Aug 1999	NC, USA	Gastroenterology outpatients	924	92	➤ IA 462/924 (50%) ➤ OHS 235/463 (51%) 35/825 (4%) referred to website by doctor
Pereira ⁷⁸	1999	Edmonton Canada	Breast cancer outpatients and families	107 (79 patients, 28 families)		➤ OHS 34/79 (43%) for breast cancer information
Ross ⁷⁹	1999	England	Genitourinary outpatients	?		➤ IA 41% Internet access ➤ OHS 10% of those with internet access for related info
Taylor ⁸⁰	Spring 2000	Colorado & Wyoming, USA	Genetics outpatients at urban and rural clinics	Self-completed 189	83	➤ OHS 73/155 (47%) 8/148 (5%) referred to internet by doctor prior to visit
Vordermark ⁸¹ abstract	May 2000	Denmark	Radiotherapy patients	Face-to-face 139		➤ OHS 37 (27%) 16 (12%) searched themselves 21 (15%). Received online information from family and friends 9/37 (24%) of OHS discussed online health information with their doctor.

IA = Internet access, OHS = online health seekers

The survey results presented in table 12 are of variable strengths, due to differing sample size and survey response rates. The reported prevalence rates of online health seeking behaviour are also wide ranging, but expected due to the differing socio-demographic characteristics associated with each clinic population and individual disease states. However, these results demonstrate that people seek online health information related to clinical diagnoses and that such information is often provided by third parties, which supports the research findings of this study. Therefore, those studies in table 12 that only measured the prevalence of online health seeking behaviour in participants with Internet access may have underestimated the number of people with access to online health information relevant to their condition and treatment.

3.4 ONLINE HEALTH SEEKING BEHAVIOUR

3.4.1 INTRODUCTION

Although it is estimated that more than one in five Australians seek online health information and 10% of online health seekers use such information to make health care decisions, it is unknown how consumers identify, appraise and interpret such information. These issues were addressed by conducting interviews with online health seekers to enhance our understanding of this behaviour and its impact on consumer health experiences and outcomes.

3.4.2 METHODS

Qualitative Methods

The strengths of using a qualitative approach include the ability to explore and discover the actions of the population of interest in a natural environment. Qualitative methods collect 'context-bound' data leading to patterns or theories that help predict, explain or understand a particular phenomenon. This data can give rise to new insights that are not self-evident from numerical comparisons. There are many different qualitative data collection strategies including direct observation, participant observation and semi structured interviewing. Appropriateness is determined by how well the sample can represent the phenomena of interest. Semi-structured interviews allow participants to

report their beliefs, attitudes actions and experiences however, the assumption is that they can articulate their experience.

Qualitative analysis is the search for general statements about relationships among categories of data to promote the emergence of substantive theory grounded in empirical data.⁸² The process of bringing order, structure and meaning to the mass of collected data does not proceed in a linear fashion. Analytic procedures fall into five modes: organising the data, generating categories, themes and patterns, testing the emergent hypotheses against the data, searching for alternative explanations for the data and writing the report.

Quantitative data for this part of the thesis were collected using semi-structured interviews conducted with Queensland Medication Helpline callers.

Data collection

Consumers who seek online information about medicines are 'hidden'. As there is no publicly accessible lists of these consumers, a purposive sampling frame of consumers who telephoned the Queensland Medication Helpline (QMH) and identified themselves as online health seekers provided a useful starting point to explore consumer issues about medicines and the Internet.

The QMH is located in Brisbane at the Mater Pharmacy Services, Mater Misericordiae Health Services. It was Australia's first state drug information telephone service for rural and metropolitan consumers. QMH pharmacists invited callers, who identified themselves as online health seekers, to voluntarily participate in the study at the conclusion of their medication related enquiry. Participants gave written informed consent and were interviewed at least two weeks post telephone enquiry. The interview guide was composed of nine open-ended questions that encouraged participants to formulate responses in their own terms (Box 3). Probing was used to clarify a response or establish the meaning of a participant's answer. A single drug information pharmacist conducted the telephone interviews, which were recorded using audiotapes and subsequently transcribed. The Standing Committee on Ethics in Research Involving Humans, Monash University, and the Mater Misericordiae Hospitals Research Ethics Committee, South Brisbane, gave ethics approval for this part of the thesis.

Box 3: Semi-structured interview guide.

1. What prompted you to seek information about medicines on the Internet?
2. Did you or someone else on your behalf search for information about medicines?
3. How do you search for information? For example, do you use general search engines, key words, questions, newsgroups, discussion lists, or specific health sites eg Medline.
4. How can you tell if a website's information is reliable?
5. What are the advantages and disadvantages of searching for medicines information via the Internet?
6. What types of online information do you find most useful?
7. How has the information you found on the Internet changed the way you manage your health or medicines?
8. What are the advantages and disadvantages of buying medicines via the Internet?
9. Do you have a positive or negative experience regarding the Internet and medicines that you would like to share with us for the benefit of others?

Box 4: The five stages of data analysis using a framework approach.

1. Familiarisation – immersion in the raw data by reading transcripts, in order to list key ideas and recurrent themes.
2. Identifying a thematic framework – Identify all the key issues, concepts and themes by which the data can be examined and referenced by drawing on prior knowledge, the aims and objectives of the study and issues raised by participants.
3. Indexing – Applying the thematic framework to all the data using codes.
4. Charting – Rearranging the data according to themes. The end result is a chart for each key theme containing distilled summaries of participants' views and experiences.
5. Mapping and interpretation – using the charts to define concepts, map the range and nature of the phenomena, create typologies and find associations between themes with a view to providing explanations for the findings

Adapted from Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In Bryman A Burgess eds Analysing qualitative data. 1993:173-94, London: Routledge.

A framework approach was employed to analyse the interview data (Box 4). This approach starts deductively (reasoning from general to particular instances) from the aims and objectives set for the study and the results are grounded (heavily based in the original accounts and observations of the people studied) and inductive (the process of inferring a principle from the observation of particular instances).⁸³ Such an approach is advantageous because the analytic process and interpretations can be viewed and assessed by people other than the primary analyst. The drug information pharmacist who originally conducted the interviews reviewed the resultant themes.

3.4.3 RESULTS

During June to August 2001, QMH staff identified 11 callers who self-reported using the Internet to seek health information. Of these 11, nine people provided informed written consent and participated in semi-structured interviews. The characteristics of participants are shown in table 13.

The majority of participants' views and experiences of online medicines information were positive. All participants found Internet access to online health information to be timely, convenient and useful. Participants stated that the Internet contained groundbreaking and up-to date information. They considered the Internet to be a credible resource for medicines information that provided them with access to in-depth information about products and medical conditions, as well as other people's personal insights into coping with a particular condition. However, participants also perceived that online health information could be scary, contained too much scientific and medical jargon, was too general at times and expressed the concern that others might be at risk of 'cyberhypochondria'.

"I had been given two different answers from two different doctors here in the area that I live in. One had said he definitely wouldn't allow me to breast feed a baby while taking this antidepressant whilst my other doctor said yes... by contacting someone who was I suppose an authority or had more information perhaps or research at their fingertips, it helped me make a conscious decision to be able to take those pills and feel that I wasn't affecting my child's health."

Table 13: Characteristics of Sample participants (n=9)

Consumer characteristics	Frequency
Computer training	4
Site of internet access	
home	8
work,	3
other	1
Frequency of internet access (including email)	
daily	3
2-6 times a week	5
once a week	1
Frequency seek online health information	
once a week	1
once a month	2
few times a year	5
first time	1
Age (yrs)	
Range	33-67
Mean	51
Location	
metropolitan	6
rural	3
Gender	8 F 1 M
Household Income	
above \$40,000	6
below \$40,000	3
Educational attainment	
left school 15 years or older	2
diploma	5
bachelor degree or higher	2

Primarily, participants' self-conducted information searches using commercial search engines such as AltaVista and used single, simple search terms comprising of product or disease names. They sought a wide range of information about chronic diseases, alternative treatments, prevention, self-referral to health professionals and medication management issues including adverse effects, interactions and breastfeeding.

Participants sought online health and medicines information because it provided them with the opportunity to address their information needs without having to 'bother their

doctor, whom may not have the knowledge or time to answer their questions satisfactorily'. Participants sought medicines information via the Internet as a second opinion, to resolve conflicting advice, find alternative treatments and supplement the advice they had been given about the benefits and risks of recommended medications.

"It (online health information) helped me make a more informed decision. When the doctor was telling me you've got to take this medication, it helped me understand why I had to take it, what the alternatives were, how the problem was caused and how it was going to be cured."

Although most participants displayed some awareness about the limitations of online health information, they found it difficult to express how they differentiated between good and poor quality information. Most commonly, they looked for the same or similar information to be published on multiple websites, and author and organisational credentials and status. Despite awareness of poor quality information on the Internet, participants felt more confident about using their medicines and used online information to make health care decisions, including the starting or ceasing of a medication. None of the participants in this sample had started self-medicating as a direct result of online health information but one consumer stopped self-medicating (using her sister's tramadol) after viewing online health information.

Although participants used online health information to address conflicting advice about medicines, most still preferred face-to-face contact with health professionals. No consumers in this sample had bought medicines via the Internet and eight were apprehensive about buying medicines online. Participants stated that online information resulted in them being more prepared to ask their doctor more pertinent questions at their next visit. Overall participants felt that access to online health information made them feel more assertive, informed, confident and gave them a better understanding of their medicines.

3.4.4 DISCUSSION

These interviews demonstrate that participants value online health information and apply it to make decisions about their medication use. It also illustrates that despite government and private investment in health portals participants used commercial

search engines to seek online health information and they are unsure about how to differentiate between good and poor quality websites. The study shows that participants use such information as a second opinion rather than an initial diagnosis or treatment recommendation. Those participants who have received conflicting advice from their health care providers also use online information to make decisions about medication management. However the subsequent health outcomes of such decisions seem variable.

Consumers need to have accurate, quality information if they are to make informed decisions about their personal health care management. However, the ranking of sites via commercial search engines is influenced not by quality but the number of hits, keywords and cash payments. Despite Government and private organisations investing large amounts of money into the development of health information portals (for example HealthInsite™) to meet consumers' information needs, none of these participants used portals to access health information.

This study also supports the results of one other Australian study where participants found online health information useful.⁶ In this study, many participants also reported using this information to make health care decisions but most did not discuss online health information with their doctor or pharmacist. Why consumers choose not to discuss online health information with their health care providers and the subsequent impact on their relationship is unknown. Although consumers find it difficult to differentiate good and poor quality online health information the health outcomes of consumers who access poor quality information are also unknown. Confident consumers acting on poor quality health information have the potential to increase the number of adverse drug events and Australian hospital admissions.

The results of this pilot study are limited to an examination of the views of a small group of online health seekers who used the QMH and it is unlikely that they reflect the experiences of the wider community. Conducting the same semi-structured interviews in a number of research sites and populations would have enhanced the generalisability of the results, but this was outside the financial scope of this project. In hindsight, a better research approach would have been to ask an additional question in the population survey, 'Would you be willing to take part in an interview or discussion

group about the Internet and health?' This method of recruitment would allow subsequent interview data to be examined in the context of the wider population.

3.5 CONCLUSION

The Internet can deliver public health, preventative and clinical information to a critical mass of Australians. However, a large number of Australians could potentially either benefit or be harmed by current online health information and resources of variable quality. Thus, the current challenge is to ensure an online health environment, which, safeguards Australians and allows the development of innovative, interactive, ethical, online health resources. These resources must be secure, valued by consumers and health care providers, yet ultimately provide value for money and facilitate positive health outcomes. Nevertheless such resources should not be developed at the expense of the elderly and the poor who may be unable to access them.

These findings also provide a starting point to better understand complex consumer decision-making and behaviour about medicines and the Internet. Future studies, encompassing a wider cross section of the online medicines information seekers may identify pathways to educate and safeguard online health care consumers, so that they may be better equipped to find, assess and interpret quality online information that meet their individual needs. Meanwhile, skilled clinicians are well placed to be online information brokers who promote the safe and appropriate use of medicines. However, to fulfil this role, clinicians themselves must have the ability to seek, identify, and critically appraise health information and resources available via the Internet. Furthermore, to use the Internet in daily practice, clinicians must overcome significant barriers including the learning of new skills, costs and workflow.

Together, these independent studies demonstrate that many Australians actively seek online health information about medicines, yet some may lack the knowledge and skills to identify fraudulent and misleading information and also be reluctant to discuss such information with clinicians. Furthermore the pattern of online health seeking associated with differing health status and disease states should be investigated in the future if we

are to harness the potential of the Internet to deliver clinical preventative and public health information and interventions to Australians.

4 SURFING, SELF-MEDICATING AND SAFETY

4.1 INTRODUCTION

Public access to many medicines is restricted by policies and legislation that aim to ensure the safe, appropriate and judicious use of affordable, effective, medicines by consumers and health professionals.⁸⁴ This regulatory framework has resulted in clinicians being the gatekeepers of prescription-only and some over-the-counter medicines. Professional practice standards and regulations also govern the prescribing and dispensing of these medicines by registered doctors and pharmacists. However, most current policies, legislation and practice standards were developed prior to the evolution of the online sale of medicines.

The Internet has revolutionised the sale of medicines, whereby consumers can self-select and buy medicines, often delivered across national and state boundaries, without face-to-face interaction with a health professional. E-pharmacies are websites selling prescription-only medicines and other products including non-prescription and complementary medicines.

The potential advantages of the online sale of medicines include competitive prices, consumer convenience, avoidance of embarrassment, timely access to quality medicines information and increased access for consumers in rural and remote areas. Disadvantages include quality assurance issues, such as counterfeit medicines, substandard products, breaches of storage conditions during delivery, lack of secure confidential medical information, delivery costs and a lack of health professional intervention.³² The Internet also blurs the division between drug information and inappropriate promotion.⁸⁵ Nevertheless, to ensure the optimal use of medicines, consumers must have timely access to quality information about the benefits, risks and appropriate use of medicines.

Consumers want medicines information, but have diverse individual needs.⁸⁶⁻⁸⁷ Clinicians who prescribe or dispense medicines have professional, ethical and legal responsibilities to provide consumers with quality information and facilitate the safe and appropriate use of medicines. Whether e-pharmacies provide such information or advice is largely unknown.

Previous published studies regarding the online sale of medicines are limited to US sites or sites selling 'lifestyle drugs' including sildenafil and finasteride.^{32,89-93} In 2001, the US Office of Criminal Investigations investigated 64 cases involving the online supply of prescription-only medicines without a medical consultation.⁹⁴ Such sales potentially result in the dangerous and inappropriate use of medicines. However, the incidence of adverse drug events associated with the online sale of medicines is unknown.⁹⁵ Furthermore, existing studies regarding quality of online information focus predominantly on specific diseases or treatments, rather than the information and advice associated with the delivery of health, and in particular pharmaceutical services.⁹⁶

4.1.1 AIMS AND OBJECTIVES

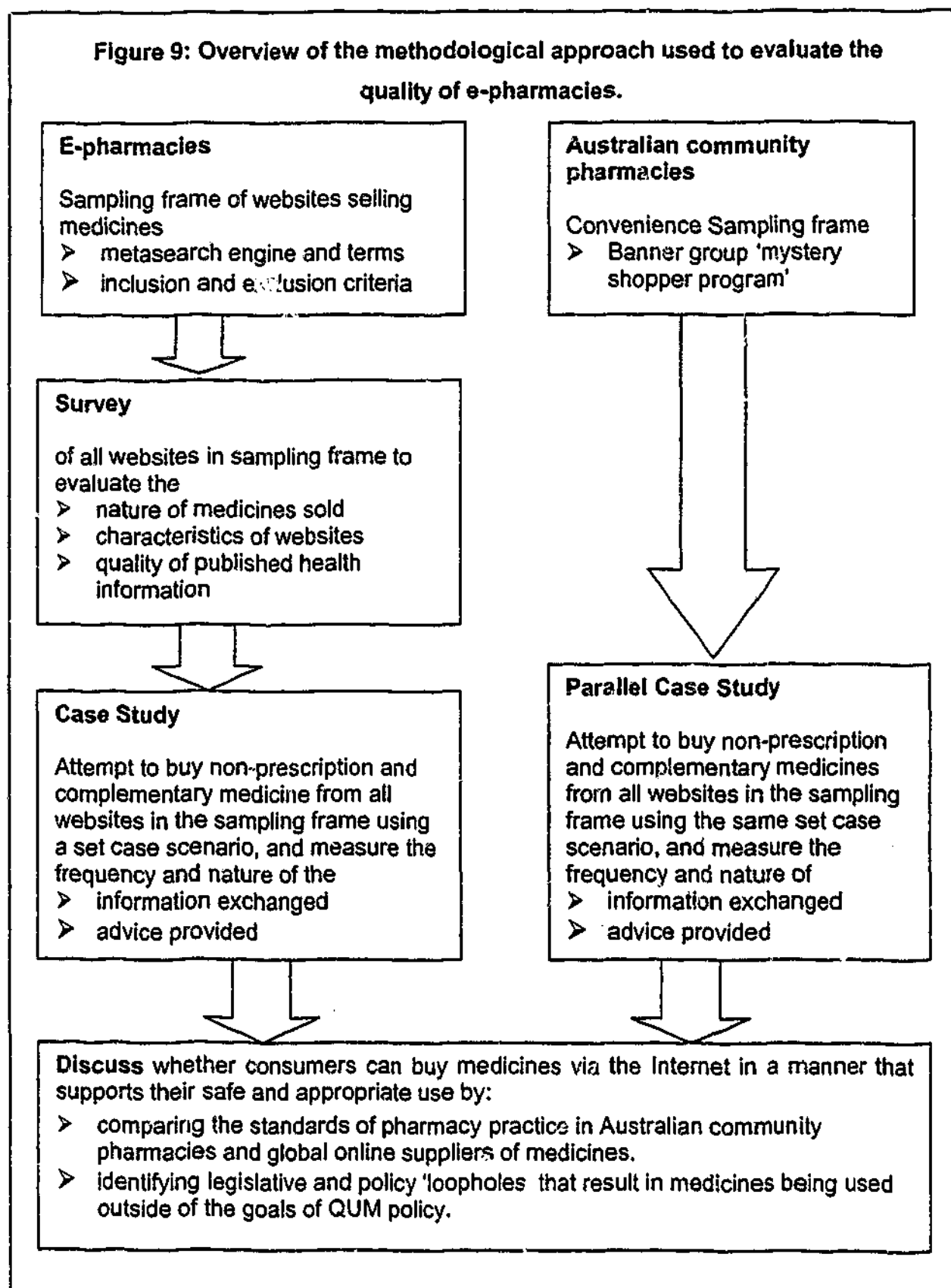
This chapter aims to examine whether buying medicines via the Internet supports their safe and appropriate use by consumers.

The objectives of this chapter are to:

- determine the nature of medicines sold via the Internet;
- evaluate the structural and process characteristics of websites supplying medicines online;
- evaluate the quality of health information published on websites selling medicines;
- examine whether website staff exchanged information with, and provided relevant advice to, consumers;
- compare the standards of pharmacy practice in Australian community pharmacies and global online suppliers of medicines; and
- identify legislative and policy 'loopholes' that result in medicines being used outside of the goals of QUM policy.

4.2 METHODS

This descriptive research was conducted in two simultaneous arms in Winter 2001, as illustrated in figure 9.



4.2.1 SAMPLING FRAMES

E-pharmacies

The sampling frame of e-pharmacies included those websites selling medicines which can be legally dispensed or sold under the supervision of registered Australian pharmacists.⁹⁷ Websites recording multiple hits were included once in the sampling frame. Websites that only offered electronic transfer of prescriptions from doctor to pharmacy or prescription refills (increasingly common in the USA), three members-only sites, four sites written in languages other than English, two sites with transmission errors, and eight sites under development were excluded.

The search terms used to identify the e-pharmacies were 'internet pharmacies', 'internet pharmacy', 'internet medicines', 'online pharmacies', 'online pharmacy' and 'online medicines'.

Australian community pharmacies

In June 2001, there were 4925 pharmacies in Australia,⁹⁸ all registered with a State Pharmacy Board. Although almost all pharmacies are independently owned by pharmacists, many join banner groups, which offer advertising, staff training, store signage, private label representation and product promotions coordinated by a management group. In 2001, AMCAL® was Australia's largest banner group comprising approximately 400 community pharmacies in metropolitan and rural locations in all states and territories. AMCAL® pharmacies were an accessible, convenience sample of Australian community pharmacies.

4.2.2 E-PHARMACY SURVEY

The public information published on all e-pharmacies in the sampling frame was surveyed. Data were collected including contact details, search functions, types of medicines available, prescription requirements, availability of online medical consultations and pharmacist advice, accreditation seals, privacy and returns policies, information types, advertising and the quality of information published about medicines. The complete survey instrument was piloted in June 2001 (Appendix 4).

The quality of health information published on these websites was also evaluated using the DISCERN® rating instrument, which was specifically developed and validated to assess a broad range of online and written consumer health information.⁹⁹ DISCERN® consists of 15 questions, each representing a unique quality criterion, plus an overall quality rating.

4.2.3 E-PHARMACY CASE STUDY

One non-prescription and one complementary medicine were purchased using a set case scenario from all possible websites within the sampling frame (box 5).

Box 5: Case scenario – 35 year old Australian woman.

Place an order for Sudafed® (preferred brand) or pseudoephedrine HCl (30-120mg) (single therapeutic ingredient), quantity 10-60 capsules/tablets and St John's Wort 100mg+, quantity 10-60 (no preferred brand) from an online supplier of scheduled medicines. Choose the cheapest Sudafed® or St John's Wort product if multiple options are available

The Sudafed® or pseudoephedrine HCl product is for your own use. You have had a runny nose for a couple of days and a friend suggested you try it - you have not used this product before or tried anything else to treat the problem. The St John's Wort is also for your own use. You have been feeling really flat and low and you read about St John's Wort in a magazine – you have not used this product before. You have taken Prozac (fluoxetine) for depression for the past 3 months after being in a car accident. You are not taking any other medications and have no other illnesses.

Sudafed® (pseudoephedrine HCl) and St John's Wort (*Hypericum perforatum*) products were chosen for the case scenario because they are both commonly used and widely available. Pseudoephedrine HCl is often illegally misused to manufacture amphetamines¹⁰⁰⁻¹⁰² and in Australia its importation requires a licence from the Therapeutic Goods Administration.¹⁰³ The researcher obtained such a licence for the purpose of this study. St John's Wort products interact with many medicines by altering drug metabolism or increasing central nervous system serotonin levels.¹⁰⁴ St John's Wort can interact with medicines including cyclosporin, digoxin, oral contraceptives,

theophylline, warfarin, anticonvulsants (carbamazepine, phenobarbitone and phenytoin), selective serotonin reuptake inhibitors (SSRIs) and related drugs (citalopram, fluoxetine, paroxetine, sertraline, nefazodone), triptans (sumatriptan, naratriptan, rizatriptan and zolmitriptan), human immunodeficiency virus (HIV) protease inhibitors, and HIV non-nucleoside reverse transcriptase inhibitors.¹⁰⁴ Serotenergic syndrome is characterised by changes in mental status, and motor and autonomic function and is a potentially serious adverse drug event that may occur when St John's Wort and fluoxetine are taken concurrently.

The frequency and nature of patient information collected by pharmacy staff; the provision of written information and advice by pharmacy staff; product recommendations; referrals; payment security; delivery costs, times and methods; customs inspections; and the condition of the product received were evaluated. The information exchanged with, and advice provided to consumers, by e-pharmacy staff was assessed using pharmacy practice standards and current guidelines.¹⁰⁵ Whether e-pharmacies had processes in place to detect the potential drug interaction between St John's Wort and fluoxetine were also assessed.

4.2.4 PARALLEL AUSTRALIAN COMMUNITY PHARMACY CASE STUDY

Banner groups often employ 'mystery shopper programs' to evaluate consumer experiences of community pharmacy. In 2001, the AMCAL® mystery buyer program employed a market research company who sent 'mystery shoppers' to purchase products from pharmacies using set case scenarios and evaluate customer service, sales processes and store environments. The consumer experience was recorded using a standard survey form and feedback was provided to the pharmacy staff within 24 hours. The purpose of the mystery shopper exercise is to encourage staff reflection and to develop operational solutions from within the pharmacy to improve customer service and loyalty. The banner group uses these results to identify and develop targeted training initiatives for its members. However, the quality of information and advice provided by pharmacy staff or their compliance with recently developed Australian professional practice standards was not measured as part of mystery shopper programs.

In December 2000, the researcher approached the AMCAL® banner group regarding the potential opportunity to incorporate the assessment of professional practice standards into their mystery shopper program, which was about to be updated. The researcher suggested that by including information about the exchange of information between pharmacy staff and consumers, improvements could be made towards compliance with recent practice standards and the professional image of AMCAL® staff by ensuring the quality of health care delivery. After several meetings with relevant AMCAL® staff, verbal agreement was reached, whereby the mystery shopper programs to be conducted in August and September 2001 would collect data using St Johns Wort and Sudafed case scenarios.

4.2.5 ETHICS

The Monash University Standing Committee on Ethics in Research Involving Humans gave ethics approval for this study.

Informed consent was not sought from e-pharmacy operators prior to buying these medicines due to the simulated nature of the project. However, in accordance with the ethics committee's recommendations, we sent e-pharmacies that delivered medicines a hard copy of the data collected from their individual website (one month post delivery) and each had the opportunity to withdraw their results from the study.

AMCAL® management were fully informed about the project and agreed to supply data that did not identify individual pharmacies or staff. As part of AMCAL® membership conditions all pharmacies participate in this type of observational survey twice a year.

4.2.6 DATA COLLECTION & ANALYSIS

All data were collected between July and September 2001 then subsequently analysed using SPSS for Windows Release 10.0.5.9. Descriptive statistics were used to summarise the data and illustrated using frequency tables.

4.3 RESULTS

4.3.1 SAMPLE SIZE OF E-PHARMACIES

In May 2001, a total of 2954 hits were identified. However the number of hits generated by each individual search varies depending upon which search terms and search engine were employed. Due to the technological constraints of Copernic Basic 2001®, it was not possible to combine the results of each individual search or to automatically remove many duplicative hits. Thus the researcher observed each of the 2954 websites from which a sampling frame of 104 e-pharmacy websites was identified (table 14).

Table 14: Number of hits generated by Copernic Basic metasearch engines and search terms in May 2001.

Search Terms	The Web	The Web Australia	Total
online pharmacy	236	243	479
online medicines	201	270	471
online pharmacies	225	239	464
internet pharmacy	184	225	409
internet medicines	181	260	441
internet pharmacies	159	222	381
(internet or online) and (pharmacy or pharmacies or medicines)	137	172	309
total number of hits	1323	1631	2954

4.3.2 QUALITY OF E-PHARMACIES

Between July and September 2001, the public information published on 104 e-pharmacy websites was surveyed. Data were collected regarding contact details, search functions, types of medicines available, prescription requirements, and the availability of online medical consultations.

E-pharmacies operated in 13 countries, however, the country of origin could not be identified for 22 websites. The frequency of individual medicines sold on websites, their prescription requirements and access to online consulting are shown in table 15. Twenty e-pharmacies supplied prescription-only medications without a prescription.

Table 15: Medicines sold with and without a prescription from e-pharmacies by geographic location.

Location	Codeine 20-50mg caps/tabs	Sildenafil 50-100mg tabs	Amoxicillin 250-500mg caps/tabs	Clotrimazole 1-3% vaginal cream	Pseudoephedrine HCl 30-120mg caps/tabs	St John's Wort 100mg+ caps/tabs	Online prescribing	Total number of sites in each country
Australasia								
Australia	4	8	9	10	9	11		12
New Zealand		5	4	7	2	8	2	13
North America								
Bermuda		1					1	1
Canada	1	3	2	2	2	2		4
Mexico			1 (1)					1
USA	6	31 (1)	23 (1)	16	15	17	8	40
Asia								
China		1(1)						1
India					1			2
Philippines		1 (1)						1
Europe								
Italy		1	1	1				1
Spain		1 (1)						1
Switzerland								1
United Kingdom	1	1	1	2	1	2		4
Unknown	4 (4)	13 (11)	12 (11)	3	1	1	1	22
Total	16 (4)	66 (15)	53 (13)	41	31	41	12	104 (20)

(n) number of e-pharmacies selling prescription-only medicines without a prescription

Thirty percent of the 104 e-pharmacies delivered nationally and 67% internationally, and the contact details including physical addresses, telephone or fax numbers, were displayed on 61, 66 and 61% of websites respectively. Consumers might expect to see details of the individuals accountable for providing their health services, but only 35% of websites published the owners' or directors' names (registered pharmacies can be owned by non-pharmacists or company structures in some countries). Although 42% of websites promoted the availability of advice from pharmacists, it is difficult to determine if registered pharmacists were involved.

Only 12 of the 104 websites displayed any form of quality accreditation. Seven websites displayed national pharmacy authority seals while two websites displayed Health on the Net (HON) and one Joint Commission on Accreditation of Healthcare Organisations (JCAHCO) logos.

Privacy statements, information disclaimers, and returns policies were shown on 40, 31 and 37% of websites respectively, but 37% of websites displayed none of these policies. Furthermore, e-pharmacies displaying such policies often placed all risk and responsibilities with the consumer and little with the website operator. For example,

"The user affirms that: they have no known allergies to, sensitivities to, or intolerance of any products ordered, no known medical conditions predisposing to adverse reactions to any products ordered, are not taking any concurrent medications with which the products ordered are likely to interact. For prescription items: they have received counselling from a health care professional about the indications, actions, interactions and side effects of any medications they have been prescribed, including the likely effects of not taking the medication."¹⁰⁶

However, the underlying philosophy of pharmacy practice is to support the optimal use of medicines by pharmacists sharing responsibility with health care professionals and consumers for the outcomes of therapy.¹⁰⁷

Direct to consumer advertising of medicines potentially alters the balance between the provision of information and stimulating the demand for medicines.¹⁰⁸ Advertisements (defined as 'any statement, pictorial representation or design, however made, that is

intended, whether directly or indirectly, to promote the use or supply of goods') were displayed on 47% of websites.¹⁰⁹ Of the 104 e-pharmacies:

- 20% promoted prescription-only medicines
- 19% non-prescription medicines
- 20% complementary medicines
- 23% health and beauty products.

Examples of inappropriate promotion included:

- 'sample packs' containing anabolic steroids, diuretics and hormones;
- bonus deals of 120 free metandienon tablets with orders of US\$100 or more; cyclosporin for hair loss;
- nicotine replacement therapies and tobacco products sold from the same site;
- bromocriptine and phenytoin promoted as smart drugs;
- clindamycin lotion for 'women who wear make-up'; and
- unproven claims about complementary products including breast enhancement creams and cellulite and vein 'erasers'.

Examples of fraudulent and dangerous practices included poor packaging and the deliberate avoidance of customs.

"We do not ship express or any other method that requires a signature, as these packages are more open to scrutiny, both entering your country and checked leaving the country of origin" and "when sending tablets, we take them out of the original bottle, as this is bulky and less likely to pass through customs. We pad the tabs with a plastic film to seal them and prevent moisture and dirt from contaminating them. It is rare that they are damaged this way, and even if they are, they are still usable."¹¹⁰

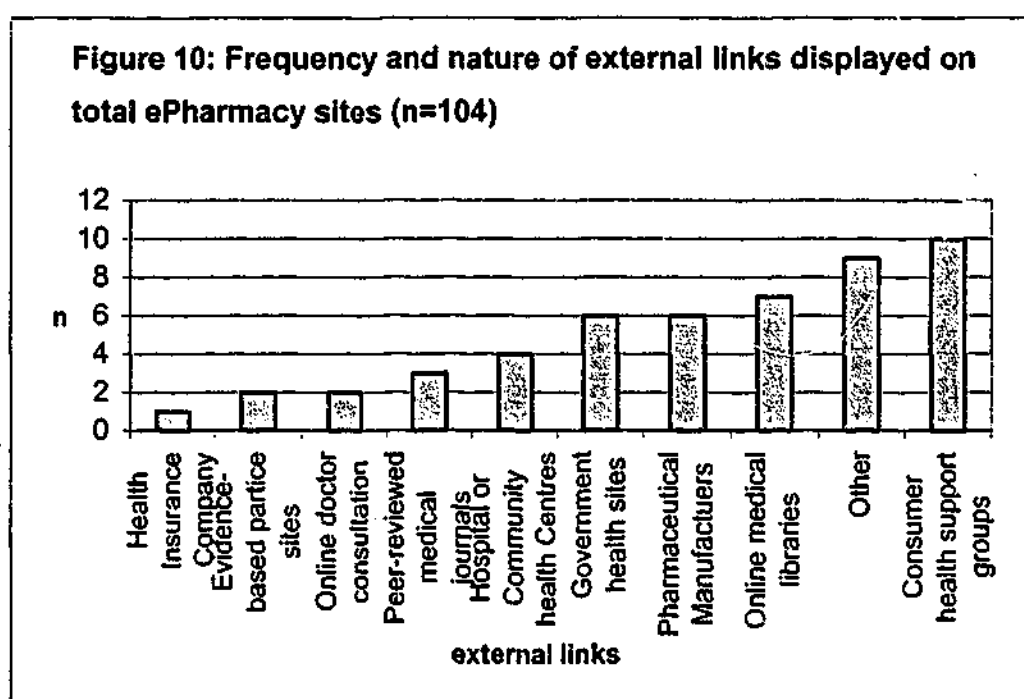
4.3.3 QUALITY OF HEALTH INFORMATION PUBLISHED ON E-PHARMACIES

Of the 104 websites, 63 provided some health information but only 51 (49%) provided some information about medicines. Thirty-one websites published disease-state information and 17 provided lifestyle information. However, 40% of sites provided no

health information and 50% published poor quality information of limited or no benefit (table 16).

Table 16: Frequency of DISCERN® ratings of health information by e-pharmacy's geographic location.							
Location	No Information	DISCERN Rating*					Total number of sites
		1	2	3	4	5	
Australasia							
Australia	2		4	6			12
New Zealand	3	1	4	5			13
North America							
Bermuda			1				1
Canada	2	1	1				4
Mexico	1						1
USA	14	1	9	7	4	5	40
Asia							
India	1	1					2
China	1						1
Philippines		1					1
Europe							
Italy	1						1
Spain			1				1
Switzerland	1						1
UK	1	2			1		4
Unknown	14	1	6	1			22
Total	41	7	26	20	5	5	104
*DISCERN® ratings 5 = High – indicates that the publication is 'good' quality – it is a useful and appropriate source of information about treatment choices. 3 = Moderate – indicates that the publication is 'fair' quality – it is useful source of information about treatment choices but has some limitations. Additional information or support would definitely be needed. 1 = Low –indicates that the publication is 'poor' quality – it has serious shortcomings and is not a useful or appropriate source of information about treatment choices. It is unlikely to be of any benefit and should not be used.							

Of the 104 websites, 50% allowed consumers to search by trade name, 53% by therapeutic class and 21% by therapeutic substance, whilst 34% offered no search function at all. Thirty websites displayed external links, most commonly to consumer health support groups and online medical libraries as shown in figure 10.



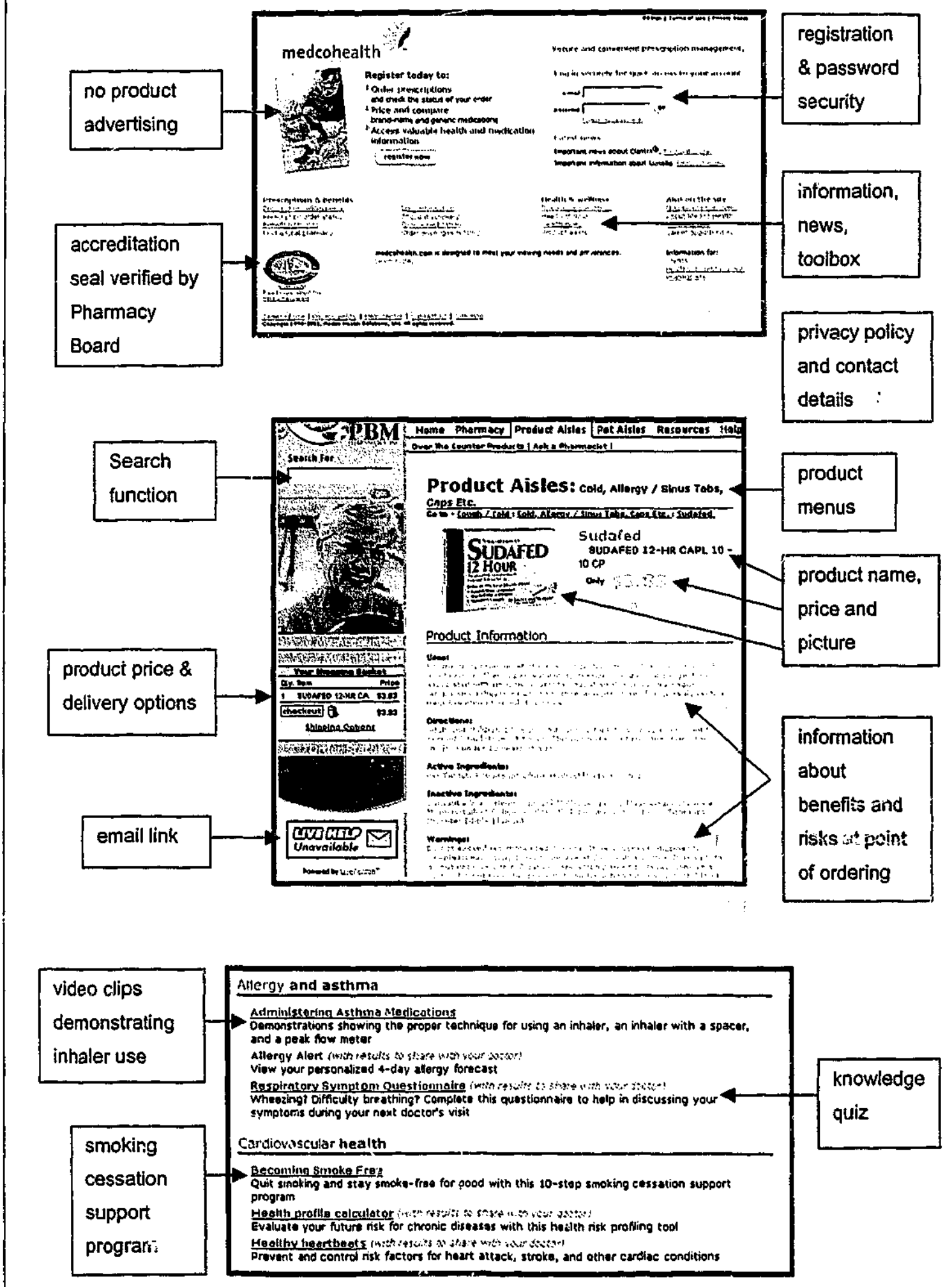
No individual e-pharmacy was observed to have all of the desirable characteristics to ensure the judicious, safe and appropriate use of effective medicines. However, examples of consumer-friendly features such are illustrated in box 6.

4.3.4 E-PHARMACY CASE STUDY

Sample size and characteristics

Of the 104 e-pharmacies 31 (30%) and 41 (40%) websites sold pseudoephedrine HCl and St John's Wort respectively. Fifteen of 31 (48%) e-pharmacies, delivered pseudoephedrine HCl (14 Sudafed® and one local generic product), whilst 26 of 41 (63%) e-pharmacies delivered various St John's Wort products to Australia. Fourteen e-pharmacies delivered both products and a total of 27 packages were received from Australia, Canada, New Zealand, United Kingdom and the USA.

Box 6: Examples of consumer-friendly e-pharmacy features.



Sixteen (52%) and 15 (37%) of e-pharmacies selling pseudoephedrine HCl and St John's Wort respectively, did not deliver these medicines to Australia largely because 31 (30%) of 104 e-pharmacies only deliver such medicines within their national borders. No e-pharmacies withdrew their results.

Of the 27 e-pharmacies that supplied medicines, 13 (48%) required consumers to register a user name and password. Twenty-five websites (93%) confirmed the order and delivery details of products via email. All sites used secure socket layer (SSL) technology for payment transactions. The operation of these e-pharmacies appeared to involve registered pharmacists and no websites sold prescription-only medicines without a prescription written by a doctor.

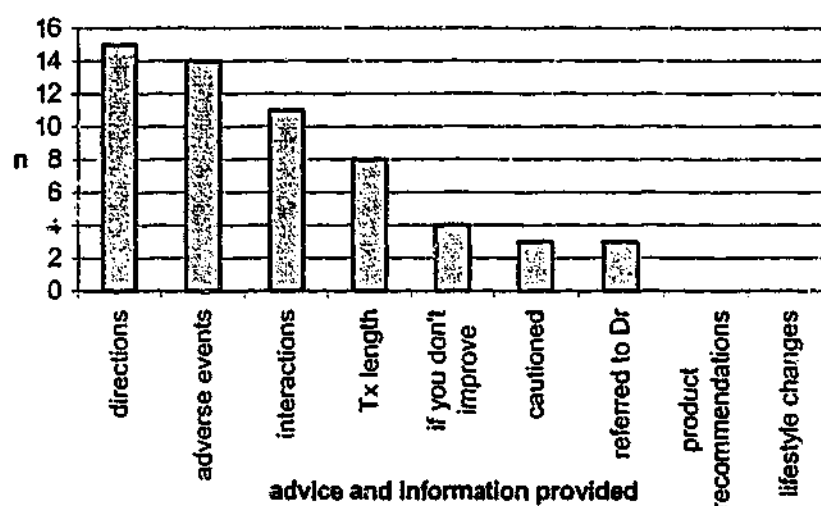
Provision of information and advice

Twenty-five websites published information about pseudoephedrine HCl. Of these 21 websites published useful information (DISCERN rating 4 or 5) about the benefits associated with taking pseudoephedrine hydrochloride, but only 13 websites published information about the potential risks. Nineteen websites published information about St John's Wort products. Overall the information about the benefits and risks of St John's Wort products were more balanced (17 and 18 websites respectively). However, the information was often of a general nature and less useful. For example, 'this medication may interact with other medicines' rather than this medicine interacts with a list of specific therapeutic substances.

Of the 27 e-pharmacies that supplied medicines, a range of information was provided either via the website, upon delivery or by verbal counselling (figure 11).

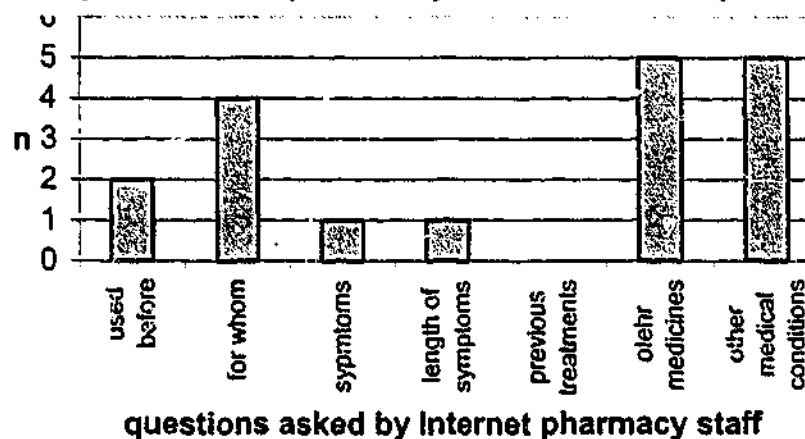
No sites suggested associated ancillary lifestyle changes. No e-pharmacy staff recommended alternative or additional products. Upon delivery, the only written medicines information received was one manufacturer's information sheet regarding the use of pseudoephedrine HCl and one information sheet regarding St John's Wort and potential drug interactions.

Figure 11: Frequency of information provided when non-prescription and complementary medicines bought from e-pharmacies.



Of the 26 e-pharmacies that supplied St John's Wort products, five websites asked for consumer information that could have enabled staff to detect the potential drug interaction involving fluoxetine and St John's Wort, but only three of these e-pharmacies contacted the consumer about this concern (figure 12). The three e-pharmacies initially communicated via email asking for additional contact. Three e-pharmacists subsequently counselled the consumer by telephone and correctly referred the consumer to see her doctor before commencing self-medication with St Johns Wort. The staff of the remaining 21 e-pharmacies could not detect this potential drug interaction because they failed to exchange relevant information with consumers.

Figure 12: Frequency of information collected by staff when purchasing non-prescription and complementary medicines from e-pharmacies (n=27).



Upon delivery

Products were received by post (12), registered post (11), and courier (4). Signatures were required on 15 occasions. Eight of 16 international deliveries were opened, inspected and resealed by Australian customs officers. Two packages containing pseudoephedrine HCl products had no tangible evidence of customs inspection. Upon delivery, we identified 16 packages by information visible on the exterior of the package, 19 by descriptions of package contents, and three packages by deduction using postmarks and dates. The products were packed in 16 boxes and 11 envelopes. Twenty-two packages contained protective packaging materials. Despite these packaging precautions, two products were damaged at the time of delivery.

Specific errors included one delivery of an out of date St Johns Wort product (expiry August 2001, delivered September 2001) and one package was sent to the billing address instead of the residential address. The e-pharmacy that supplied the out-of-date product was contacted by email and a refund was offered. One pharmacy also substituted a different brand of St John's Wort from that originally ordered with no notification or explanation about the change.

Costs

The product costs, postage and handling charges, and delivery times were highly variable (figures 13 to 15). For example, the product costs of a total daily dose of pseudoephedrine HCl 240mg ranged from A\$0.82 to \$3.04, (mean A\$1.50, 95%CI \$1.13 to \$1.87). Costs of St John's Wort products also varied but were not comparable due to inconsistent recommended daily dosages and the often non-standardised nature of some complementary medicine products. Postage and handling charges ranged from A\$3.28 to \$62.70, (median \$7.54). Both product and postage and handling costs were most expensive for deliveries from the USA. Delivery times ranged from 2 to 18 days, (mean 6 days, (95%CI 4.5 to 7.5 days).

Figure 13: Box and whisker plot of the cost of a daily dose of pseudoephedrine HCl (240mg) versus the country of origin of the e-pharmacy (n=15)

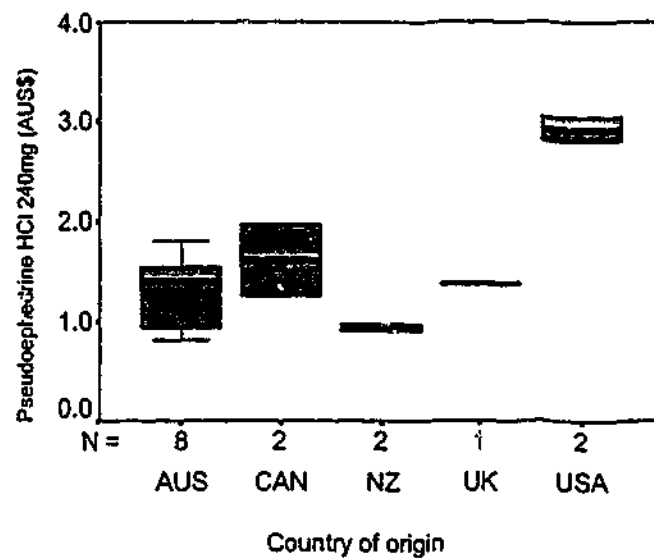


Figure 14: Box and whisker plot of the delivery time of case study purchases versus the country of origin of the e-pharmacy (n=26)

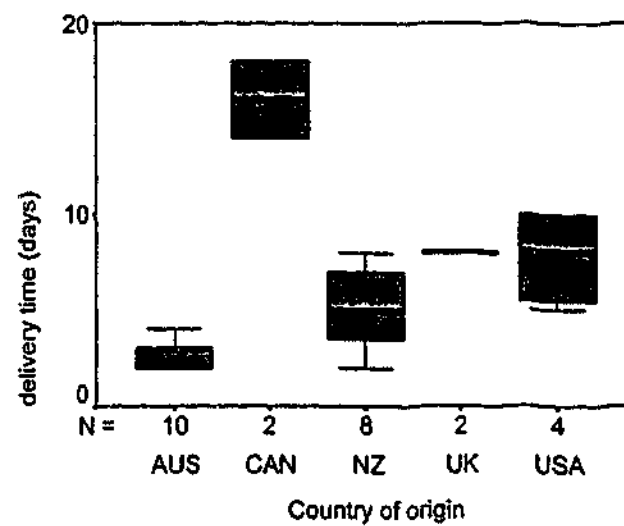
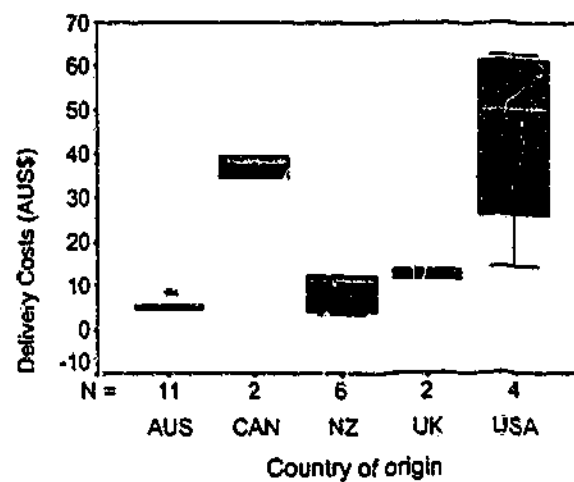


Figure 15: Box and whisker plot of the delivery costs of case study purchases versus the country of origin of the e-pharmacy (n=25)



4.3.5 PARALLEL AUSTRALIAN COMMUNITY PHARMACY CASE STUDY

The case scenarios used in the mystery shopper program were changed just prior to data collection. These changes occurred without reference to the researcher and were apparently due to a staff change and a lack of internal communication within the AMCAL® management group. Subsequently the opportunity to collect data regarding the direct comparison of online and Australian community pharmacies was lost.

4.4 DISCUSSION

4.4.1 MAJOR FINDINGS

These studies demonstrate that many e-pharmacies undermine the safe and appropriate use of medicines because good practice, organisation and support functions necessary to provide quality of care are largely absent. E-pharmacies selling anabolic steroids, human growth hormone, drugs of addiction and antibiotics (often in inappropriate quantities) without prescriptions or medical consultations, inappropriate promotion of medicines and poor packaging and handling practices were observed. These actions potentially lead to inappropriate medication use, adverse events, and could worsen global problems such as antibiotic resistance. Furthermore, consumers cannot make an informed decision about purchasing a medicine using information provided by e-pharmacies because balanced information about the benefits and risks of taking medicines was largely not available or of poor quality, and written information was rarely provided upon delivery.

4.4.2 LIMITATIONS OF THE STUDIES

The results of these studies are tempered by some methodological limitations. Although a broad search was conducted using a rigorous identification strategy, it is difficult to determine whether this sample of 104 websites was representative, as the total current number of e-pharmacies operating at any one time is unknown. Due to the nature of the Internet, it is difficult to evaluate whether an e-pharmacy is 'bona fide', unless the site

displays a seal that can electronically verified by an independent pharmacy statutory body.¹¹¹ Thus, it is almost impossible to know with whom you are dealing or the location or ownership of e-pharmacies. Of the 27 e-pharmacies that supplied medicines to us, all appeared to involve a qualified pharmacist, but whether qualified or unqualified staff supervised our medication order was unknown. Whilst most countries legally permit the export and import of non-prescription medicines for personal use, only approximately half of the e-pharmacies selling pseudoephedrine HCl and St John's Wort products delivered such medicines to Australia. The reasons for this are unknown but limited the sample size of this case study.

The proposed parallel case study of Australian community pharmacies sought to employ a convenience sample of pharmacies. This non-random sampling frame is thus a biased view of Australian community pharmacies because AMCAL® pharmacies are likely to be larger than average Australian community pharmacies, employ more staff, and less likely to be located in rural areas with small populations. These differences would have limited the application of study results to the broader population of Australian community pharmacies as well as restricting comparisons with e-pharmacies.

Despite these limitations, this study provides a unique insight into e-pharmacy practice in 2001. The research findings support the results of a pilot study conducted at a mail centre in Carson City, California where US customs officers inspected 1908 suspicious parcels, of which 721 parcels contained 197 different types of medicines obtained from 19 different countries. These medicines included drugs of potential addiction and abuse, antibiotics, steroids and medicines with narrow therapeutic indices.⁹⁴ The US researchers concluded that these medicines were primarily obtained via Internet sales and estimated that approximately two million parcels containing scheduled medicines for personal use enter the USA each year, which places an overwhelming burden on US customs.

4.4.3 IMPROVING THE QUALITY OF E-PHARMACIES

Strategies to improve the quality of online health information that are equally applicable to the improvement of e-health services include:

- independent third-party regulation of providers;
- evaluation and enforcement of sanctions in cases of dissemination of fraudulent or harmful information and practices;
- self-regulation; and
- consumer education.¹¹²

Nonetheless, there are significant barriers to the implementation of each of these strategies. For example, regulatory change lags behind the evolution of Internet technologies, considerable resources are needed to evaluate and enforce legislation pertaining to cyberspace activities, state or national legislation cannot effectively regulate a global online environment due to jurisdictional uncertainties, and some argue that regulation should not impede innovation.

4.4.4 REGULATION AND OVERCOMING LEGAL LOOPHOLES

Many countries have national medicines policies, legislation, and standards to support the safe and appropriate use of medicines, but much of this legislation was written without reference and prior to the evolution of electronic technologies. For example, although it has always been illegal for New Zealand pharmacists or any other person to provide prescription medicines to New Zealanders without a prescription written by a registered New Zealand doctor, the same safeguards did not extend to non-New Zealanders. Until November 2000, it was legal but unethical, for New Zealand pharmacists to export medicines without a prescription. However, after the discovery of large amounts of sildenafil, orlistat and finasteride being sent from New Zealand to the United States and the United Kingdom, the New Zealand Ministry of Health introduced new legislation requiring a prescription to be written by a New Zealand doctor before pharmaceuticals are supplied overseas.¹¹³ Furthermore, the Medical Council of New Zealand's guidelines now require the doctor and the consumer to have met on at least one occasion.

E-pharmacies found to be operating and supplying consumers within the geographic bounds of one country are subjected to the national regulatory framework and jurisdiction of that country. Legal jurisdiction is dependent upon physical location

within national or state boundaries. However, national regulatory measures do not protect the global public from poor practices involving the online sale of medicines because the Internet operates independently of geographic boundaries. Legal jurisdiction can be difficult to establish in a global online environment.¹¹⁴ For example, there is potential for disputes about whose law should apply if the website is in Spain, the server for that site is in the UK, the medicines are dispatched in Mexico, the money is transferred to Switzerland, and the consumer is in Australia. Furthermore this study demonstrates that it is difficult to identify the country of origin of the website selling the medicines. Jurisdictional issues also apply to other consumer protection mechanisms such as privacy, information disclaimers and returns policies. Some of the jurisdictional issues in cyberspace are currently being addressed, especially with regard to fraud, paedophilia and gambling, and these outcomes may also apply to the delivery of e-health services.

Unethical website operators use these ambiguities to circumvent regulatory interventions put in place to protect consumers from harm. Although the US Food and Drug Administration conducted the first prosecution involving medicines and the Internet in 1994,¹¹⁵ the resources required to enforce regulations are extensive and beyond the means of many countries. Other actions such as the sending of warning letters to firms selling unapproved new drugs online and issuing 'import alerts' to online sellers of foreign pharmaceuticals are more cost-effective and timely.

This study demonstrates that a wide range of medicines can be bought from many countries around the world, including some countries that do not have adequate regulatory frameworks for the safe and appropriate use of medicines. However, banning the sale or importation of medicines via the Internet restricts consumer access to pharmaceuticals and protects the status quo of 'bricks and mortar' pharmacies by diminishing competition. For example, thousands of Americans, who do not have universal access to medicines, cross the Mexican and Canadian borders each year to buy medicines that they can now import via the Internet.¹¹⁶ Similarly, Germans have imported medicines from the Netherlands.¹¹⁷

International cooperation is needed to stamp out fraudulent and dangerous practices such as the supply of prescription-only medicines without a medical consultation.

International treaties or conventions whereby uniform laws are enacted or agreed upon by each country could achieve this end, however reaching consensus is both lengthy and difficult. Consideration should be given to other approaches, such as enforcing Internet Service Providers to banish sites that do not adhere to standards, and the development of a 'cybercourt' jurisdiction.¹¹⁸

4.4.5 SELF-REGULATION

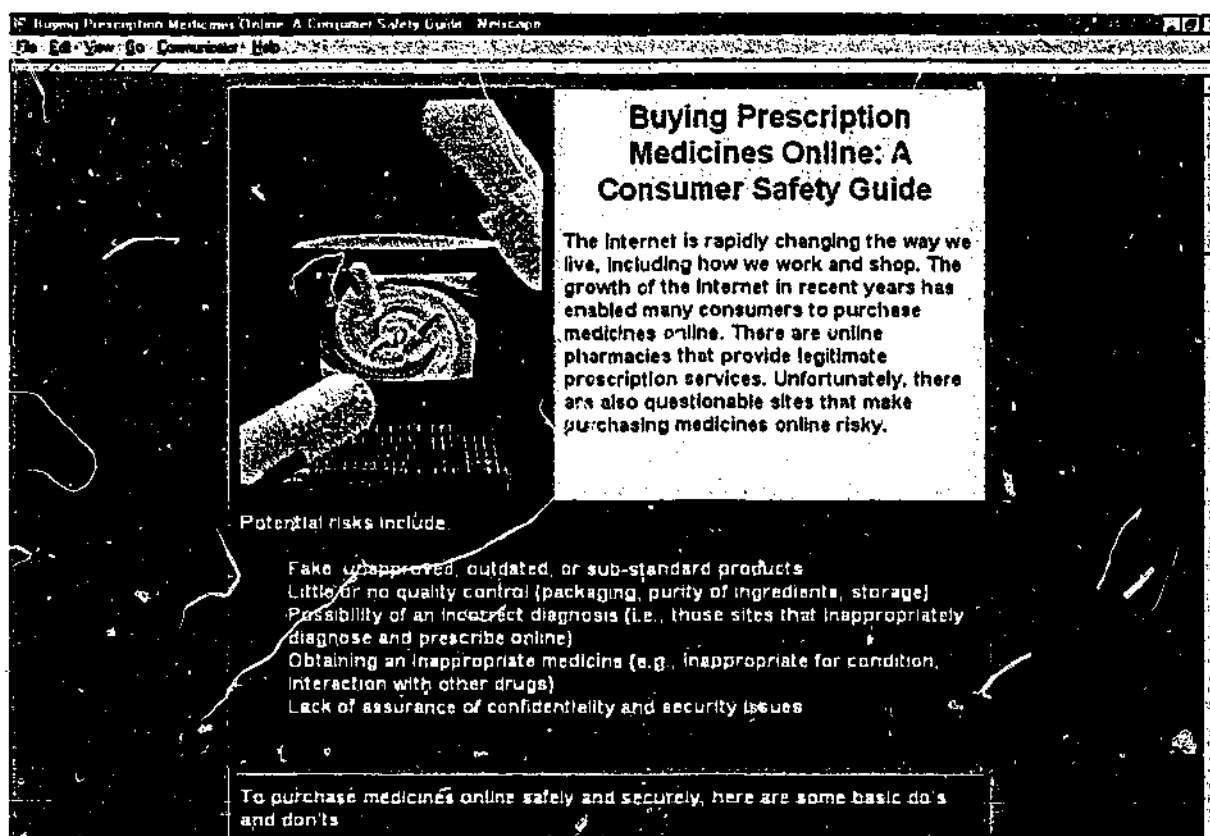
Self-regulation relies upon people voluntarily complying with standards rather than having standards forced upon them. The USA, UK, Canada, Australia and New Zealand have introduced self-regulatory Internet pharmacy practice standards.¹¹⁹⁻¹²² However, the results of this case study demonstrate that not all e-pharmacies operating within these countries comply with these standards. Self-regulation is ineffective due to the inherent global nature of the Internet. For example, despite Australia's self-regulatory guidelines that ban direct-to-consumer-advertising of prescription-only medicines,¹²³ this study demonstrates that this type of promotion reaches consumers via e-pharmacies because such activities are legal in the USA and New Zealand. To successfully direct consumers to e-pharmacies accredited by independent third-party authorities, consumer education and awareness programs must accompany these initiatives.

4.4.6 EDUCATION

Interventions aimed at educating consumers about the benefits and risks of buying medicines online are vital. Information about the potential risks of buying medicines online can be found on increasing numbers of government and consumer association websites, for example the US Food and Drug Administration webpage shown in box 7. Yet online pharmacy brokers promote the availability of medicines whereby no prescription is necessary. Additionally, news and current affairs programs facilitate consumer awareness about these brokerage services. Surely the media has a role to promote the safe and appropriate use of medicines by providing a balanced view about the benefits and risks of buying medicines online.

Box 7: US Food and Drug Administration Consumer Guide to Buying Medicines Online

<http://www.fda.gov/cder/drug/consumer/buyonline/guide.htm>



To purchase medicines online safely and securely, the recommended do's and don'ts are:

Meet with Your Doctor to Obtain Any New Prescription

DO: Take only medications that have been prescribed by your doctor or other authorized health care provider.

DO: Consult with your doctor on whether you need to take any special steps in filling your prescription.

DON'T: Buy online from sites that offer to prescribe a medicine for the first time without a physical exam by your doctor or that sell a prescription medicine without a prescription.

Ensure that You are Dealing with a Legitimate Pharmacy

DO: Buy only from sites that require prescriptions from a physician or other authorized health care provider and that also verify each prescription before dispensing the medication. A written verification policy is usually posted on the site.

DO: Use sites that provide convenient access to a licensed pharmacist who can answer your questions.

DO: Make sure that the site is a licensed pharmacy in good standing in your state. Check with your state board of pharmacy or with the National Association of Boards of Pharmacy (NABP) at www.nabp.net. Some sites display the NABP VIPPS™ (Verified Internet Pharmacy Practice Sites) seal, an assurance that such sites are meeting all applicable state and federal requirements.

DON'T: Buy from sites that sell prescription medicines without a prescription.

DON'T: Buy from sites that sell medicines not approved by FDA.

Box 7 contd: US Food and Drug Administration Consumer Guide to Buying Medicines Online

Know from Whom You are Buying

DO: Buy only from U.S.-based sites.

DON'T: Buy from sites without posted customer service policies.

Safeguard Your Privacy and Security

DO: Look for easy-to-find and understand privacy and security policies.

DON'T: Provide any personally identifiable information (social security number, credit card, and health history) unless you are confident that the site will protect them. Make sure the site does not share your information with others without your permission.

Trust Your Instincts

DO: Use common sense when purchasing prescription medications online. Apply the same standards you'd use for any place of business when looking for a reputable pharmacy site.

DON'T: Buy from sites that include undocumented case histories claiming amazing medical results.

Take Action to Protect Yourself and Other Consumers

DO: Report problems. If you suspect a site is not a licensed pharmacy, do not buy from it. Report the site and any complaints to FDA at www.fda.gov/oc/buyonline/buyonlineform.html. To purchase medicines online safely and securely, here are some basic do's and don'ts: Meet with Your Doctor to Obtain Any New Prescription

DO: Take only medications that have been prescribed by your doctor or other authorized health care provider.

DO: Consult with your doctor on whether you need to take any special steps in filling your prescription.

DON'T: Buy online from sites that offer to prescribe a medicine for the first time without a physical exam by your doctor or that sell a prescription medicine without a prescription.

Ensure that You are Dealing with a Legitimate Pharmacy

DO: Buy only from sites that require prescriptions from a physician or other authorized health care provider and that also verify each prescription before dispensing the medication. A written verification policy is usually posted on the site.

Buying prescription medicines online may be a beneficial option for you and your family. Just make sure you know all the facts before making a purchase. For additional information, go to www.fda.gov and click on "Buying Medicines and Medical Products Online" or call 1-888-INFOFDA (1-888-463-6332).

4.4.7 PROVIDING QUALITY ONLINE INFORMATION AND ADVICE

Australian Internet pharmacy practice standards state that "the pharmacist provides medicines and devices through the internet in a manner which safeguards the privacy and confidentiality of the patient, delivers the correct product with appropriate information to the patient, and promotes safe, correct and appropriate use of medicines."¹²¹ Despite the introduction of similar standards and guidelines in Canada, New Zealand, UK and the USA,^{111,119-120,122} most e-pharmacies (including ones operating in these countries) selling non-prescription and complementary medicines fail to uphold the intent of these standards. In 2001, consumers who choose to self-select non-prescription medicines from e-pharmacies are potentially at risk of experiencing medication misadventures.

Although, packaging contains some information, it alone does not adequately protect consumers from harm.¹²⁴ Pharmacists have a duty of care to ensure that consumers are provided with sufficient information to assist the safe and effective use of medicines to optimise health outcomes.¹²⁵ E-pharmacy operators must be encouraged to provide consumers with quality balanced pharmaceutical information at the right place and time: information linked to individual products at the point of ordering and upon delivery.

Medical and consumer literature identifies the importance of consumers and health professionals exchanging and sharing information to achieve positive health outcomes.¹²⁶ In traditional 'bricks and mortar' practices, consumers can be provided with, or ask for, advice about medicines, and such advice is generally valued.¹²⁷ Pharmacists also refer consumers to their doctor when necessary. UK research demonstrates that one quarter of pharmacist-consumer consultations result in no sale with pharmacists often recommending customers to see their doctor.¹²⁸ In an online environment, the exchange of information between pharmacists and patients requires easy-to-use and secure electronic communication processes. Thus, it is disturbing that the majority of e-pharmacy staff were unable to detect a potentially serious drug interaction, as processes were not in place to obtain relevant information about consumers, including their current medications.

4.4.8 CONSUMER CHOICE AND COMPETITION

One of the potential strengths of the Internet is to provide consumers with informed choices. As medicines can have many different trade names, and the same therapeutic substances can have different approved names in different countries; for example paracetamol (UK) and acetaminophen (USA). Consumers wishing to compare brands, formulations and prices of similar products should be able to search by therapeutic substance or class, but less than half the e-pharmacies provided such a capability. E-pharmacies could incorporate these and other consumer-friendly online features, including drug-drug and drug-disease interaction checks, self-monitoring tools, medication charts and diaries.

Despite cost being a major driver of online consumerism and the relatively free trade of non-prescription medicines, we observed large price disparities between medicines sold by e-pharmacies operating in different countries. Consumers are more likely to realise cost savings from e-pharmacies when purchasing multiple items, and whether they consequently buy more products than those immediately required is unknown.

Ultimately, consumers will decide whether or not to purchase medicines from e-pharmacies, as safeguarding the privacy and confidentiality of the consumers is paramount to its sustainability as a commercial resource. Although discrete packaging protects consumers from potential embarrassment, the origin of medicines sent via the postal system should be identifiable by customs officers and consumers. All packages should include contact details of the sender. Furthermore, errors and the damaged condition of some products upon delivery may deter consumers from repeated use of e-pharmacies.

4.4.9 COMPARING GLOBAL E-PHARMACIES WITH AUSTRALIAN COMMUNITY PHARMACIES

The lost opportunity to collect data regarding the direct comparison of online and Australian community pharmacies was reported earlier in this chapter. The e-pharmacy case study results found that only three of 25 pseudo-patients received adequate information and advice from e-pharmacies to prevent a potentially significant drug

interaction and adverse event. Anecdotally, baseline results of the *Implementation Mechanism to raise Standards of Practice re Supply of Pharmacy & Pharmacist Only Medicines in Community Pharmacy* project describe similar levels of advice and information provided by the staff of Australian community pharmacies¹²⁹ These data were data collected in 2000/1, but this report was not yet publicly available as of November 12, 2002.

4.5 CONCLUSION

Selling medicines via the Internet is a global issue. National pharmaceutical budgets are increasing around the world and subsequent economic restraints may limit consumer access to medicines and adversely encourage consumers to buy medicines in a price competitive market via the Internet. However in 2001, surfing and self-medicating is not safe.

Internet technologies should be employed to develop ethical and innovative practice models that make the management of medications for consumers easier, simpler and safer to achieve positive health outcomes. Consumer education about the benefits and risks of buying medicines via the Internet is needed because national e-pharmacy standards alone do not adequately address the overall lack of information and advice provided by e-pharmacies. It is vital that such standards address the need for pharmacists and consumers to exchange information and prevent self-medication misadventures. To support the safe and appropriate use of non-prescription and complementary medicines, e-pharmacies must go beyond satisfying minimum practice standards and deliver consumer focussed services including the provision of quality medicines information linked to the product at the time of ordering, and written information upon the delivery of medicines.

Safeguarding consumers and improving the quality of websites that sell medicines across state and national boundaries is both complex and difficult. The development of Internet regulatory technologies themselves and the resolution of jurisdictional issues offer some solutions. The challenge is to share evaluation, regulatory and educational resources to discourage fraudulent and misleading websites but permit the development

of innovative, ethical e-pharmacy services. To achieve positive change requires international cooperation and a partnership approach between all stakeholders. The debate about how to improve the quality of e-pharmacies and best safeguard the global public needs input from consumers, health professionals, policymakers, media and lawyers. Now is the time for that debate.

5 AUSTRALIANS BUYING MEDICINES ONLINE

5.1 INTRODUCTION

Chapter two demonstrated that there is a lack of rigorous research regarding the effects of consumer use of the Internet on health outcomes. Chapter three estimated that approximately half of all Australian adults had Internet access and one quarter sought online health information, whilst less than 1% had bought medicines online. Chapter four determined that the quality of information and services provided by websites selling medicines online in winter 2001 was determined to be highly variable, sometimes misleading and deliberately fraudulent. Furthermore, information about the safe and appropriate use of medicines was sadly lacking both at the times of ordering and upon delivery. Thus the Internet provides Australians with access to vast amounts of online health information and global pharmaceutical services of variable quality, which have the potential to cause both harm and good. But what are the views and experiences of the small number of Australians whom are buying medicines online and are they at risk of medication misadventures?

5.1.1 AIMS AND OBJECTIVES

This chapter aims to examine the views and experiences of Australians who have bought medicines via the Internet. The objectives include identifying:

- why these consumers bought medicines online;
- how they identified and assessed websites;
- which medicines were purchased;
- what consumers perceive to be the benefits and risks of buying medicines in this manner;
- consumer satisfaction of the services delivered by e-pharmacies; and comparisons of online and Australian community pharmacy services.

5.2 METHODS

5.2.1 RESEARCH APPROACH

The methodological challenge for this research component of the thesis was the identification of the 'hidden' group of consumers whom bought medicines online. In particular, in order to maximise the credibility of the data collected, consumers had to be recruited who had sought to circumvent current pharmaceutical and or customs legislation. Furthermore, consumers may value the anonymity of the Internet and buy medicines online to ensure their privacy or they may live in remote or rural locations.

The Internet is a natural setting for consumers who buy medicines online and qualitative research is clearly the method of choice for understanding social phenomena in natural settings. (The strengths and weaknesses of qualitative and quantitative research methods were outlined in chapter three.) Thus the Internet was used as a tool to collect data about the views and experience of consumers whom buy medicines online.

Current online health research methods are largely limited to utilising text, although the nature of this text can be informal and conversational in nature. In the future, as the adaptation of Internet technologies evolves, group discussions via online video may also be possible. Meanwhile consideration was given to the potential advantages and disadvantages of employing online focus groups, discussion lists or surveys to gather qualitative data in 2002 were considered (table 17). An online survey method was chosen to potentially maximise consumer participation and protect their privacy.

5.2.2 RECRUITMENT STRATEGY

Identifying and recruiting small hidden populations is difficult. Snowball sampling is the usual method employed by health researchers to conduct research in small hidden populations such as homeless people, illicit drug users or sex workers. This technique has also been employed with the participants of online newsgroups whereby people who come together in a virtual community and offer each other support and information. However, Australians who buy medicines online may not be in a particular geographical location or social network, nor participate in newsgroups. Thus participants for this

project were recruited using the Australian media, government and consumer newsletters.

Table 17: The potential advantages and disadvantages of online health research methods.

Method	Potential Advantages	Potential Disadvantages
Focus Group	➤ Allows participants to interact and bounce ideas off each other, often producing a richer depth of discussion. ➤ Fast intensive data gathering in 60 to 90 minutes.	➤ Conducted in 'real-time' and may limit likelihood of participation. ➤ Unknown whether people feel comfortable discussing personal health matters in this online environment. ➤ Participants may have little in common and thus not interact. ➤ Can potentially be monopolised by those participants who type fastest ➤ Not easily moderated.
Discussion List	➤ Conversational threads can provide rich discussion. ➤ Can be moderated to protect participants from inappropriate and inflammatory remarks.	➤ Asynchronous (takes place in non-real time). ➤ Takes time to build interest and participation rates variable thus discourse occurs intermittently and over a longer period of time. ➤ Use of discussion lists by the wider Australian population assumed to be low.
Newsgroup	➤ As for discussion list but not usually moderated.	➤ Few existing Australian newsgroups, none appear to address broad consumer health issues. ➤ Use of newsgroups by the wider Australian population assumed to be low.
Survey using structured questionnaire	➤ Participation can occur at any time of day or week. ➤ Privacy of participant protected.	➤ No interaction between participants and no opportunity to probe therefore no capacity to enrich or tease out issues.

Between June and September 2002, a media release was sent to national, and state media outlets via the Monash University, Media Unit Media Fax Stream Service. The release was also emailed to 86 rural newspapers and published on the Monash University website, Monash News, faculty newsletters, advertising bulletins and

Monash Institute of Health Services Research (MIHSR) website and electronic newsletter. Two 7cm x 2 column advertisements (box 8) were also placed in the early general news section of *The Australian* newspaper (Wednesday July 24, page 2 and Saturday August 24 page 6, 2002). Community service announcements were also sent to the Consumer's Health Forum, Australian Consumers Association, Multicultural Australia, Council on the Ageing, Carers Australia, e-bility (an online resource for people with disabilities). The respective State government Offices of Consumer Affairs and Fair Trading were contacted and their support was sought to promote the survey via their newsletters.

Box 8: Advertisement

Buying Medicines Online

Have you bought prescription, over-the-counter or complementary medicines via the Internet?

The Internet is revolutionising the sale of medicines and we want to hear about your views and experiences.

The Monash Institute of Health Services Research is conducting a world-first study into the benefits and risks of buying medicines online.

If you have bought medicines from Australian or overseas websites, please consider spending ten minutes to complete the online survey, at <http://netmedicines.med.monash.edu.au>

More information about the Monash Institute of Health Services Research can be found at www.med.monash.edu.au/healthservices/



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5.2.3 QUESTIONNAIRE & WEBSITE DEVELOPMENT

The project information and questionnaire were subsequently published on webpages designed by the webmaster for the Faculty of Medicine, Nursing and Health Sciences, Monash University. Meta-tags (key words used by search engines to find relevant web pages) were hidden on the information page only: netmedicines, net medicines, survey, medicines, pharmacy, internet, online and chemist. The information web page was publicly accessible via links on the Monash Institute of Health Services Research (MIHSR) website or <http://netmedicines.med.monash.edu.au/>. The survey could only be accessed via the information page and after the participant voluntarily consented.

The content of the project information and linked questionnaire web pages (Appendix 5) were developed by the researcher and reviewed by supervisors and MIHSR non-research personnel for clarity and understanding. The structured questionnaire consisted of 10 open-ended and one closed question about consumers' views and experiences of buying medicines via the Internet and five demographic questions.

A primary analysis of the data by theme was conducted due to the limited number of participants and their somewhat diverse and conflicting opinions.

5.3 RESULTS

5.3.1 PARTICIPANT CHARACTERISTICS

Twenty-five participants (8 males and 15 females) completed the online survey. The average age of participants was 43 years (95%CI, 38 to 48 years) and ranged from 20 to 67 years. Five participants self-reported household incomes less than \$40,000 whilst 13 participants had incomes greater than \$60,000 (five were greater than \$100,000), and five participants chose not to report their household income. Four participants spoke an Asian language other than English. Participants resided in five different Australian states (Figure 16) and five participants lived in non-metropolitan postcode areas.

5.3.2 RECRUITMENT

The 25 participants, were recruited from numerous and varied resources (table 18). However, two radio interviews with presenters at ABC Radio Renmark and Launceston and coverage in the e-disability newsletter failed to successfully recruit any participants. This research was also referred to in a Sydney Morning Herald article about 'cyberhypocondria' but the survey website address (URL) was not published. Furthermore, information about the project may have been published in other papers and newsletters without the knowledge of the researcher.

Figure 16: Number of participants residing in each Australian State (n=25)

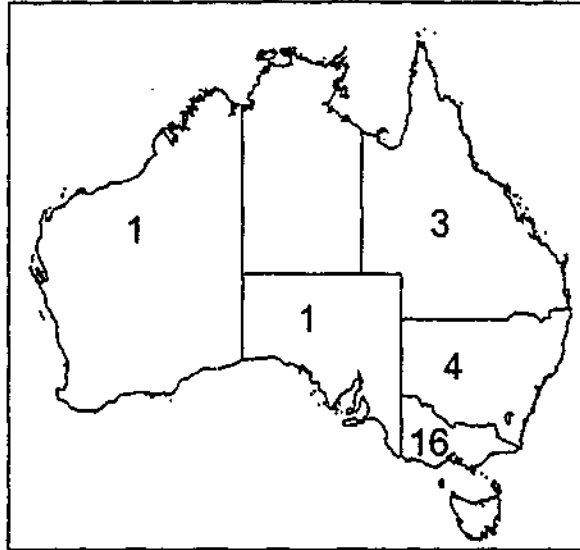


Table 18: Frequency and Location of Participant Recruitment

Recruitment site	Frequency	Description
Newspapers		
The Age newspaper	1	Victorian Broadsheet
The Age online	1	Online summary of Victorian Broadsheet
The Advertiser	1	South Australian tabloid
Herald Sun	4	Victorian tabloid
The Australian (advertisement)	2	National broadsheet
Weekend Australian (advertisement)	4	National broadsheet
Cooma Express	1	Local area tabloid- letter to the editor.
Websites		
Monash University	3	Published on University, Faculty and Institute homepage.
Southern Health	1	Intranet site for a metropolitan local health area.
Electronic Newsletters		
Australian Diabetics	1	Member newsletter
Monash University	1	Global newsletter to staff
MIHSR	1	Sent to MIHSR contact list
Other		
Email at work	3	Unknown origin or nature
Total	24	

5.3.3 WHY CONSUMERS BUY MEDICINES ONLINE

Overwhelmingly these participants self-reported that cheaper prices (18) and convenience (11) prompted them to buy medicines via the Internet. Convenience is defined as 'the quality of being convenient' that is 1. agreeable to the needs or purpose; well-suited with respect to facility or ease in use; favourable easy or comfortable for use; 2. at hand; easily accessible.¹³⁰ In this context, participants described convenience as the 'ability to place the order at any time, day or night', 'not having to run around with the kids' and 'door-to-door delivery'. Other prompts included a reward points scheme (1), no prescription required (2), access to medicines (2), anonymity (1) and 'conquering the chemist cartel' (1).

5.3.4 HOW CONSUMERS IDENTIFIED AND ASSESSED THE QUALITY OF WEBSITES

Participants used a variety of resources to identify websites from which to purchase medicines as shown in table 19.

Table 19: Consumer source of information about websites selling medicines.

Source	Frequency
advertising brochures delivered in the post box	7
advertising of unknown origin,	4
search engines	4
personal recommendations (including one from participant's doctor)	4
television news or current affairs programs	3
webpage links	2
webpage advertisements	1
reward Schemes – preferred partner	1
brochures sent after website visit	1
unsolicited emails	1
Total	28

Participants could give more than one source of information.

5.3.5 WHICH MEDICINES WERE BOUGHT ONLINE

Twenty-four participants purchased 59 scheduled medicines from Australian websites. The nature and frequency of these sales are displayed in table 20.

Table 20: The nature of medicines bought from Australian e-pharmacies (n=24)

	Prescription -only	Pharmacist/ Pharmacy -only	General Medicine	Total
Allergy				8
Antihistamine -less sedating		6		6
Antihistamine -sedating		1		1
Nasal Corticosteroid		1		1
Analgesic				19
Non-opioid,		8		8
Compound		4		4
Non-steroidal anti-inflammatory	2	5		7
Anorectics				3
Weight loss	3			3
Cardiovascular				2
Antihypertensive	2			2
Dermatological				3
Soap substitutes & lotions			2	2
Topical corticosteroids	1			1
Drug dependence				1
Nicotine Replacement		1		1
Ear, Nose, Throat				1
Cerumenolytic			1	1
Eyes				3
Ocular lubricant			1	1
Antihistamine/ decongestant		2		2
Gastrointestinal				3
Antispasmodic		1		1
Hyperacidity, reflux and ulcers	2			2
Gynaecological				6
Hormone Replacement	2			2
Oral contraceptive	4			4
Neurological				3
Antimigraine	2			2
Antidepressant	1			1
Respiratory				7
Inhaled bronchodilators	3*			3
Inhaled corticosteroids	1			1
Cough & cold		3		3
Total	23	32	4	59

* 2 of these purchases may have been either S4 or S3.

Six of the 23 prescription-only products are not subsidised by the Australian Pharmaceutical Benefits Scheme, also referred to as private prescriptions. Of the 17 remaining prescription-only products, two medicines were possibly private or required a restricted authority prescription and two were potentially either prescription-only or pharmacist-only products. The twenty-fifth participant imported Meridia® (sibutramine hydrochloride, a weight loss drug that is not approved for use in Australia) from the United States. Nine of the 25 participants purchased a total of 14 vitamin and 9 complementary medicines including glucosamine, omega-3, melatonin, cranberry and bee pollen products from Australian websites.

5.3.6 ADVANTAGES & BENEFITS

Participants also reported that buying medicines online allowed them to avoid queues or the need to wait for service. They also perceived that there was less embarrassment buying some products such as condoms online instead of face-to-face, and that the internet provided them with more choice and control of the decision-making process. Three participants reported that the ability to buy multiples of products was advantageous, two for reasons of price and one because 'it makes me feel very safe.' Buying medicines online allowed two participants to access medicines that were unavailable locally (one prescription-only product and one complementary medicine). Whilst one participant reported that being able to email or telephone the online pharmacy that held their repeats for quick processing and delivery was advantageous (although this service is generally available in most Australian community pharmacies).

Only one participant self-reported importing medicines that that doctors would not prescribe for her in Australia.

"I like to make my own decisions about what I need. For example, I wanted to try Meridia® or phentermine to lose weight but every doctor I went to said I was already thin enough which I disagree with. Also buying over the internet saves me the embarrassment of having to pick it up at the chemist."

5.3.7 DISADVANTAGES & RISKS

The majority of participants were cautious and unsure about buying medicines from overseas. However they perceived that it was safe to buy medicines online within Australia and that there were few or no risks in this local context. The following comment summarises the views of many participants.

"If medicines are bought from a local source that is governed by the same regulations as local pharmacies, and there is a pharmacist available by either phone or internet to give advice, then there should be little risk in buying medicines via the internet."

Although participants felt strongly that it was safe to buy medicines only within Australia, they also perceived that in an online environment the risk lies more with the consumer than the provider. They identified the following quality and safety issues:

- unpredictable delivery times
- lack of temperature control throughout delivery process
- incorrect self-diagnoses
- patient fraud by the provision of inaccurate information as part of an online consultation.
- lack of credit card security.
- potential drug interactions
- fraud
- lack of consumer protection complaints mechanisms.

Four of the 25 participants considered that they did not have adequate experience or were unsure about how to identify websites that would deliver safe and effective products and services and thereby minimise the risks of buying medicines via the Internet. However the remaining 21 participants considered many website features and 12 participants used behavioural strategies to minimise risks (table 21). Consumer did not consider the availability of medicines information to be a feature that may minimise risks.

Table 21: Website features and strategies considered by consumers to minimise risks when buying medicines online

Website features	Description of feature
Security	➤ secure encrypted ordering technology seal ➤ confirm order with receipt number ➤ guarantee published on website
Pharmacy Details	➤ pharmacy registration details ➤ contact address and phone numbers or enough information to check credentials ➤ Australian company only ➤ trusted and known company name
Appearance	➤ professional website appearance, good search capacity, full description with images, organised information and access to prices
Practice	➤ whether a prescription written by a doctor is required. ie seem to do things legally ➤ sell well-known product brands
Behavioural strategies	➤ only purchase brand names that they have used before ➤ only buy non-prescription medicines ➤ initially check them out by purchasing small order ➤ phone first before going online ➤ only use web sites that have been personally recommended.

5.3.8 COMPARISONS BETWEEN ONLINE AND LOCAL AUSTRALIAN COMMUNITY PHARMACIES.

Participants primarily preferred online pharmacies for reasons of cost and convenience but still dealt with the local pharmacy sometimes to meet their medication needs. Participants recognised that the services provided by local community pharmacies were vital for the immediate fulfilment of urgent prescriptions and that usually the cost involved was no different because such medicines were PBS subsidised and therefore price controlled.

The general feeling of many participants was reflected by the following comment:

"I must say that the local pharmacist is very good and I like dealing with her, the tablets that I bought were just easier [to obtain] and cheaper online."

Additional comparisons about service, information and advice were common but often conflicting. For example, some participants self-reported that a lack of personal interaction in an online environment was advantageous because there was no 'insincerity or unwanted advice'. These participants preferred to compare prices and products without the intervention of pharmacy staff and these views are illustrated by the following comments:

"There are many products with descriptions, dosages etc (online) and I can take my time to browse whereas, if I buy from a pharmacy, most products are behind the prescription counter and the staff recommend which product they think would be best."
and

"I can buy paracetamol and codeine in bulk without the pharmacist looking at you suspiciously I am aware of the daily dosage limits of paracetamol and never exceed it."

and

"Pharmacy assistants only mean to help you but can get carried away asking you all sorts of personal questions that you'd rather not answer to a complete stranger! All the information you need about the product is on the packaging anyway."

While, other participants perceived that Australian community pharmacy staff do not actively provide information and advice. For example websites are 'less personal but information and advice are not necessarily forthcoming when dealing at a regular pharmacy.' Furthermore those participants who did seek information and advice also had contrasting opinions about the counselling provided online compared with traditional Australian community pharmacies. For example,

"A face-to-face interaction at the pharmacy has the advantage of easily discussing options and alternatives."

and

"More information is provided by staff at the pharmacy and if I was unsure about a medicine, I would definitely go to a pharmacy rather than buy it over the Internet."

contrasts with

"Via the pharmacy website there is a counselling service available on a free call number which I found very useful. I also sent an email with a query about a prescription medicine and received a very prompt and thorough return email. You would never get that from a chemist."

and

"When buying from the Internet I am far more aware of exactly what the medication is, what it does and side effects. There are certain links, which provide detailed information such as RxList (website) which even describes clinical trials."

One participant described how he used his local pharmacy as an information resource but bought products via the internet because they were cheaper.

"(Online there) is much less written information when choosing a product – sometimes you cannot read what the product is for or the generic drug names – usually you can read this on the packet in the pharmacy.... however if the product is cheaper via the net you can check out what you want in the pharmacy then buy it on the net."

5.3.9 CONSUMER SATISFACTION

Overwhelmingly, these participants found purchasing medicines via the internet to be a positive experience. Their self-reported actions of repeat buying of medicines online and recommendations to family and friends support this view. However, participants also identified areas for process improvement, such as delivery times, occasional provider software problems and the non-return of repeat prescriptions.

"I thought having our goods mailed to us would be more convenient than having to visit the nearest shopping centre. However, we both work and Australia Post® cannot deliver without obtaining a signature. I had to make the time to get to our local post office, during business hours, to take collection of our order."

No participants complained about the quality of the products they received from websites selling medicines. When participants were asked about where they would seek advice if they were concerned about the authenticity of a product they reported that they would approach the local pharmacist (12), doctor (5), manufacturer (4), provider (3, via

email or telephone), online information (2), Natural College of Medicine (1), health food shop (1), Australian Consumer and Competition Commission and the Australian Drug Centre (1). One participant was unsure.

5.3.10 IMPORTING MEDICINES VIA THE INTERNET

Only one participant reported importing a medicine not approved for use in Australia. She provided the following insights about Australian regulations and customs controls:

"The only reason I would recommend buying from the internet is to obtain medication that doctors won't prescribe Australian websites have far more stricter controls so there would be no point.for people who already have a prescription it is far easier to go to their local pharmacy."

and

"I have heard about people who have had their orders seized by customs either because it was a controlled substance or the quantity was too high. They did not get a refund and lost hundreds of dollars. Apparently this doesn't happen too often and can be avoided by buying from certain pharmacies/countries and not ordering via express mail."

5.4 DISCUSSION

5.4.1 MAJOR FINDINGS

This study highlights how difficult it is to recruit Australians who have bought medicines online. However these results also provide the first insights into why Australians buy medicines online and may provide the basis for future research in this area. In particular, this study demonstrates that individual consumers can deliberately and knowingly import prescription-only medicines that may result in self-harm but the prevalence of such events are unknown.

Participants perceived that Australian e-pharmacies provided them with more choices and control than traditional community pharmacies. These results found that all participants (with one exception) appeared to be cautious about buying medicines online

and largely restricted the initial nature of their purchases to non-prescription products from Australian websites. Furthermore these participants had faith in the Australian regulatory system to adequately protect them. Although participants generally perceived that buying medicines online placed more risks with the consumer than the provider, they felt there was marginal or no risk difference between buying medicines online from Australian websites and traditional community pharmacies. However, they used their local pharmacy staff as a 'safety net' for advice about new products at times of uncertainty such as buying a product for the first time.

The results demonstrated that the participants were largely satisfied with the advice, information and services offered by websites selling medicines in Australia and that they would recommend these websites to family and friends. Their decisions whether to buy a medicine online or locally was primarily due to price and convenience, and to a lesser extent their preferences about personal communications with pharmacy staff.

Although, participants were cautious about buying medicines from overseas, there is potential for this attitude to change as Australians gain familiarity with other online retail activities, such as banking, and booking airfares, accommodation and entertainment. If this attitude prevails there is a potential dichotomy between the risk of buying medicines online as perceived by the researcher in chapter 4 and these consumers.

5.4.2 LIMITATIONS OF THE STUDY

Although, the data provided by individual participants were rich in nature, they are limited by the inability of the researcher to check meaning and understanding or to tease out participants' responses and the small number of participants. Although, in spring 2000 the prevalence of consumers buying medicines online in Australia was less than 1%, it is likely that this has increased as illustrated by the growth in ePharmacy (www.epharmacy.com.au). This Australian e-pharmacy opened its first distribution warehouse in October 2001, initially employing six staff and as of December 2002, they employ thirty-one staff and their turnover has increased around four hundred percent. Furthermore this rapid growth is expected to continue as they plan to open another 2-3 stores in the Brisbane area, one in Townsville, and one in Sydney in 2003.¹³¹ Thus, the

results of this study are unlikely to represent those of the wider population of consumers who buy medicines online. For example, these results failed to gather much information about Australians who import medicines from overseas. With these limitations in mind, the above results were presented mainly at a descriptive or first order level. Nonetheless, these results provide some insight into the potential growth of e-pharmacies in Australia.

5.4.3 POTENTIAL GROWTH OF E-PHARMACIES IN AUSTRALIA

There are many social, political, economic and professional issues that will determine the growth of e-pharmacies now and in the future. These issues are discussed in concert with the survey results.

Social issues

Sociological debate informs us about the expectations of society and the shaping of health care services to meet those expectations. Sociology informs us that as paternalistic doctor-patient relationship changes to one of informed consumer-provider, more consumers are likely to challenge health service provider's advice and authority, and also change the way they seek health care services.¹³² This survey found that the Internet could deliver such changes. Small numbers of participants sought to buy medicines online to avoid personal communication or the interaction with pharmacy staff. From a sociological perspective, if people choose to buy medicines via the Internet en masse because they don't value or want pharmacists' advice, the once personal concern of a few individuals becomes a public issue. This issue not only impacts on the community's relationship with pharmacists but in turn pharmacists' relationships with other health professionals and the Government. However in 2002 Australian community pharmacists appear to have the broad support of the public.

The results of this survey found that most participants were cognisant of the risks of buying medicines online and were reluctant to buy medicines from overseas but attitudes about the risks associated with technology have change rapidly, as illustrated by the rapid growth of online banking. Theoretical models in the sociological literature also contribute to our understanding about technology and society. The concept of the

'risk society' is concerned with how the risks and dangers of a modern society which are systematically produced as a consequence of advanced modernisation may be prevented, made harmless or channelled away so that they neither hinder the process of modernisation nor result in self-endangerment that overstep socially and in this case medically acceptable boundaries.¹³³ Thus how concerns about risks are addressed in the future within a complex and highly regulated health system will either enhance or diminish the growth of e-pharmacies.

How society behaves is not solely attributable to the free will of individuals but is also shaped by policies and regulations that serve and protect the public interest. Changes to health care policy can be seen as the outcomes of conflicts between three major groups; monopolistic health professionals, government administrators and corporate rationalisers, and the often less powerful community interest groups. Thus all partners involved in the use of medicines may shape policies that determine the potential growth of e-pharmacies, although some stakeholders will have more influence than others.

Political issues

The current Australian political environment broadly features a mix of globalisation, deregulation and increasing privatisation as illustrated by recent past events in telecommunications, media, dairy and corrective service industries. Throughout the past decade there has also been substantial interest in health care reform, in particular the focus has centred on the cost and quality of health care. This focus has been accompanied by a trend that reduces the reliance on labour intensive processes and increasingly uses technology, for example automated hospital dispensing systems. There has also been a slight shift towards a more privatised health system as illustrated by Government subsidies of 'lifetime cover' private health insurance plans. These changes have occurred in a political environment facing an ageing population and a Government concerned with financial restraint. Spending more money on health care does not guarantee greater life expectancy or quality of life. Currently, there is an increased focus on evidence, accountability and greater transparency in decision-making.

In Australia, the Federal Government controls the price and subsidises the costs of 90% of the prescription-only medicines to the community via the Pharmaceutical Benefits Scheme. The PBS aims to ensure timely access to the medicines that Australians need, at a cost individuals and the community can afford. However the PBS is currently the fastest growing area of health expenditure in Australia. In the 2001-2002 financial year, PBS expenditure is estimated to cost \$4.837 billion.¹³⁴ Currently consumers pay the same costs for PBS pharmaceuticals from online or local community pharmacies however potential growth of e-pharmacies may be realised if there are dramatic structural changes to the PBS. Although the monopolistic Federal Government controls the costs of these medicines to the consumer, Australians currently pay far less for medicines than US consumers. However, if the Federal Government adopted a more US style of privatised health care whereby there was deregulation of pharmacy and a reduction in cost control measures, the resultant lack of universal access to pharmaceuticals would potentially drive consumers to seek medicines online at cheaper prices in the competitive market place. However, despite US e-pharmacies operating in a somewhat deregulated and competitive marketplace, many Americans cannot access medicines due to a lack of affordability and therefore seek to buy medicines from other countries.¹³⁵ The importation of medicines in the USA has also led to strain on other Government resources such as US customs officers who cannot cope with the amount of medicines imported via the Internet from offshore websites.

Although wholesale health care reform is spoken about it is rarely achieved. Since World War II most health care reform has been incremental in nature, exceptions being the introduction of the PBS, Medicare and casemix funding in hospitals¹³⁶ Thus the Federal Government is more likely to make smaller changes to the PBS such as switching more medicines for the treatment of minor health problems from prescription-only to pharmacist-only or pharmacy only status which would be largely popular with all three groups except some low income consumers with chronic illnesses who would no longer be able to access such medicines at PBS concessional prices (\$3.60 in 2002).¹³⁷ This survey found that consumers most often use e-pharmacies to buy non-prescription and private prescription medicines, often to treat chronic conditions for reasons of cost and convenience. The Federal government does not control the costs of such medicines and consumers reported paying cheaper prices from e-pharmacies, particularly when they bought more than one product. Thus the incremental switching

of pharmaceuticals from the PBS to non-prescription status may facilitate the growth of Australian e-pharmacies.

In Australia there are existing opportunities for increased levels of competition for PBS products that cost less than the general co-payment (\$22.40 in 2002). Although evidence of discounted PBS listed pharmaceuticals has not yet been commonly observed in Australian community or e-pharmacy practices, perhaps due to inelasticity in the highly cost-controlled PBS sector. Although this may change in the near future as increasing numbers of e-pharmacy operators seek to gain a greater slice of the pharmaceutical market by employing aggressive marketing campaigns focussed on product costs rather than services. Furthermore, competition and the ways in which consumers access health services may change due to the imminent introduction of the electronic transfer of prescriptions.

In 1999, the Federal Government released Australia's Health Online, a national health information plan. In 2002 the National Health Information Advisory Council (NHMAC) is overseeing many of the structural changes necessary to progress the use of information technology in the health sector, including the use of electronic health records and the transfer of prescriptions from general practice to pharmacy. While the full-scale realisation of e-prescribing and the electronic transfer of prescriptions should result in reduced waiting times in traditional community pharmacies it could also increase e-pharmacy market growth. Consumers choosing to use e-pharmacies will no longer be required to post hard copy prescriptions via the postal services (also referred to as snail mail). Prescriptions will be securely encrypted and emailed from the clinicians desktop or palm held computing device to a pharmacy nominated by the consumer via an electronic clearing house, thereby reducing the delivery time of medicines to the consumer from e-pharmacies by up one or two days. However, the electronic transfer of prescriptions may also reduce waiting times in community pharmacies.

From the research results the advice and information provided by e-pharmacy staff when purchasing non-prescription medicines was limited. The quality of information published on e-pharmacy websites was also limited. Speculatively, if greater numbers of pharmaceuticals are supplied by Australian e-pharmacies and such practices are more

profitable due to potentially lower overheads and improved workflows, then the Government cognisant of such gains could potentially negotiate to decrease dispensing fees paid to pharmacists who fulfil a supply function only. If, a two-tier dispensing fee was implemented, (whereby a higher fee for original prescriptions, personal counselling or pharmacists interventions are demonstrated and documented, and a lower fee when no direct information and advice is exchanged between pharmacists and consumer as appears to occur upon the dispensing of repeat prescriptions from e-pharmacies) the resultant reduction in dispensing fees for the supply of medication only, would force some pharmacies to close or change the nature of their practices.

Local pharmacies are vital to meeting the acute prescription needs of the community. Survey participants recognised this acute service and also used community pharmacists as 'information and advice safety net'. Consumers would most likely oppose any reduction in local pharmacy closures bought about by increased competition from e-pharmacies although they may not prevent such closures as illustrated by the uptake of online banking facilities and branch closures. Any reduction in local pharmacy numbers would also be strongly opposed by the pharmacy profession whose professional interests play a significant role in shaping health policies.

Professional issues

"It is difficult to imagine a situation less conducive to the enthusiastic uptake of new technology than one that consumes tremendous time and energy in its adoption, while simultaneously threatening the autonomy or livelihood of the user."¹³⁸

Professional interests often oppose barriers to health care reform, especially when these changes may challenge the status quo, threaten vested financial interests or alter professional boundaries and responsibilities.¹³⁹ Currently pharmacists are being encouraged to develop and uptake cognitive services to improve the quality use of medicines in Australia, for example Home Medication Reviews. However to fulfil these new professional roles pharmacists must learn new skills using information technology, the same technology that threatens their traditional role as the supplier of medicines. To

fulfil these new roles pharmacists must be able to use the Internet and information technology in their daily practice to:

- Access health journals
- Appraise information for patients
- Conduct business with product suppliers and the Government
- Communicate via email
- Participate in professional development and education
- Record electronic consumer health information.

This transition also requires a financial commitment by existing community pharmacists to invest in information technology hardware and software and suitable professional development programs.

Despite this opposition from some pharmacists this professional role transition is already occurring in mainstream Australian pharmacy practice, as illustrated by aged care and home medication reviews, and hospital-community liaison pharmacists. There is also potential for the range of these roles to further expand as demonstrated by pharmacist prescribing in the United Kingdom. To support these changes and to alleviate workforce shortages, the role of pharmacy technicians are also being considered,¹⁴⁰ although some pharmacists wishing to maintain focus on the supply of medications, may perceive such changes as the "McDonaldisation or deprofessionalisation" of pharmacy.¹⁴¹

Economic issues

Economics is about choice and 'it attempts to maximise social benefit from resources available subject to reasonable concerns with justice.'¹⁴² The goal of economics is to improve efficiency, from a societal rather than individual viewpoint and to do so in a manner that is fair to all. However some of the assumptions that underlay economic theory do not always hold true for health and health care. For example, market failure where the patterns of supply and demand for health care services differ from those usually observed for other commodities such as groceries.

Market failure in health care is associated with several factors including:

- lack of consumer sovereignty due to information asymmetries between clinicians and consumers;
- demand for health care is irregular and unpredictable;
- illness can be expensive;
- entry to health professions is restricted;
- limited price competition; and
- perverse health insurance incentives.

Based upon the results of this thesis, Internet access can facilitate consumers' involvement in health care decision-making by potentially reducing the information asymmetries between consumers and clinicians, but the degree of such changes is unknown. It also has introduced more price competition between e-pharmacies and local pharmacies. Furthermore, it provides consumers with an alternative method of accessing medicines and hence new opportunity costs, which may subsequently shift the relationship between supply and demand for e-pharmacy services. Survey participants who expressed convenience as a reason for using e-pharmacies provide evidence of these opportunity costs. Nonetheless, whether the potential amelioration of market failure is associated with consumers making decisions that lead to positive or negative health outcomes is unresolved and an important area for future research.

5.5 CONCLUSION

This study provides the first insights into Australian consumer's use of the Internet to buy medicines online. Although the number of participants was limited, their views and experiences of purchasing medicines were positive. Consumers online behaviour was generally cautious in nature, although one consumer reported importing a medicine that may lead to self-harm.

Current and future sociological, political, professional and economic issues will shape the growth of e-pharmacies however there are other influences as well. Globalisation and increasing technological developments will have an impact on the delivery of e-health services and information. For example, advances in pharmacogenomics may change the focus of health care towards prevention rather than treatment. Perhaps, the

only thing that won't change is that people will expect more, but want to pay less. Although, the growth of e-pharmacies in Australia is currently uncertain, I believe that they will continue to grow, as consumers increasingly demand the convenience of e-health services, and that in the short term such services will remain complementary to existing local pharmacy services. Furthermore, the growth of e-pharmacies may increase the uptake of cognitive service roles by Australian community pharmacists.

6 DISCUSSION

6.1 INTRODUCTION

Between March 2000 and October 2002, several studies were developed and conducted to address the following research questions and the results of each study were discussed in the four proceeding chapters.

- What are Australians' views and experiences of obtaining medicines and related information via the Internet?
- Can consumers buy medicines via the Internet in a manner that supports their safe and effective use?

This chapter aims to discuss the influence of the Internet on the Quality Use of Medicines based upon the integrated results of these studies. Furthermore, consideration is given to the complexity, methodological challenges, strategies and future research necessary to support QUM in an online environment.

6.2 AN INTEGRATED VIEW OF THE RESEARCH

Australians value online health resources. Consumers use online health information as a part of their overall information toolbox and view online health resources as useful and complementary to existing health care services.

Online health seeking behaviour is not a passive activity; it empowers consumers by allowing them to have a greater degree of control and input into health care decision-making. Participants seek online health information as a second opinion and to resolve conflicting advice from clinicians, and subsequently they use this information to make decisions about medication management, including whether or not to take a medicine. Consumers also demonstrated caution about using online health information for initial diagnoses or treatment recommendations. However many consumers chose not to discuss online health information with their health care providers, although some

participants who bought medicines online used the local pharmacy as an information safety net.

Currently, only a small (but increasing) number of Australians buy medicines via the Internet for reasons of costs and convenience. However, this increase is likely to be incremental, unless PBS policy reforms diminish universal access to medicines and consumers are forced to pay a greater share of the cost of prescription medicines.

Consumers who bought medicines from Australian e-pharmacies perceived little risk difference when comparing the purchase of medicines from a local community pharmacy or e-pharmacy. However, their caution regarding the importation of medicines from overseas websites was largely well founded because the quality of services and care delivered by global e-pharmacies is variable. Some practice differences result from diverse regulatory frameworks and levels of resources to enforce these frameworks. Several developed countries have introduced e-pharmacy practice standards however the case study results demonstrated that these standards may not protect consumers from inadvertent adverse events. Furthermore, many websites lack or publish poor quality information thus consumers were unable to make informed decisions about the safe, and appropriate use of medicines at the point of sale.

6.3 METHODOLOGICAL CHALLENGES

This thesis demonstrates the feasibility and difficulties encountered when researching an evolving and rapidly changing area. In March 2000, little was known about consumer use of the Internet for health care and the subsequent data collection undertaken throughout this thesis was at time challenging. However, the collection of descriptive data are vital to inform future studies that will realise the potential of the Internet to deliver information, interventions and services in a manner that changes behaviour and optimises the quality use of medicines.

The South Australian population health survey described in chapter three was methodologically rigorous and reflected the use of online health information in the wider population. While the number of questions that could be asked in this survey

limited the method of data collection, the use of qualitative data enriched the researcher's understanding of online health behaviour from a consumer viewpoint. However, in hindsight the qualitative data collection may have been strengthened if the recruitment of consumers were tied directly to the South Australian Health Omnibus survey rather than recruiting a convenience sample of consumers using the Queensland Medication Helpline.

The collection of qualitative data about online health behaviour is feasible but difficult because existing data collection techniques employed to sample hidden populations, such as snowball sampling, are not necessarily applicable in an online environment. The small number of participants limited the generalisation of the qualitative data collected throughout this thesis. However, these data make a significant contribution to our knowledge about Australian's online behaviour and medicines by providing the first Australian insights and a starting point for future research in this area. Furthermore, the methods used to study consumer online behaviour are not well established. Two recent studies of 21 and 4 participants respectively, both employed a combination of survey, observation and online surveillance using Internet tracking technologies to examine how consumers search and assess the quality of online health information and this may be a useful approach in future studies.¹⁴³⁻¹⁴⁴ Alternatively consumer newsgroups, mailing and discussion lists may be a rich source of qualitative information about online consumer behaviour but at the time of this study no such existing groups appeared suitable.

While the large number of participants in the survey of global e-pharmacies (n=104) was likely to reflect the broader population of global e-pharmacies, it cannot be substantiated without the known number of e-pharmacies operating at that time (a known denominator). Potential estimates about the number of e-pharmacies operating at any one time could be sought from customs data, particularly in the US where the number of people who import medicines for personal use is higher than in countries such as Australia, although such data was not available at the time of the website survey. Alternatively, estimates of the number of e-pharmacies operating over time could be measured using a repeated search strategy and capture-recapture techniques to provide a time-trend analysis.

Despite reasonable media coverage, it was difficult to recruit consumers who had bought medicines online, and seemingly more difficult to recruit people who imported medicines. Although, it may have been possible to recruit more participants by placing an advertisement on selected e-pharmacy websites this recruitment strategy would bias the population sample. Future approaches could include the potential sampling of sub-populations such as bodybuilders or athletes who may import human and veterinary anabolic steroids for the purpose of building muscle mass. However the importation of these substances is illegal, thus the feasibility of such a study may be limited by ethical, privacy and legal concerns. Alternatively, to gain a better understanding of what and why people import medicines via offshore websites, one could monitor the legal importation of medicines for personal use in conjunction with the Australian Customs Office. A collaborative observational study could estimate the prevalence of importing medicines via the Internet into Australia. Furthermore, the researcher could potentially follow-up the recipients of such parcels to examine the reasons for their importation, pending privacy concerns and ethics approval. This approach would also be advantageous because the data would have a specified denominator and thus estimates could be applied to the wider Australian population.

6.4 INTERNET, QUM & THE FUTURE

The Internet and QUM are integral to Australia's health care system, and the Internet can both positively and negatively influence QUM. The Internet provides consumers with access to health information and resources that were previously not publicly available. It can empower consumers whereby they take more control of their health care decisions, which is desirable in a patient-centred health system. However, participants were typically unsure about detecting poor and misleading information, and misinformed consumers are potentially at risk of adverse events. Furthermore, the impacts of conflicting information on clinician-consumer relationships and thus also on the continuum of care is unknown. Future studies examining how consumers evaluate the quality of online health information and the impacts of this information on consumer-clinician relationships are needed to support QUM in an online environment.

To support QUM, there is a need to for comprehensive, online medicines information and furthermore such information should be easy for consumers, clinicians and the media to locate. A national medicines websites could provide a 'one stop shop' by publishing information including consumer medicines information (CMI), pharmacy locations, media releases, Pharmaceutical Benefits Advisory Committee (PBAC) decisions, and information about the importation of medicines for personal use. An example is New Zealand's Medsafe® website (www.medsafe.govt.nz). A national medicines website could be linked to HealthInsite® (www.healthinsite.gov.au) which aims to promote the use of evidence-based online health information. Furthermore, the many consumers who use commercial search engines need education regarding the identification and assessment of quality online health information.

Despite few reports of adverse events associated with consumer use of online information or medicines sold via the Internet, the quality of information and services delivered by many e-pharmacies undermined the safe and appropriate use of medicines. Nonetheless, these events are likely to be underreported because many consumers do not discuss online health behaviour with clinicians. However, if the Internet empowers consumers to make health care decisions about medicines, they should also have the opportunity to report adverse drug reactions and such reports could also be submitted online. The Consumer Reporting of Adverse Drug Reactions (CRADE) should also ask consumers if they bought medicines or sought related information via the Internet. This CRADE data would be valuable for future studies examining the impact of e-pharmacies and consumer use of online health information on health outcomes.

The deliberate misuse of medicines may be facilitated by the sale of medicines via the Internet, as illustrated by the participant, who reported importing a weight loss product online, after she was unable to obtain prescriptions from face-to-face consultations with local Australian doctors. Although, the prevalence and outcomes resulting from the importation of medicines for personal use in Australia is unknown, conducting the aforementioned collaborative study with the Australian Customs Office could fill this knowledge gap. This future study is needed to inform policymakers and regulators about the resources required to monitor and evaluate such activities and whether legislative changes may be warranted. Currently, in view of the potential but little evidence of harm associated with the online sale of medicines, a 'wait and see'

approach may be apt because introducing legislative change to protect consumers from importing medicines for personal use may result in unintended and unforeseen consequences. For example, orphan drugs may be the most safe, effective and appropriate for small numbers of consumers with rare diseases. However, these medicines may not be readily available in Australia due to the small market size, thus it is essential that affected consumers be allowed to import them for personal use via the Internet. However, the media promotion of online pharmacy brokers must be discouraged and increasing consumer awareness about the risks of importing medicines for personal use via the Internet must be considered.

The development of emerging Internet technologies outstrips the pace of new legislation and policies designed to protect the public from fraudulent and misleading online health care services and information. Although, Australia cannot control the practice of e-pharmacies in other countries, it could set an example and provide a future model for other countries. Australia has introduced pharmacy practice standards for e-pharmacies but so far has not introduced a quality assurance system to monitor, evaluate and improve these services. Meanwhile, the introduction of a national registration system or the adoption of consistent State Pharmacy Board registration and regulations is required to overcome potential jurisdictional issues arising from e-health services.

Ultimately, the Internet can deliver improved public access to information and pharmaceuticals including QUM activities, however it can also potentially isolate consumers from the Australian health care system.

"If one group is not included in the [QUM] process, the inter-relationships suffer and outcomes may be compromised."³⁷

With this in mind, Australia has the capacity to lead the world in the integration of consumer online health behaviour into the wider health care system. Australia has a national e-health plan and is currently set to implement e-prescribing and e-health records. However a number of barriers need to be overcome to realise the potential of the Internet to improve QUM including privacy and security issues, clinician's online communication skills, workflows, remuneration and satisfaction, guidelines for email communication between clinicians and consumers, and consumer's satisfaction and health outcomes. The Internet and related technologies have the potential to decrease preventable adverse drug events and the associated morbidity and mortality. However,

a partnership approach will be needed to develop interventions that support QUM and positive health outcomes in an online environment.

7 CONCLUSION

This thesis began with the notion that many Australians were increasingly using the Internet as part of their daily lives and that consumer use of online health information and services could impact on the safe and appropriate use of medicines.

Despite numerous anecdotes and opinions, there was a lack of research about this issue, thus a research plan was designed to collect descriptive data examining the influence of the Internet on the Quality Use of Medicines. This research was conducted in discrete projects that were both innovative and original. The research plan included the:

- first Australian population survey of consumers' online health seeking behaviour;
- first large survey examining the quality of information and services offered by websites selling medicines to the public; and
- qualitative data were collected to enhance the understanding of the views and experiences of Australians who use online health information and e-pharmacies.

This thesis demonstrates that the Internet is an integral part of Australian health care system and that it can cause both harm and good. The results of this research make a significant contribution to the large gaps in knowledge about the influence of the Internet on the Quality Use of Medicines, in particular:

- 26-28% of South Australians aged 15 to 54 years had searched for online health information, in Spring 2000 but those with the greatest health needs may not be able to access it;
- consumers value online health information and use it to make health care decisions but often do not discuss it with their doctor;
- consumers find it difficult to assess the quality of online health information, and
- less than 1% of Australians bought medicines online in spring 2000;
- the quality of information published on websites selling medicines in winter 2001 was of poor quality or absent;
- e-pharmacies in winter 2001 do not adequately safeguard consumers from adverse events; and

- Australians who buy medicines via the Internet are cautious about importing medicines from overseas in 2002.

Furthermore these results were of local and international interest as illustrated by the multiple peer-reviewed conference abstracts and publications.

Whilst the research conducted throughout this thesis has significantly contributed to knowledge about the influence of the Internet on the Quality Use of Medicines, further research regarding the online behaviour of consumers is required to harness the full potential of the Internet to deliver quality health resources to society. The limitations of current observational and qualitative research methodologies must be overcome and new methodologies that protect the privacy of individuals but utilise the data-mining and communication capabilities of the Internet must be developed to realise this potential.

Australians who use the Internet to meet health care and in particular medication needs, require interventions based upon a systems approach to achieve QUM. These interventions require strategic partnerships and commitment to overcome numerous barriers. Meanwhile the growth of e-pharmacies is set to increase although current and future social, political, professional and economic interests will shape it.

Ultimately, adverse drug events and harm associated with online health care should be informed by further research and minimised by a combination of consumer and clinician education, communication and regulation. While the quality use of medicines and benefits of online health care should be maximised by integrating consumer online behaviour, expectations and experiences within the provision of increased access to evidence-based health care services and information.

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APPENDIX 1:

PUBLISHED PAPERS

Bessell TL, Anderson JN, Silagy CA, Sansom LN, Hiller JE. Surfing, Self-Medicating and Safety: Buying Non-Prescription and Complementary Medicines via the Internet. Quality, Safety and Health Care (in press, publication in February 2003).

Bessell TL, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Quality of Global E-pharmacies: Can we safeguard consumers? European Journal of Clinical Pharmacology 2002;58:567-572.

Bessell TL, Whitty JA, McGuire TM, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Medicines and the Internet: a qualitative study of the views and experiences of online medicines information seekers. Australian Pharmacist 2002;21:361-65.

Bessell TL, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Prevalence of South Australia's Online Health Seekers. Australian New Zealand Journal of Public Health 2002;26:75-77.

Bessell TL, McDonald S, Silagy CA, Anderson JN, Hiller JE, Sansom LN. Do Internet interventions cause more harm than good? A systematic review. Health Expectations 2002;5:28-37.

ORIGINAL ARTICLE

Surfing, self-medicating and safety: buying non-prescription and complementary medicines via the internet

T L Bessell, J N Anderson, C A Silagy, L N Sansom, J E Hiller

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Objective: To examine whether the sale of medicines via the internet supports their safe and appropriate use.

Design: e-Pharmacy websites were identified using key words and a metasearch engine and the quality of information published on these websites was surveyed using the DISCERN tool. A case scenario and internet pharmacy practice standards were also used to evaluate the quality of care delivered.

Setting and participants: Between July and September 2001 104 websites were surveyed and 27 sent either Sudafed (pseudoephedrine HCl), St John's wort products, or both to a residential address in Melbourne, Australia.

Main outcome measures: Quality of health information (DISCERN ratings), information exchanged between e-pharmacy staff and consumers, and product and delivery costs.

Results: Of 104 e-pharmacies from at least 13 different countries, 63 websites provided some health information but overall the quality of the information was poor. Only three website operators provided adequate advice to consumers to avoid a potential drug interaction. The costs for a daily dose of pseudoephedrine HCl (240 mg) ranged from A\$0.81 to A\$3.04, and delivery costs from A\$3.28 to A\$62.70.

Conclusion: Consumers who self-select medicines from websites have insufficient access to information and advice at the point of ordering, and on delivery to make informed decisions about their safe and appropriate use.

The internet provides consumers with global access to health information, services and support. It has revolutionised the sale of medicines so that consumers can self-select and buy medicines, often delivered across national and state boundaries, without face to face interaction with a health professional. e-Pharmacies are websites selling prescription only medicines and other products including non-prescription and complementary medicines.

To ensure the optimal use of medicines, consumers should have timely access to quality information about their benefits, risks, and appropriate usage.¹ Consumers want information about medicines but have different individual needs.²⁻⁴ Health professionals who prescribe or dispense medicines have professional, ethical, and legal responsibilities to provide consumers with quality information and facilitate the safe and appropriate use of medicines. Whether e-pharmacies provide such information or advice is largely unknown.

Previous studies of e-pharmacies are limited to American websites or those selling lifestyle medications, including sildenafil and finasteride.⁴⁻¹⁰ Most studies regarding quality of online information focus on specific diseases or treatments, rather than the information and advice associated with the delivery of pharmaceutical services.

As controversy brews over the announcement of a German health insurance company that encourages consumers to buy medicines via the internet,¹¹ this study aims to examine whether consumers can do so safely. It is the first study to evaluate the quality of information published on global e-pharmacy websites and to determine what happens when a consumer orders a non-prescription or complementary medicine from an e-pharmacy. In particular, we examined whether staff exchanged information with, and provided relevant advice to, consumers to promote the safe and appropriate use of non-prescription and complementary medicines.

METHODS

In May 2001 e-pharmacy websites were identified using Copernic (www.copernic.com), a metasearch engine that simultaneously searches 10 global commercial search engines. Search terms employed were "internet pharmacies", "internet pharmacy", "internet medicines", "online pharmacies", "online pharmacy", and "online medicines". Websites recording multiple hits were included only once in the sampling frame. Those that only offered electronic transfer of prescriptions from doctor to pharmacy or prescription refills (increasingly common in the USA), three members only sites, four sites written in languages other than English, two sites with transmission errors, and eight sites under development were excluded.

Between July and September 2001 we surveyed all websites in the sampling frame. The survey collected data in two distinct sections—the quality of health information published on e-pharmacies and a case study where medicines were purchased via the internet.

The quality of health information was evaluated using the DISCERN rating instrument which was specifically developed and validated to assess a broad range of online and written consumer health information.¹² DISCERN consists of 15 questions, each representing a unique quality criterion, plus an overall quality rating.

The case study was undertaken by one of us (TB) acting as a consumer who attempted to purchase one non-prescription and one complementary medicine using a set case scenario (box 1). Standardised patients are a useful method to assess the quality of primary health care including pharmacy practice.¹³⁻¹⁷ All products were to be delivered to a residential address (not a post office box) in Melbourne, Australia.

We chose Sudafed (pseudoephedrine hydrochloride) and St John's wort (*Hypericum perforatum*) tablets for the case

Box 1. Case scenario of 35-year-old Australian woman

Place an order for Sudafed (preferred brand) or pseudoephedrine HCl (30-120 mg) (single therapeutic ingredient), quantity 10-60 capsules/tablets and St John's wort 100 mg, quantity 10-60 (no preferred brand) from an online supplier of scheduled medicines. Choose the cheapest Sudafed or St John's wort product if multiple options are available.

The Sudafed or pseudoephedrine HCl product is for your own use. You have had a runny nose for a couple of days and a friend suggested you try it; you have not used this product before or tried anything else to treat the problem. The St John's wort is also for your own use. You have been feeling really flat and low and you read about St John's wort in a magazine; you have not used this product before. You have taken Prozac (fluoxetine) for depression for the past 3 months after being in a car accident. You are not taking any other medications and have no other illnesses.

scenario because they are both commonly used and widely available. Pseudoephedrine HCl is often illegally misused to manufacture amphetamines^{28,29} and in Australia its importation requires a licence from the Therapeutic Goods Administration.²¹ St John's wort products interact with many medicines by altering drug metabolism or increasing central nervous system serotonin levels.²² It can interact with medicines including cyclosporin, digoxin, oral contraceptives, theophylline, warfarin, anticonvulsants (carbamazepine, phenobarbitone and phenytoin), selective serotonin reuptake inhibitors (SSRIs) and related drugs (citalopram, fluoxetine, paroxetine, sertraline, nefazodone), triptans (sumatriptan, naratriptan, rizatriptan and zolmitriptan), human immunodeficiency virus (HIV) protease inhibitors, and HIV non-nucleoside reverse transcriptase inhibitors.²⁴ Serotonergic syndrome is characterised by changes in mental status and motor and autonomic function and is a potentially serious adverse drug event that may occur when St John's wort and fluoxetine are taken concurrently.

Data on the nature of patient information collected by pharmacy staff; the provision of written information and advice by pharmacy staff; product recommendations; referrals; payment security; delivery costs, times and methods; customs inspections; and the condition of the product received were collected. The information exchanged with and advice provided to consumers by e-pharmacy staff was assessed using pharmacy practice standards and current guidelines.²⁷ We also assessed whether e-pharmacies had processes in place to detect the potential drug interaction between St John's wort and fluoxetine. (A copy of the survey tool is available upon request from the first author.)

The Monash University Standing Committee on Ethics in Research Involving Humans gave ethics approval for this study. Informed consent was not sought from e-pharmacy operators before buying these medicines because of the simulated nature of the project. However, in accordance with the recommendations of the ethics committee, we sent e-pharmacies that delivered medicines a hard copy of the data collected from their individual website 1 month after delivery and each had the opportunity to withdraw their results from the study.

The data were summarised using descriptive statistics.

RESULTS

Quality of information

We identified and surveyed 104 unique e-pharmacy websites from at least 13 different countries; 63 (61%) provided some health information, 51 (49%) provided some information

about medicines, 31 (30%) published information on disease states, 17 (16%) provided lifestyle information, 41 (40%) provided no information, and 53 (51%) published poor quality information of limited or no benefit (table 1).

Of the 104 e-pharmacies, 52 (50%) allowed consumers to search by trade name, 55 (53%) by therapeutic class, and 22 (21%) by therapeutic substance, while 35 (34%) offered no search function at all. Thirty (29%) websites displayed external links, most commonly to consumer health support groups and online medical libraries, but others included one online gambling site and two news websites.

Twenty five websites published information about pseudoephedrine HCl. Of these, 21 (84%) published useful information (DISCERN rating 4 or 5) about the benefits associated with taking pseudoephedrine HCl but only 13 (52%) published such information about risks. Nineteen websites published information about St John's wort products and overall the information about the benefits and risks of these products was more balanced (17 and 18 websites, respectively). However, the information was often of a general nature and less useful. For example, "this medication may interact with other medicines" rather than "this medicine interacts with a list of specific therapeutic substances".

Case study

Of the 104 e-pharmacies, 31 (30%) and 41 (40%) websites sold pseudoephedrine HCl and St John's wort, respectively. Fifteen of the 31 (48%) delivered pseudoephedrine HCl (14 Sudafed and one local generic product) while 26 of the 41 (63%) delivered various St John's wort products to Australia. Fourteen e-pharmacies delivered both products and a total of 27 packages were received from Australia, Canada, New Zealand, UK, and the USA. Sixteen (52%) and 15 (37%) of the e-pharmacies selling pseudoephedrine HCl and St John's wort, respectively, did not deliver these medicines to Australia, largely because 31 (30%) of the 104 e-pharmacies only deliver such medicines within their national borders. No e-pharmacies withdrew their results.

Of the 27 e-pharmacies that supplied medicines, 13 (48%) required consumers to register a user name and password. Twenty five websites (93%) confirmed the order and delivery details of products via email. All sites used secure socket layer (SSL) technology for payment transactions. The operation of these e-pharmacies appeared to involve registered pharmacists and no websites sold prescription only medicines without a prescription written by a doctor.

Of the 27 e-pharmacies that supplied medicines, 15 (56%) provided information about directions for use, eight (30%) about treatment length, 14 (52%) about potential adverse events, 11 (41%) about interactions, and four (15%) offered what to do if their condition did not improve. No sites suggested associated ancillary lifestyle changes, and no e-pharmacy staff recommended alternative or additional products. Upon delivery the only written information about the medicines received was one manufacturer's information sheet regarding the use of pseudoephedrine HCl and one information sheet regarding St John's wort and potential drug interactions.

Of the 26 e-pharmacies that supplied St John's wort products, five (19%) websites asked for consumer information that could have enabled staff to detect the potential drug interaction involving fluoxetine and St John's wort, but only three (12%) contacted the consumer about this concern. The three e-pharmacies initially communicated via email asking for additional contact. Three e-pharmacists subsequently counselled the consumer by telephone and correctly referred the consumer to see her doctor before commencing self-medication with St John's wort. The staff of the remaining 21 (81%) e-pharmacies could not detect this potential drug interaction because they failed to exchange relevant information with consumers.

Table 1 Frequency of DISCERN ratings of health information given by e-pharmacies by geographical location

Location	Total no	No	DISCERN rating*				
			1	2	3	4	5
Australasia							
Australia	12	2		4	6		
New Zealand	13	3	1	4	5		
North America							
Bermuda	1			1			
Canada	4	2	1	1			
Mexico	1	1					
USA	40	14	1	9	7	4	5
Asia							
India	2	1	1				
China	1	1					
Philippines	1		1				
Europe							
Italy	1	1					
Spain	1			1			
Switzerland	1	1					
UK	4	1	2			1	
Unknown	22	14	1	6	1		
Total	104	41	7	26	20	5	5

*DISCERN ratings: 5=high, indicates that the publication is of "good" quality (a useful and appropriate source of information about treatment choices); 3=moderate, indicates that the publication is of "fair" quality (a useful source of information about treatment choices but has some limitations; additional information or support would definitely be needed); 1=low, indicates that the publication is of "poor" quality (has serious shortcomings and is not a useful or appropriate source of information about treatment choices; it is unlikely to be of any benefit and should not be used).

Products were received by post (12, 44%), registered post (11, 41%), and courier (4, 15%) and signatures were required on 15 (56%) occasions. Eight of 16 (50%) international deliveries were opened, inspected, and resealed by Australian customs officers. Two packages (13%) containing pseudoephedrine HCl products had no tangible evidence of customs inspection. Upon delivery, we identified the sender of 16 (60%) packages by information visible on the exterior of the package, 19 (70%) by descriptions of package contents, and three (11%) packages by deduction using postmarks and dates. Sixteen (60%) were packed in boxes and 11 (40%) in envelopes. Twenty two (81%) packages contained bubble wrap or similar materials. Despite these packaging precautions, two (7%) products were damaged at the time of delivery.

Specific errors included one delivery of an out of date St John's wort product (expired August 2001, delivered September 2001) and one package was sent to the billing address instead of the residential address. The e-pharmacy that supplied the out of date product was contacted by email and a refund was offered. One pharmacy also substituted a different brand of St John's wort from that originally ordered with no notification or explanation about the change.

The product costs, postage and handling charges, and delivery times were highly variable. For example, the product costs of a total daily dose of pseudoephedrine HCl 240 mg ranged from A\$0.82 to A\$3.04 (mean A\$1.50, 95% CI 1.13 to 1.87). Costs of St John's wort products also varied but are not comparable because of inconsistent recommended daily dosages and the non-standardised nature of some complementary medicine products. Postage and handling charges ranged from A\$3.28 to A\$62.70 (median A\$7.54). The product, postage and handling costs were most expensive for deliveries from the USA. All costs are given in Australian dollars (A\$) where A\$1=£0.37 and US\$0.52. Delivery times ranged from 2 to 18 days (mean 6 (95% CI 4.5 to 7.5)).

DISCUSSION

Australian internet pharmacy practice standards state that "the pharmacist provides medicines and devices through the internet in a manner which safeguards the privacy and confidentiality of the patient, delivers the correct product with appropriate information to the patient, and promotes safe, correct and appropriate use of medicines."²⁴ Despite the introduction of similar standards and guidelines in Canada, New Zealand, the UK and the USA,²⁵⁻²⁸ we found that most e-pharmacies (including those operating in these countries) selling non-prescription and complementary medicines failed to uphold the intent of these standards. This study shows that consumers who self-select non-prescription medicines from e-pharmacies are at risk of medication misadventures.

Consumers cannot make an informed decision about purchasing a medicine using information provided by e-pharmacies because balanced information about the benefits and risks of taking medicines was largely not available or of poor quality. Furthermore, written information was rarely provided upon delivery. Although the packaging contains some information, it alone does not adequately protect consumers from harm.²⁹ Pharmacists have a duty of care to ensure that consumers are provided with sufficient information to assist the safe and effective use of medicines to optimise health outcomes.³⁰ e-Pharmacy operators must be encouraged to provide consumers with quality balanced pharmaceutical information at the right place and time: information linked to individual products at the point of ordering and upon delivery.

Medical and consumer literature identifies the importance of an exchange and sharing of information between consumers and health professionals to achieve positive health outcomes.³¹ In traditional "bricks and mortar" practices consumers can be provided with, or ask for, advice about medicines, and such advice is generally valued.³² Pharmacists also refer consumers to their doctor when necessary. UK

research has shown that, in about a quarter of pharmacist-consumer consultations, no sale is made and pharmacists often recommend customers to see their doctor." In an online environment the exchange of information between pharmacists and patients requires easy to use and secure electronic communication processes. It is therefore disturbing that the majority of e-pharmacy staff were unable to detect a potentially serious drug interaction because processes were not in place to obtain relevant information about consumers, including their current medications.

One of the potential strengths of the internet is to provide consumers with informed choices. Medicines have many different trade names, and the same therapeutic substances have different approved names in different countries—for example, paracetamol (UK) and acetaminophen (USA). Consumers wishing to compare brands, formulations, and prices of similar products should be able to search by therapeutic substance or class, but less than half the e-pharmacies provided such a capability. e-Pharmacies could incorporate these and other consumer friendly online features including drug-drug and drug-disease interaction checks, self-monitoring tools, and medication charts and diaries.

Despite cost being a major driver of online consumerism and the relatively free trade of non-prescription medicines, we observed large price disparities between medicines sold by e-pharmacies operating in different countries. Consumers are more likely to realise cost savings from e-pharmacies when purchasing multiple items, and whether they consequently buy more products than those immediately required is unknown.

Ultimately, consumers will decide whether or not to purchase medicines from e-pharmacies, as safeguarding the privacy and confidentiality of the consumers is paramount to its sustainability as a commercial resource. Although discrete packaging protects consumers from potential embarrassment, the origin of medicines sent via the postal system should be identifiable by customs officers and consumers. All packages should include contact details of the sender. Furthermore, errors and the damaged condition of some products upon delivery may deter consumers from repeated use of e-pharmacies.

The results of this study are tempered by some methodological limitations. Although we searched broadly using a rigorous identification strategy, it is difficult to determine whether this sample of 104 websites was entirely representative because the total current number of e-pharmacies operating at any one time is unknown. Due to the nature of the internet, it is difficult to evaluate whether an e-pharmacy is bona fide unless the site displays a seal that can be electronically verified by an independent pharmacy statutory body.²⁷ Furthermore, it is almost impossible to know with whom you are dealing or the location or ownership of e-pharmacies. Of the 27 that supplied medicines to us, all appeared to involve a qualified pharmacist, but whether qualified or unqualified staff supervised our medication order was unknown. Most countries legally permit the export and import of non-prescription medicines for personal use, but only approximately half of the e-pharmacies selling pseudoephedrine HCl and St John's wort products delivered such medicines to Australia. The reasons for this are unknown, but limited the sample size of the case study. Despite these limitations, this study provides a unique insight into e-pharmacy practice in 2001.

We conclude that internet technologies should be used to develop ethical and innovative practice models that make the management of medications for consumers easier, simpler, and safer to achieve positive health outcomes, but surfing and self-medicating is currently not safe. Consumer education about the benefits and risks of buying medicines via the internet is needed because national e-pharmacy standards alone do not adequately address the overall lack of information and advice provided. It is vital that such standards address the

Key messages

- Health information published on many e-pharmacy websites is absent or of poor quality.
- Despite the introduction of e-pharmacy practice standards, consumers may not be safeguarded from inadvertent medication misadventures.
- Consumers should be provided with balanced information about the benefits and risks of medicines at the point of ordering and upon delivery.
- Consumer education about the benefits and risks of buying medicines online is needed.

needs for pharmacists and consumers to exchange information and prevent self-medication misadventures. To support the safe and appropriate use of non-prescription and complementary medicines, e-pharmacies must go beyond satisfying minimum practice standards and deliver consumer focused services including the provision of quality medicines information linked to the product at the time of ordering, and written information on the delivery of medicines.

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SPECIAL ARTICLE

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Quality of global e-pharmacies: can we safeguard consumers?

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Abstract Objective: E-pharmacies are web sites selling prescription-only medicines and other products including non-prescription and complementary medicines to consumers via the internet. This study aims to evaluate the quality of global e-pharmacies, discuss whether e-pharmacies support the safe and appropriate use of medicines, and consider how we can protect consumers in the future.

Methods: A survey of public information published on global e-pharmacy web sites was conducted between July and September 2001. We used a meta-search engine, Copernic, and the search terms of 'online' or 'internet', and 'pharmacy', 'pharmacies' and 'medicines' to identify a sampling frame of global e-pharmacies. We surveyed all web sites in the sampling frame except those under construction or only offering electronic refills, members-only and non-English web sites. Survey data included country of origin, range of medicines sold, prescription requirements, availability of online medical consultations and pharmacists' advice, quality accreditation seals, policies and advertisements.

Results: E-pharmacies operated in at least 13 countries; however, the country of origin could not be identified for

22 web sites. Twenty web sites (19%) appeared to supply prescription-only medicines with no prescription required. Only 12% of e-pharmacies displayed quality accreditation seals. We observed information published on e-pharmacy web sites that potentially undermines the safe and appropriate use of medicines.

Conclusion: Safeguarding consumers and ensuring the quality of web sites that sell medicines across state and national boundaries is both complex and difficult. Strategies to improve the quality of e-pharmacies include independent third-party regulation of providers, evaluation and enforcement of sanctions in cases of dissemination of fraudulent or harmful information and practices, self-regulation and consumer education. The development of internet regulatory technologies themselves and the resolution of jurisdictional issues offer future solutions but international co-operation is vital.

Keywords Internet · Quality · Regulation

Introduction

Public access to many medicines has been restricted by policies and legislation that aim to ensure the safe, appropriate and judicious use of affordable, effective, medicines by consumers and health professionals [1]. This regulatory framework has resulted in health professionals being the gatekeepers of prescription-only and some over-the-counter medicines. Professional practice standards and regulations also govern the prescribing and dispensing of these medicines by registered doctors and pharmacists. Internet access now enables consumers to order medicines that are supplied and delivered, often across national or state borders, without face-to-face interaction with a health professional.

The potential advantages of the online sale of medicines include competitive prices, consumer convenience, avoidance of embarrassment, timely access to quality medicines information and increased access for consumers in rural and remote areas. Disadvantages include

The Standing Committee on Ethics in Research Involving Humans at Monash University granted ethics approval for this project and survey questions.

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quality assurance issues, such as counterfeit medicines, substandard products, breaches of storage conditions during delivery, lack of secure confidential medical information, delivery costs and a potential lack of health professional intervention [2]. The internet also blurs the division between drug information and inappropriate promotion [3].

In 2001, the US Office of Criminal Investigations investigated 64 cases involving the online supply of prescription-only medicines without a medical consultation [4]. Such sales potentially result in the dangerous and inappropriate use of medicines. Previous published studies regarding the online sale of medicines are limited to US sites or sites selling lifestyle drugs including sildenafil and finasteride [2, 5, 6, 7, 8, 9, 10]. The incidence of adverse drug events associated with the online sale of medicines is unknown [11].

Most current drug policies, legislation and practice standards were developed prior to the evolution of the online sale of medicines. Potentially the greatest risk to consumers occurs when they buy medicines from countries that have inadequate regulatory frameworks or resources to safeguard consumers. In 1999, 92 of 135 (68%) countries had a basic drug regulatory system including legislation and authority functions. Additionally, 87 of 139 (62%) countries reported quality assurance procedures such as good manufacturing processes and sampling to test drugs, and 142 of 191 (74%) countries participated in the WHO Certification Scheme on the Quality of Pharmaceutical products in International Commerce [12].

The aim of this study was to examine the quality of global e-pharmacies, defined as web sites selling controlled (drugs with the potential for addiction or abuse), prescription-only, pharmacist-only or pharmacy-only medicines [13]. In many developed countries, these medicines are not for general sale in supermarkets or other retail outlets. We surveyed the availability of these medicines and the frequency of structural quality indicators published on web sites. Subsequently, we discuss whether e-pharmacies appear to support the safe and appropriate use of medicines, and examine how the quality of e-pharmacies could be improved by regulation.

Methods

E-pharmacy web sites were identified using Copernic, a meta-search engine that simultaneously searches ten global commercial search engines. Search terms included 'internet pharmacies', 'internet pharmacy', 'internet medicines', 'online pharmacies', 'online pharmacy' and 'online medicines'. The sampling frame comprised those web sites selling medicines dispensed or sold under the supervision of Australian pharmacists. Web sites recording multiple hits were included once in the sampling frame. We excluded web sites that only offered electronic transfer of prescriptions from doctor to pharmacy or prescription refill (increasingly common in the USA), three members-only sites, four sites written in languages other than English, two sites with transmission errors and eight sites under development.

Between July and September 2001, we surveyed all web sites in the sampling frame and evaluated the quality of the e-pharmacies. Quality can be described in terms of structure, process and outcomes where structure relates to material resources, facilities, equipment and range of services at the practice level, process relates to what is done in giving and receiving care (e.g. the consultation, ordering tests, prescribing), and outcomes relate to the effects of care on the health status of patients and community (e.g. immunisation rates) [14]. We collected data using public information published on the web sites about structural indicators including contact details, search functions, types of medicines available, prescription requirements, availability of online medical consultations and pharmacist advice, accreditation seals, privacy and returns policies, information types and disclaimers, and advertising. These indicators were based on Australian Internet Pharmacy Standards [15]. All data were summarised using descriptive statistics. The Monash University Standing Committee on Ethics in Research Involving Humans gave ethics approval for this study.

Results

We identified and described the characteristics of 104 unique e-pharmacy web sites (Table 1). Although, 30% of the 104 e-pharmacies delivered nationally and 67% internationally, the contact details including physical addresses, telephone or fax numbers were displayed on 61, 66 and 61% of web sites, respectively. E-pharmacies appeared to be operating in 13 countries; however, the country of origin could not be identified for 22 web sites. The availability of individual medicines for sale on web sites, their prescription requirements and access to online consulting are shown in Table 2. Twenty web sites supplied prescription-only medications without a prescription.

Consumers might expect to see details of the individuals accountable for providing their health services, but only 35% of web sites published the owners' or directors' names (registered pharmacies can be owned by non-pharmacists or company structures in some countries). Although 42% of web sites promoted the availability of advice from pharmacists, it is difficult to determine whether registered pharmacists were involved.

Only 12 of 104 (12%) web sites displayed any form of quality accreditation. Seven web sites displayed national pharmacy authority seals while two web sites displayed Health on the Net (HON) and one Joint Commission on Accreditation of Healthcare Organisations (JCAHCO) logos.

Table 1 Key characteristics of e-pharmacies (*n* = 104)

67% Delivered internationally
61% Displayed addresses
60% Displayed any health information
42% Promoted the availability of pharmacist's advice
40% Displayed privacy statements
21% Unidentified country of origin
20% Advertised prescription-only medicines
19% Sold prescription-only medicines without a prescription
12% Displayed quality accreditation seals
12% Offered online prescribing
4% Displayed last date of update

Table 2 Frequency of medicines sold with and without a prescription from e-pharmacies by geographic location

Location	Codeine (20-50 mg caps/tabs)	Sildenafil (50-100 mg tabs)	Amoxicillin (250-500 mg caps/tabs)	Clotrimazole (1-3% vaginal cream)	Pseudoephedrine HCl (30-120 mg caps/tabs)	St John's Wort (100mg + caps/tabs)	Online prescribing	Total number of sites in each country
Australasia								
Australia	4	8	9	10	9	11		12
New Zealand		5	4	7	2	8	2	13
North America								
Bermuda		1					1	1
Canada	1	3	2	2	2	2		4
Mexico			1 (1)					1
USA	6	31 (1)	23 (1)	16	15	17	8	40
Asia								
China		1 (1)						1
India					1			2
Philippines		1 (1)						1
Europe								
Italy		1	1	1				1
Spain		1 (1)						1
Switzerland								1
United Kingdom	1	1	1	2	1	2		4
Unknown	4 (4)	13 (11)	12 (11)	3	1	1	1	22
Total	16 (4)	66 (15)	53 (13)	41	31	41	12	104 (20)

(n Number of e-pharmacies selling prescription-only medicines without a prescription)

We found privacy statements, information disclaimers, and returns policies on 40, 31 and 37% of web sites, respectively, but 37% of web sites displayed none of these policies. Furthermore, e-pharmacies displaying such policies often placed all risk and responsibilities with the consumer and little with the web site operator. For example, "the user affirms that: they have no known allergies to, sensitivities to, or intolerance of any products ordered, no known medical conditions predisposing to adverse reactions to any products ordered, are not taking any concurrent medications with which the products ordered are likely to interact. For prescription items: they have received counselling from a health care professional about the indications, actions, interactions and side effects of any medications they have been prescribed, including the likely effects of not taking the medication" [16]. Yet the underlying philosophy of pharmacy practice is to support the optimal use of medicines by pharmacists sharing responsibility with health care professionals and consumers for the outcomes of therapy [17].

Direct to consumer advertising of medicines potentially alters consumer behaviour and may stimulate inappropriate and unnecessary prescription drug use [18]. Advertisements, defined as 'any statement, pictorial representation or design, however made, that is intended, whether directly or indirectly, to promote the use or supply of goods', were displayed on 47% of web sites [19]. Of the 104 e-pharmacies, 20% promoted prescription-only medicines, 19% non-prescription medicines, 20% complementary medicines and 23% health and beauty products. Examples of inappropriate promotion included 'sample packs' containing anabolic steroids, diuretics and hormones; bonus deals of 120 free met-andienon tablets with orders of US \$100 or more; cyclosporin for hair loss; nicotine replacement therapies

and tobacco products sold from the same site; the use of bromocriptine and phenytoin to improve mental abilities such as memory, learning, attention, concentration, problem solving and reasoning in healthy people with no cognitive impairment; clindamycin lotion for 'women who wear make-up'; and multiple unproven claims about complementary products including breast enhancement creams and cellulite and vein crushers. Examples of fraudulent and dangerous practices included poor packaging and the deliberate attempt to avoid custom checks. "We do not ship express or any other method that requires a signature, as these packages are more open to scrutiny, both entering your country and checked leaving the country of origin" and "when sending tablets, we take them out of the original bottle, as this is bulky and less likely to pass through customs. We pad the tabs with a plastic film to seal them and prevent moisture and dirt from contaminating them. It is rare that they are damaged this way, and even if they are, they are still usable" [20].

Discussion

This study demonstrates that many e-pharmacies may undermine the safe and appropriate use of medicines because the good practice, organisation and support functions usually considered necessary to provide quality of care appear to be largely absent. For example, although pharmacists' advice may not be advertised within a bricks-and-mortar pharmacy, these consumers can seek face-to-face advice from a pharmacist, whilst those consumers using e-pharmacies can only access such advice if e-mail or alternative contact details are published on the web site. We found e-pharmacies that appear to be selling anabolic

steroids, human growth hormone, drugs of addiction and antibiotics (often in inappropriate quantities) without prescriptions or medical consultations, inappropriate promotion of medicines and in one case suggesting poor packaging and handling practices. These actions potentially lead to inappropriate medication use, adverse events, and could worsen global problems such as antibiotic resistance.

It is difficult to determine whether our sample of 104 web sites is representative of the wider population of sites selling scheduled medicines because the total current number of e-pharmacies operating at any one time is unknown. Nonetheless, our results support those of a pilot study at a mail centre in Carson City, California, where US customs officers inspected 1908 suspicious parcels, and found 721 parcels containing 197 different types of medicines obtained from 19 different countries, including medicines of potential addiction and abuse, antibiotics, steroids and medicines with narrow therapeutic indices [4]. They concluded that these medicines were primarily obtained via internet sales and estimated that approximately two million parcels containing scheduled medicines for personal use enter the USA each year, which places an overwhelming burden on US customs.

Strategies to improve the quality of online health information that are equally applicable to the improvement of e-health services include independent third-party regulation of providers, evaluation and enforcement of sanctions in cases of dissemination of fraudulent or harmful information and practices, self-regulation and consumer education [21]. Nonetheless, there are significant barriers to the implementation of each of these strategies. For example, regulatory change lags behind the evolution of internet technologies, considerable resources are needed to evaluate and enforce legislation pertaining to cyberspace activities, state or national legislation cannot effectively regulate a global online environment due to jurisdictional uncertainties, and some argue that regulation should not impede innovation.

Many countries have national medicines policies, legislation and standards to support the safe and appropriate use of medicines, but much of this legislation was written without reference and prior to the evolution of electronic technologies. For example, although it was always illegal for New Zealand pharmacists or any other person to provide prescription medicines to New Zealanders without a prescription written by a registered New Zealand doctor, the same safeguards did not extend to non-New Zealanders. Until November 2000 it was legal but unethical for New Zealand pharmacists to export medicines without a prescription. However, after the discovery of large amounts of sildenafil, orlistat and finasteride being sent from New Zealand to the United States and the United Kingdom, the New Zealand Ministry of Health introduced new legislation requiring a prescription to be written by a New Zealand doctor before pharmaceuticals are supplied overseas [22]. Furthermore, the Medical Council of New Zealand's

guidelines now require the doctor and the consumer to have met on at least one occasion.

E-pharmacies found to be operating and supplying consumers within the geographic bounds of one country are subjected to the national regulatory framework and jurisdiction of that country. Legal jurisdiction is dependent on physical location within national or state boundaries. However, national regulatory measures do not protect the global public from poor practices involving the online sale of medicines because the internet operates independently of geographic boundaries. Legal jurisdiction can be difficult to establish in a global online environment [23]. For example, there is potential for disputes about whose law should apply if the web site is in Spain, the server for that site is in the UK, the medicines are dispatched in Mexico, the money is transferred to Switzerland and the consumer is in Australia. Furthermore, this study demonstrates that it is difficult to identify the country of origin selling the medicines. Jurisdictional issues also apply to other consumer protection mechanisms such as privacy, information disclaimers and returns policies. Some of the jurisdictional issues in cyberspace are currently being addressed, especially with regard to fraud, paedophilia and gambling, and these outcomes may also apply to the delivery of e-health services.

Unethical web site operators use these ambiguities to circumvent regulatory interventions put in place to protect consumers from harm. Although, the US Food and Drug Administration conducted the first prosecution involving medicines and the internet in 1994 [24], the resources required to enforce regulations are extensive and beyond the means of many countries. Other actions such as the sending of warning letters to firms selling unapproved new drugs online and issuing 'import alerts' to online sellers of foreign pharmaceuticals are more cost-effective and timely.

This study demonstrates that a wide range of medicines can be bought from many countries around the world, including some countries that do not have adequate regulatory frameworks for the safe and appropriate use of medicines. However, banning the sale or importation of medicines via the internet restricts consumer access to pharmaceuticals and protects the status quo of 'bricks and mortar' pharmacies by diminishing competition. For example, thousands of Americans, who do not have universal access to medicines, cross the Mexican and Canadian borders each year to buy medicines that they can now import via the internet [25]. Similarly, Germans have imported medicines from the Netherlands [26].

International co-operation is needed to stamp out fraudulent and dangerous practices such as the supply of prescription-only medicines without a medical consultation. International treaties or conventions whereby uniform laws are enacted or agreed upon by each country could achieve this; however, reaching consensus is both lengthy and difficult. Other approaches such as enforcing internet service providers to banish sites that

do not adhere to standards and the development of a 'cybercourt' jurisdiction should be considered [27].

Self-regulation relies on people voluntarily complying with standards rather than having them forced upon them. The USA, UK, Canada, Australia and New Zealand have introduced self-regulatory internet pharmacy practice standards [15, 28, 29, 30, 31]. Still, not all e-pharmacies operating within these countries comply with these standards. To successfully direct consumers to e-pharmacies accredited by independent third-party authorities, consumer education and awareness programs must accompany these initiatives. Self-regulation may be ineffective due to the inherent global nature of the internet. For example, despite Australia's self-regulatory guidelines that ban direct-to-consumer-advertising of prescription-only medicines [32], this study demonstrates that this type of promotion reaches consumers via e-pharmacies because such activities are legal in the USA and New Zealand.

Information aimed at educating consumers about the benefits and risks of buying medicines online is vital and can be found on increasing numbers of government and consumer association web sites. Yet online pharmacy brokers promote the availability of medicines whereby no prescription is necessary. Additionally news and current affairs programs facilitate consumer awareness about these brokerage services. We argue that the media has a role to promote the safe and appropriate use of medicines by providing balanced information about the benefits and risks of buying medicines online instead of promoting the availability of medicines with no prescription required.

Conclusion

Selling medicines by the internet is a global issue. National pharmaceutical budgets are increasing around the world. Subsequent economic restraints may limit consumer access to medicines and encourage consumers to buy medicines in a price-competitive market via the internet. Safeguarding consumers and improving the quality of web sites that sell medicines across state and national boundaries is both complex and difficult. The development of internet regulatory technologies themselves and the resolution of jurisdictional issues offer some solutions. The challenge is to discourage fraudulent and misleading web sites but permit the development of innovative, ethical e-pharmacy services. To achieve positive change will require international co-operation, surveillance and a partnership approach between all stakeholders where evaluation, regulatory and educational resources can be shared. The debate about how to best safeguard the global public and ensure that standards of care provided by e-pharmacies are commensurate across and within countries needs input from consumers, clinicians including clinical pharmacologists, other health professionals, policy makers, media and lawyers. Now is the time for that debate.

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Medicines and the Internet: a qualitative study of the views and experiences of online medicine information seekers.

Abstract

Objectives: To explore the views of Australian online medicine information seekers about medicines and the Internet, particularly the identification of what prompted consumers to look for online information about medicines, the search methods used, and the nature, assessment and application of such information in the context of their own health care management.

Design: Qualitative study using semi-structured telephone interviews.

Setting: Queensland, June to August 2001.

Subjects: Nine self-reported online health seekers who sought information from the Queensland Medication Telephone Helpline.

Results: Participants sought medicines information via the Internet to resolve conflicting advice, find alternative treatments and supplement the advice they had been given about the

benefits and risks of recommended medications. They sought a wide range of information and used simple search strategies. Participants displayed some awareness about the limitations of online health information but were unsure about how to differentiate between good and poor quality websites. Despite this, participants used such information to make decisions about their medication use that sometimes conflicted with the advice provided by doctors. They used online health information as a second opinion rather than seeking an initial diagnosis or treatment recommendation. Overall participants' views and experiences of online medicines information were positive and they felt more confident about using their medicines.

Conclusions: Currently, pharmacists are well placed to be online information brokers but they require both information technology and critical appraisal skills to be effective in the information age.

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Conflicts of interest

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Ethics Approval

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Introduction

Currently more than 50% of Australian adults and 37% of households have Internet access and consumers can potentially access much of the same information as health professionals.¹ Internet access to quality health information potentially assists people to make informed decisions in a timely and convenient manner about the safe and appropriate use of medicines. However despite this potential, there remain concerns including the variable quality of the online information^{2,3} and a lack of research about whether or not such information leads to more harm than good.⁴ Furthermore, there is limited research about how consumers search for and assess the quality of health information.⁵

While Australians increasingly access the Internet regularly, little is known about the views and experiences of those who seek health information in this way.^{6,7} The objectives of this project include identifying what prompted consumers to look for online information about medicines, the search methods consumers use, and the nature, assessment and application of such information in the context of their own health care management.

Method

Consumers who seek online information about medicines are 'hidden'. As there are no publicly accessible lists of these consumers, a purposive sampling frame of consumers who telephoned the Queensland Medication Helpline (QMH) and identified themselves as online health seekers provided a useful starting point to explore consumer issues about medicines and the Internet.

The QMH is located in Brisbane at the Mater Hospital's Pharmacy Department. It was Australia's first state drug information telephone service for rural and metropolitan consumers. QMH pharmacists invited callers, who identified themselves as online health seekers, to voluntarily participate in the study at the conclusion of their medication related inquiry. Participants gave written informed consent and were interviewed at least two weeks post telephone inquiry. The interview guide was composed of nine open-ended questions that encouraged participants to formulate responses in their own terms (Box 1). Probing was used to clarify a response or establish the meaning of a participant's answer. A drug information pharmacist (JW) conducted all of the interviews by telephone and they were recorded using audiotapes and transcribed. The Standing Committee on

Ethics in Research Involving Humans, Monash University, gave ethics approval for this study.

Qualitative research methods were employed to collect 'context-bound' data that help to predict, explain or understand a particular phenomenon. These methods are well suited to exploring new research issues. Qualitative analysis is the process of bringing order, structure and meaning to the mass of collected data and a framework approach was employed by Tracy Bessell to analyse the interview data (Box 2). This approach starts deductively (reasoning from general to particular instances) from the aims and objectives set for the study and the results are grounded (heavily based in the original accounts and observations of the people studied) and inductive (the process of inferring a principle from the observation of particular instances).⁸ Such an approach is advantageous because the analytic process and interpretations can be viewed and assessed by people other than the primary analyst. The resultant themes were reviewed by JW.

Results

During June to August 2001, QMH staff identified 11 callers who self-reported using the Internet to seek health information. Of these, nine people

Box 2: The five stages of data analysis using a framework approach

1. Familiarisation – immersion in the raw data by reading transcripts, in order to list key ideas and recurrent themes.
2. Identifying a thematic framework – identify all the key issues, concepts and themes by which the data can be examined and referenced by drawing on prior knowledge, the aims and objectives of the study and issues raised by participants.
3. Indexing – applying the thematic framework to all the data using codes.
4. Charting – rearranging the data according to themes. The end result is a chart for each key theme containing distilled summaries of participants' views and experiences.
5. Mapping and interpretation – using the charts to define concepts, map the range and nature of the phenomena, create typologies and find associations between themes with a view to providing explanations for the findings.

Adapted from: Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess RG eds. Analysing qualitative data. London: Routledge, 1993:173-94.

Box 1: Semi-structured interview guide

1. What prompted you to seek information about medicines on the Internet?
2. Did you or someone else on your behalf search for information about medicines?
3. How do you search for information? For example, do you use general search engines, key words, questions, newsgroups, discussion lists, or specific health sites e.g., Medline.
4. How can you tell if a website's information is reliable?
5. What are the advantages and disadvantages of searching for medicines information via the Internet?
6. What types of online information do you find most useful?
7. How has the information you found on the Internet changed the way you manage your health or medicines?
8. What are the advantages and disadvantages of buying medicines via the Internet?
9. Do you have a positive or negative experience regarding the Internet and medicines that you would like to share with us for the benefit of others?

provided informed written consent and participated in semi-structured interviews. The characteristics of participants are shown in Table 1.

The majority of participants' views and experiences of online medicines information were positive. All participants found Internet access to online health information to be timely, convenient and useful. Participants stated that the Internet contained groundbreaking and up-to-date information. They considered the Internet to be a credible resource for medicines information that provided them with access to in-depth information about products and medical conditions, as well as other people's personal insights into coping with a particular condition.

Table 1: Characteristics of Sample participants (n=9)

Consumer characteristics	Frequency
1. Computer training	4
2. Site of Internet access	
Home	8
Work	3
Other	1
3. Frequency of Internet access (including e-mail)	
Daily	3
2-6 times a week	5
Once a week	1
4. Frequency of seeking online health information	
Once a week	1
Once a month	2
Few times a year	5
First time	1
5. Age (yrs)	
Range	33-67
Mean	51
6. Location	
Metropolitan	6
Rural	3
7. Gender	8 F 1 M
8. Household Income	
Above \$40,000	6
Below \$40,000	3
9. Which of these best describes the highest education qualification you have obtained?	
Left school 15 years or older	2
Diploma	5
Bachelor degree or higher	2

However, participants also perceived that online health information could be scary, contain too much scientific and medical jargon, be too general at times and expressed the concern that others might be at risk of cyber-hypochondria.

I had been given two different answers from two different doctors here in the area that I live in. One had said he definitely wouldn't allow me to breastfeed a baby while taking this antidepressant whilst my other doctor said yes... by contacting someone who was, I suppose, an authority or had more information perhaps or research at their fingertips, it helped me make a conscious decision to be able to take those pills and feel that I wasn't affecting my child's health.

Primarily, participants self-conducted information searches using commercial search engines such as AltaVista and used single, simple search terms comprising of product or disease names. They sought a wide range of information about chronic diseases, alternative treatments, prevention, self-referral to health professionals and medication management issues including adverse effects, interactions and breastfeeding.

Participants sought online health and medicines information because it provided them with the opportunity to address their information needs without having to bother their doctor, who may not have the knowledge or time to answer their questions satisfactorily. Participants sought

medicines information via the Internet as a second opinion, to resolve conflicting advice, find alternative treatments and supplement the advice they had been given about the benefits and risks of recommended medications.

It (online health information) helped me make a more informed decision. When the doctor was telling me you've got to take this medication, it helped me understand why I had to take it, what the alternatives were, how the problem was caused and how it was going to be cured.

Although most participants displayed some awareness about the limitations of online health information they found it difficult to express how they differentiated between good and poor quality information. Most commonly, they looked for the same or similar information to be published on multiple websites, and author and organisational credentials and status. Despite awareness of poor quality information on the Internet, participants felt more confident about using their medicines and used online information to make health care decisions, including the starting or ceasing of a medication. None of the participants in this sample had started self-medicating as a direct result of online health information but one consumer stopped self-medicating (using her sister's tramadol) after viewing online health information. Although participants used online health information to address conflicting advice about medicines, most still preferred face-to-face contact with health professionals. No consumers in this sample had bought medicines via the Internet and the majority were apprehensive about buying medicines online. Participants stated that online information resulted in them being more prepared to ask their doctor more pertinent questions at their next visit. Overall, participants felt that access to online health information made them feel more assertive, informed and confident and gave them a better understanding of their medicines.

Discussion

The study demonstrates that participants value online health information and apply it to make decisions about their medication use. It also illustrates that, despite government and private investment in health portals, participants used commercial search engines to seek online health information and they were unsure about how to differentiate between good and poor quality websites. The study shows that consumers use such information as a second opinion rather than an initial diagnosis or treatment recommendation and those consumers who have received conflicting advice from their health care providers use online information to make decisions about medication management. However the subsequent health outcomes of such decisions seem variable.

Consumers need to have accurate, quality information if they are to make informed decisions about their personal health care management. However, the ranking of sites via commercial search engines is influenced not by quality but the number of hits, keywords and cash payments. Despite Government and private organisations investing large amounts of money in the development of health information portals (for example HealthInsite) to meet consumers' information needs, none of these participants used portals to access health information.

This study supports the results of two other Australian studies in that the majority of participants found online health information useful and many reported using it to make health care decisions.^{4,7} However, the participants in these studies did not discuss online health information with their doctor or pharmacist. Why consumers choose not to discuss online health information with their health care providers and the subsequent impact on their relationship is unknown. Although consumers find it difficult to differentiate good and poor quality online health information, the health outcomes of consumers who access poor quality information are also unknown. Confident

consumers acting on poor quality health information have the potential to increase the number of medication misadventures and Australian hospital admissions.

This pilot study was limited to an examination of the views of a small group of online health seekers who used the QMH. This is a select population of online health information seekers who were motivated to call a consumer information service and their experiences and views may not reflect those of the wider community. Semi-structured interviews allow participants to report their beliefs, attitudes, actions and experiences, but what people say and what they do, are not always the same. A larger observational or outcomes study of consumers' online behaviour may overcome these limitations but this was outside the scope of this study.

Conclusion

'The art of coping with the Internet is selecting that part of it that will benefit you most.'

Harry Haxton
(information management speaker)

This pilot study provides a starting point for better understanding complex consumer decision-making and behaviour about medicines and the Internet. Future studies, encompassing a wider cross-section of online medicines information seekers, may identify pathways to educate and safeguard online health care consumers, so that they may be better equipped to find, assess and interpret quality online information to meet their individual needs. Until this is realised skilled pharmacists are well placed to be online information brokers who promote the safe and appropriate use of medicines.

While personal computers with drug information packages and a list of recommended quality websites are valuable, they often fail to address consumer questions about 'that new medicine I saw on TV' or 'I found this information on the Net - what do you think?'. To fulfil the role of online information broker, pharmacists themselves

must have the ability to seek, identify, and critically appraise the wider health resources available via the Internet. To use the Internet in daily practice pharmacists must overcome significant barriers including skills, costs and workflow. However, if pharmacists are not willing to overcome these barriers to become effective online brokers of medicines information, one only needs to look at UK nurses and NHS Direct Online to see that the service will be provided in some other way, which excludes pharmacists.

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Prevalence of South Australia's online health seekers

Abstract

Objective: To determine the proportion of South Australians accessing online health care information, predictive characteristics of online health seekers, nature of the information sought and consumer behaviour.

Methods: A probability-based survey of 3,027 South Australians, aged 15 years and older, as part of the Spring 2000 South Australian Health Omnibus.

Results: Internet access decreases with age, while the prevalence of online health seekers is constant (26% to 28%) among people aged between 15 and 54 years. Predictive characteristics of online health seekers include gender, age, education and income. 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 (11%).

Conclusions: The Australian prevalence of online health seekers is likely to be slightly higher than 21%.

Implications: The Internet can deliver preventative and clinical health information to a critical mass of Australians, but poorer and older Australians may be unable to access it.

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Consumers seeking a range of online health services and information are driving the Internet revolution in healthcare.¹ Consumers access information, electronic medical records, home monitoring, clinical consultations (telemedicine) and buy medicines via the Internet.² However, online health information and services lack quality assurance and issues such as security, privacy and practice standards are not always addressed. Although consumers can access online health resources to potentially inform personal health care decisions, use of these resources can also have an impact upon safety, health provider-consumer relationships, costs and outcomes.

The Australian Bureau of Statistics (ABS) estimates that 50% of all Australian adults had accessed the Internet in the 12 months prior to November 2000.³ Although evidence about Australian use of the Internet for health care is lacking, it is necessary to inform policymakers, managers and clinicians about the potential to deliver quality preventive and clinical health information to consumers, particularly those with the greatest health needs.

The aim of this study was to determine

the proportion of South Australians who use the Internet to access health care information. The objectives included identifying the types of health information sought, subsequent actions taken by consumers using such information and the predictive characteristics of online health seekers.

Methods

Survey

The data were collected in the 2000 South Australian Health Omnibus (September 2000 to January 2001), a representative survey of people aged 15 years or older ($n=3027$, response 70%).⁴ The survey was a multi-stage, systematic, clustered area sample of people who live in metropolitan Adelaide and major country centres in South Australia with a population of more than 1,000. The survey districts were selected from a random sample of Australian Bureau of Statistics collector districts. Within each collector's district a random starting point was selected and from this point 10 households were selected using a fixed skip interval. Hotels, motels, hospitals, nursing homes and other institutions were excluded. The

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person whose birthday was next in each selected household was interviewed face-to-face in their home by trained health interviewers. There was no replacement for non-respondents. Up to five call-backs were made in an attempt to interview the selected person. The data were weighted by age, sex, and geographic region to the estimated resident population data so that the analysis would be representative of the South Australian population. We asked four questions concerning use of the Internet for health information (see Box 1). Demographic data collected included age, gender, country of birth, marital status, education, employment, annual household income and postcode.

The Standing Committee on Ethics in Research Involving Humans at Monash University granted ethics approval for this project and survey questions.

Data analysis

Data were weighted by household size, age, sex and geographical region to benchmarks derived from the 1999 Estimated Resident Population figures for South Australia.⁵ We subsequently adjusted the Health Omnibus data by age and gender to represent the wider Australian population and compared the observed and expected rates (ABS) of Internet use to validate our data.³ We calculated 95% confidence intervals (95% CI) associated with estimates of Internet use and online health information seeking.

We analysed demographic data for Internet users and non-users, online health seekers and non-health seekers using SPSS for Windows Release 10.0.5.9. We produced frequency tables and examined demographic variables using logistic regression to identify independent predictive characteristics of online health seekers. We used the direct entry method whereby the contribution of each variable is evaluated after removal of the effects of all other variables.

Results

The prevalence of South Australian online health seekers was 21% (n=643, 95% CI 20-22%) (see Table 1). Of the 3,027 respondents, 46% (n=1,380; 95% CI 44%-48%) had used the Internet, 31% were frequent users (twice a week to daily) and 15% were infrequent users (few times a year to fortnightly). The 1,307 Internet users accessed the Internet at home (70%), work (40%), family or neighbours (10%), school (9%), tertiary institution (8%), public library (7%) and shop or telecafe (2%). About half (46%) of the Internet users accessed the Internet from both home and another site.

The types of health information sought by the 643 online health seekers include cause or description of disease or health condition (60%), management or treatment of a disease or health condition (45%), complementary medicine (including vitamins, herbal treatments and alternative medicines) (18%), prescription or over-the-counter medicine (10%), support groups (9%) and health appliances (3%). Participants could select more than one type of health information. Furthermore, 486 (76%) of online health information seekers reported that what they found was useful.

Box 1: SA Health Omnibus Questions.

1. How often do you use the Internet including e-mail?
 - Daily
 - 2-6 times a week
 - Once a week
 - Once every 2 weeks
 - Once a month or less
 - Never → go to Q3
2. In the past 12 months where have you accessed the Internet from? (More than one answer may be recorded.)
 - Home
 - Work
 - Friend or neighbour's house
 - Tertiary Institutions/TAFE
 - Public library
 - Shop/store/telecafe
 - Schools
 - Government agencies or departments
 - Other
3. In the past 12 months have you (or someone else on your behalf) used the Internet to search for health information on any of these topics? (More than one answer may be recorded.)
 - I have not searched for any health information → go to next section
 - Cause or description of a disease or health condition
 - Management or treatment of a disease or health condition
 - Prescription or over-the-counter medicine
 - Complementary medicine (includes vitamins, herbal treatments & alternative medicines)
 - Support group
 - Health appliance e.g. nebuliser
 - I have searched for other health information
4. As a result of this information, did you? (More than one answer may be recorded)
 - Find the information useful
 - Use it as a second opinion
 - Discuss it with your doctor or pharmacist
 - Buy a medicine online
 - Buy a medicine from a pharmacy or other shop
 - Change the way you manage your health care
 - Use it to choose a health care provider

Consumers subsequently either used this information as a second opinion (19%), discussed it with their doctor or pharmacist (16%), changed the way they managed their health care (11%), bought a medicine from a pharmacy or other shop (4%), used it to choose a health care provider (3%), or bought a medicine online (1%).

Variables that best predicted being an online health seeker were identified using logistic regression, and included being male, aged between 15 and 55 years, still at school or having a higher education certificate or degree, and household income greater than \$40,000 (see Table 2). Variables that were not predictive of online

health seeking included employment status, residence in a non-metropolitan location, marital status and country of birth. Internet use was not included in the logistic regression analysis as it is closely associated with being an online health seeker (82% of online health seekers are Internet users).

Discussion

This study presents the first representative South Australian population data of online health seekers. The prevalence of Internet use determined in South Australia (46%; 95% CI 44%-48%) and Australia (50%; 95% CI 48%-52%) is similar. Furthermore, comparing age-standardised data, the ratios of observed to expected Internet users varied between 0.75 (for 55 years and over) and 1 (40 to 54 years). Internet use in South Australia is slightly lower than the general Australian population and online health seeking is strongly associated with Internet use, thus we argue that the

Australian prevalence of online health seekers is likely to be slightly higher than 21%.

While Internet access decreases with age, the prevalence of seeking online health information is relatively constant (26% to 28%) among people aged between 15 and 54 years. Two US studies conducted in 1999 and 2000 found that 31% (aged less than 60 years, $n=1,237$)⁶ and 27% ($n=12,751$)⁷ of all American adults sought health information via the Internet. In 2000, 49% of US adults had Internet access.⁸

Although the prevalence of online health seeking and Internet access in Australia and the United States is similar, public health messages may reach different target audiences in their respective countries. US studies showed that the Internet was an effective means of delivering health information to lower income, less educated, and minority Americans (except low-income black Americans) while we determined that both income and education were predictive of online health-seeking behaviour in Australia.

Table 1: Prevalence of Internet use and online health information seekers^a ($n=3,027$).

	Internet users ^a			Health seekers ^a		
	n	%	95% CI	n	%	95% CI
Age						
15-24	379	75	(71-79)	140	28	(24-32)
25-34	287	53	(49-57)	142	26	(22-30)
35-44	332	58	(54-62)	149	26	(22-30)
45-54	257	50	(46-54)	138	27	(23-31)
55-64	84	24	(20-28)	47	14	(10-18)
65+	42	8	(6-10)	26	5	(3-7)
Gender						
Male	759	51	(48-54)	287	19	(17-21)
Female	621	40	(38-42)	357	23	(21-25)
Region						
Metro	981	47	(45-49)	447	22	(20-24)
Non-metro	400	42	(39-45)	196	21	(18-24)
Income^b						
\$0-\$39,999	344	26	(24-28)	173	13	(11-15)
\$40,000+	801	64	(61-67)	379	31	(28-34)
Education						
Left before 15 years/trade qual	186	21	(18-24)	99	11	(9-13)
At school	139	91	(86-96)	56	37	(29-45)
Left at /after 15	425	43	(40-46)	176	18	(16-20)
Certificate/diploma/degree	631	65	(62-68)	313	32	(29-35)
Employment						
Employed	954	59	(57-61)	430	27	(25-29)
Not employed	427	30	(28-32)	213	15	(13-17)
Country of birth						
Australia	1,108	48	(46-50)	515	22	(20-24)
Other	272	39	(35-43)	128	18	(15-21)
Marital status						
Married/de facto	780	43	(41-45)	401	22	(20-24)
Separated/widowed/divorced	106	23	(19-27)	59	13	(10-16)
Never married	494	67	(64-70)	183	25	(22-28)
Total	1,380	46	(44-48)	643	21	(20-22)

Notes:

(a) Proportions are of all participants in each category.

(b) 472 participants did not state their income.

Table 2: Logistic regression analysis to identify predictive characteristics of online health information seekers.^{a,b}

Variable	Reference variable	Sig	Odds ratio	95% CI for odds ratio
At school	Left school 15+	0.002	2.8	1.5-5.4
Under 34	55+ years	0.000	2.3	1.6-3.3
Aged 35-54	55+ years	0.000	2.2	1.6-3.1
Degree/certificate	Left school 15+	0.000	1.3	1.4-2.3
Total household income \$40,000+	THI > \$40,000	0.000	1.8	1.4-2.3
Gender	Female	0.001	1.4	1.2-1.7
Employed	Not employed	0.09	1.3	1.0-1.6
Married/de facto	Never married	0.46	1.1	0.8-1.5
Non-metropolitan	Metropolitan	0.54	0.9	0.7-1.2
Separated/divorced/separated	Never married	0.73	0.9	0.6-1.4
Early leaver/trade	Left school 15+	0.21	0.7	0.5-0.9

Notes:

(a) 78% of the variance was explained by the variables in the equation.

(b) df=1.

More Australian males access the Internet, yet approximately equal percentages of males and females are online health seekers, perhaps because females are the predominant health care decision-makers and carers in society. This study also determined that 18% of online health seekers used a third party to access information and that Internet access is highly correlated with online health seeking. In 2001, Australians who are young, affluent and highly educated are more likely to have Internet access, thus people with the poorest health status are less likely to have access to online health information. However, as web-based television and mobile hand-held devices gain popularity, Internet service provider and computer package costs decrease. In addition, as school-children (all of whom have some Internet access and resources) age, the Australian 'digital divide' will potentially narrow, albeit at different rates among population sub-groups.

Despite the variable quality of online health information,^{9,10} 76% of online health seekers perceived it to be useful and many used it to make health care decisions, yet only 16% discussed this information with their doctor or pharmacist. Whether consumers can identify and apply quality online health information and the subsequent effects on health outcomes is unknown. Our findings also support those of a 1999 study of Western Australian radiology patients (n=174 consecutive patients, 97% response rate) that found one-third of participants sought online health information related to their illness, and of those 47% reported that such information was at variance with their care plan. But only half of these patients discussed such information with their doctor.¹¹ The reasons consumers choose not to discuss online health information with their doctor, particularly when this information conflicts with advice, and the subsequent impact on healthcare provider-consumer relationships requires further research.

Conclusion

The Internet can deliver public health, preventative and clinical information to a critical mass of Australians. The challenge is to ensure an online health environment that safeguards

Australians and allows the development of innovative, interactive, ethical, health resources that are secure, valued by consumers and health care providers, yet ultimately provide value for money and facilitate positive health outcomes. However, such resources should not be developed at the expense of the elderly and the poor who may be unable to access them.

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Do Internet interventions for consumers cause more harm than good? A systematic review

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Abstract

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Keywords: consumers, information,
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Objective To systematically review the effect of consumer use of online health information on decision-making, attitudes, knowledge, satisfaction and health outcomes and utilization.

Search strategy Electronic databases searched included the Cochrane Controlled Trials Register, MEDLINE, PREMEDLINE (to 14 March 2001), CINAHL, Australian Medical Index, Health and Society, National Institutes of Health Clinical Trials Database and CenterWatch.

Inclusion criteria All post-1995 comparative studies (including controlled studies, before and after studies, and interrupted time series analyses) of Internet users vs. non-Internet users and other communications mediums, and Internet characteristics such as e-mail vs. other communication mediums, were included. Outcomes included consumer decision-making, attitudes, knowledge, satisfaction and measurable changes in health status or health utilization.

Data extraction and synthesis One reviewer screened all papers then two reviewers independently assessed studies against the selection criteria and any discrepancies were resolved by discussion with a third reviewer. No attempt was made to combine the data for further statistical analysis.

Main results We identified 10 comparative studies. Studies evaluated the effectiveness of using the Internet to deliver a smoking cessation programme, cardiac and nutrition educational programmes, behavioural interventions for headache and weight loss, and pharmacy and augmentative services. All studies showed some positive effects on health outcomes, although the methodological quality of many studies was poor.

Conclusions Despite widespread consumer Internet use to obtain health-care information, there is almost a complete lack of evidence of any effects this may have on health outcomes.

Introduction

In November 2000 more than 400 million people around the world accessed the Internet.¹ The Internet is a communications medium that delivers information and services via text, graphics, sound and video. However, unlike other forms of communication the Internet is a global, open, public environment forum. The Internet also has multiple, discrete, characteristics such as the World Wide Web, e-mail, chat rooms and discussion lists.

The Internet provides consumers with access to a wealth of health information and services whereby consumers can now access the same online information as health-care providers. Consumers use the Internet-based information to shape treatment preferences and select health-care providers.^{2,3} Consumers seek online consultations, support, self-management and screening tools, and buy medicines online.⁴⁻⁷ Health-care services can now be delivered by virtual health-care providers, located anywhere in the world, to consumers who never have to leave home. Pragmatically the Internet is becoming much more than just a communications medium.

Consumer use of the Internet has the potential to benefit or harm consumers who use it to manage their health. The quality of information and services on the Internet is variable and not regulated.^{8,9} Legislation aimed at protecting consumers from fraudulent health-care claims and practices lacks the development of technology and is difficult to enforce due to the global and open nature of the Internet.¹⁰

In countries including Australia, Canada, Denmark, Finland, Iceland, Netherlands, Norway, Sweden and the United States of America (USA) more than 40% of the population is estimated to use the Internet.¹ Two USA studies conducted in 1999 and 2000 found that 31% (aged less than 60 years, $n = 1237$) and 27%

($n = 12751$) of all American adults, respectively, sought health information via the Internet.^{11,12} Furthermore, both studies determined that Internet use is associated with being younger, more affluent and better educated.

As Internet access increases and consumer demand for online health services and information grows there is an urgent need for information about whether this causes more harm than good. Our primary hypothesis is that consumer access to the extensive and variable quality of health information and services available via the Internet affects their decision-making, attitudes, knowledge, satisfaction and health outcomes and utilization. Our secondary hypothesis is that the discrete communication features of the Internet also affect these outcomes.

The materials for this systematic review are all the post-1995 comparative studies of consumer use of online health information and services. We examine Internet users vs. non-users, Internet users vs. other communication mediums and Internet users using discrete characteristics of the Internet. For example, we are interested in studies that compare consumers who use online smoking cessation programmes vs. face-to-face counselling and consumers who communicate with doctors via e-mail vs. the telephone.

Methods

Inclusion criteria

We include all comparative studies of consumers using the Internet to access healthcare information and services. We included controlled studies, before and after studies, and interrupted time-series analyses of Internet users vs. non-Internet users, Internet vs. other communication mediums and specific Internet characteristics such as e-mail vs. other communication mediums. Outcomes of interest included consumer decision-making, attitudes, knowledge,

satisfaction and measurable changes in health status or health utilization.

Exclusion criteria

Non-Internet computer-based consumer information systems, e.g. information kiosks, Intranets and CD-ROMs, were excluded. Whilst these might be good quality resources, their access is restricted and evaluating their use does not inform us about the risks and benefits of public access to the variable quality of information and services on the Internet. A suitable analogy is that studying the effects of access to a library is not the same as studying the effects of access to four specifically chosen books. We did not consider studies of Internet use by health professionals because we perceive them to have skills and training that enable them to interpret the quality of health information in a manner different to the general public. Studies pre-1995 have been excluded because at that time the Internet was not widely used by the general public. In 1995 there were less than 10 million computers with registered Internet service provider addresses, compared with more than 100 million at the end of the year 2000.¹³ The World Wide Web was developed in 1991 and the first commercial search engines only became available in 1995.¹⁴

Identification of studies

Studies were identified from the Cochrane Controlled Trials Register (Cochrane Library Issue 1, 2001) and MEDLINE (1966, December, week 4, 2000), PREMEDLINE (14 March 2001), CINAHL (February 2001), Australian Medical Index (February 2001), Health and Society (January 2001) and the National Institutes of Health Clinical Trials Database (14 March 2001) available at <http://www.clinicaltrials.gov> and CenterWatch Clinical Trials Listing Services (14 March 2001) available at <http://www.centerwatch.com/patient/trials.html>.

The MEDLINE search terms included Internet, online, World Wide Web, web, e-mail

or e-mail; or electronic mail, mail list, discussion list, chat room and newsgroup (tw). These terms were combined with study terms including evaluation studies, intervention studies, cohort studies, controlled studies or study, comparative study, before and after study, clinical trial and pilot projects (tw). The combined results were restricted to years 1995 to 14 March 2001. Searching was not restricted by language. The terms Internet, online, World Wide Web and web were limited to (ti) to reduce the number of citations from approximately 2500 to 597. The strategy designed for MEDLINE was adapted and used to search all other databases. Copies of the searches are available on request. All searches were conducted in March 2001.

Study selection and data extraction

Citations retrieved by the searches were downloaded via bibliographic software (EndNote 4.0) to form a single library from which duplicates were removed. The first reviewer screened each citation for possible inclusion according to the selection criteria and only those studies that did not meet the selection criteria were discarded. Full texts of the remaining citations were sought and independently appraised by two of us (TB and SM). Discrepancies were resolved by discussion with CS.

Ethics approval

The Standing Committee on Ethics in Research Involving Humans at Monash University granted ethics approval for this project and survey questions.

Statistical analysis

We intended to assess the relative contribution of included studies to describe the current state of knowledge and to generate hypotheses for future research using a random effects model, but the nature of the studies did not allow data pooling or further statistical analysis.^{15,16}

Description of studies

Our search identified 599 citations from which we identified 10 comparative studies.¹⁷⁻²⁶ We also identified 44 descriptive studies (Appendix 1) and two case reports.^{27,28} The majority of citations were excluded because they were concerned with 'webs' of a non-Internet nature or non-consumers. Although it was not our intention to identify descriptive studies as part of this review we have included a list of such studies for interest, as they may be the precursors to future comparative studies. We also identified two further comparative studies; the first is in progress and will conclude in the later half of 2001,²⁹ whilst the second study's results were reported in a press release but not in the medical literature.³⁰

Results

All proposed outcomes and reported results of comparative studies are shown in Table 1.

Takahashi demonstrated that the Internet is a medium in which effective smoking cessation intervention can be delivered. They reported that 52% of smokers and 43% of heavy smokers had quit 12 months after enrolling in an online smoking cessation programme. This programme was not limited to a restricted sample size and was accessible to all members of the public able to access the Internet in a convenient and timely manner.

Cellio, Winzelberg and Winett examined the effect of delivering education via the Internet on the eating habits, body image or physical activity of young women and all three studies found positive outcomes in the Internet intervention group. Scherrer-Bannermann also examined the effect of delivering education via the Internet, comparing Web-based and printed patient education manuals for consumers on cardiac surgery waiting lists. They reported that the Internet-based intervention provided increased social support, decreased social anxiety and improved attitudes towards surgery.

Tate compared the use of a 6 month weight loss Internet-based education programme and beha-

viour therapy intervention, comprising e-mail-facilitated weekly lessons, support and bulletin board, with an Internet-based education programme only. They showed that the additional Internet-based resources did improve the numbers of people achieving weight loss goals and mean weight loss 6 months post-intervention.

The quality of the remaining four studies was poor. MacKinnon showed that e-mail is a useful adjunct for some people with disabilities when using an augmentative communication service. Wagner compared the structural and cost outcomes of online and traditional US/A pharmacies and showed that online pharmacies have higher consumer costs due to handling and delivery charges but more comprehensive consumer medicines information. However, the small sample sizes in the MacKinnon and Wagner studies do not allow robust conclusions to be drawn. Jones compared Internet users vs. outpatients seeking Viagra repeats; however, the control group of inner-city outpatients is likely to have lower health, social and educational status than Internet users. Furthermore, consumers who experienced an adverse event are unlikely to request a repeat prescription. Strom conducted a controlled trial for self-help treatment of recurrent headache for consumers randomized to an Internet-based intervention or waiting list but 56% of participants dropped out of the study. Overall the results of these four studies are not reliable.

Discussion

The strongest finding to emerge from this systematic review is the lack of rigorous research regarding the effects of consumer Internet use on health outcomes. Given the widespread use of the Internet and the claims that are frequently made about its benefits as a tool for communicating health information and empowering consumers in health-care decision-making, this lack of research evidence is disturbing.

Firstly, this lack of research may be due to the provision of consumer Internet health-care services being a recent and evolving phenomenon. Secondly, just as the Internet-based

Table 1 Characteristics of included studies

Author	Study design & number of participants	Comparison groups	Intervention	Outcome	Absolute change		Relative change	Quality
Cello 2000	Controlled trial (n = 76)	Internet (n = 24) vs. classroom (n = 15) vs. no intervention (n = 19) for young women at a US private university	Education programme for reducing risk factors for eating disorders	At 6 months: relative effect sizes and absolute mean differences for: Body image score Bulimia Drive for thinness Weight/shape concerns Eating concerns Restraint Social support	Net vs. no intervention	Classroom vs. no intervention	30% 3% 19% 14% -8% 34%	Drop-out rate in classroom group (40% was higher than the Internet group)
Jones 2000	Retrospective quantitative analysis of patient records (n = 346)	Patients from an online health clinic (n = 310) vs. a USA inner-city hospital clinic (n = 36)	Seeking repeat requests for Viagra	Sex life satisfaction Patient complaints	Not reported Nil reported			Recruitment bias and poor choice of control group
MacKinnon 1995	Randomised controlled trial (n = 16)	E-mail (n = 7) vs. normal service (n = 9)	Clinical and technical assistance to physically disabled persons from an augmentative communication service	Mean service Number of contacts to clinicians and staff over 6-month period	0.2 points 36 contacts		4% 500%	Small sample size Randomization method not stated
Scherrer-Bannerman 2000	Controlled trial (n = 72)	Patients with Internet access vs. no Internet access, waiting for cardiac surgery in Vancouver	Website vs. written manual	Social support Anxiety Lifestyle changes Attitude to surgery	Not reported		Not reported	Bias. Internet group provided training Numbers of participants in each group not reported Convenience sample - only those with Internet access

Table 1 (Continued)

Author	Study design & number of participants	Comparison groups	Intervention	Outcome	Absolute change	Relative change	Quality
							assigned to intervention group and all others to control group Drop-out rate 56%
Strom 2000	Controlled trial (n = 102)	E-mail-/internet (n = 20) and no intervention (n = 25) for chronic headache sufferers in Sweden	Applied relaxation and problem solving in the treatment of recurrent headache	Mean difference for: Headache Index improvement Frequency (days/week) Peak intensity	0.5 points NS NS	50%	
Takahashi 1999	Before and after study (n = 102)	Japanese smokers	Web page info Daily e-mail E-mail support	Smoking cessation > 30 per day < 30 per day	53 53	52% 43%	
Tate 2001	Randomized controlled trial (n = 91)	Internet behaviour therapy (n = 33) vs. Internet education (n = 32) in healthy, overweight US hospital employees	Weekly e-mail lessons, monitoring tool, individual feedback, and bulletin board	At 6 months Mean body weight loss Mean decreased waist circumference Achievement of 5% body weight loss	2.5 kg 3.3 cm 15 people	3% 3% 23%	71% of patients had complete data
Wagner 2001	Comparative survey (n = 8)	Internet (n = 4) vs. traditional US pharmacy services (n = 4)	Supply of medication and information from pharmacies	Costs Delivery times Response times to questions Quality of information provided	NS NS NS NS		Small sample size
Winzelberg 2000	Randomized controlled trial (n = 60)	Internet (n = 24) vs. no intervention (n = 20) in young women at a public US university	Education programme for reducing risk factors for eating disorders	Mean difference at 3 months (high risk participants): Body image score Bulimia Drive for thinness Weight concerns Shape concerns	22 (20) points 3.1 (4) points 5.3 (4.8) points 1.6 (0.8) points 0.8 (0.6) points		73% of participants had complete data Method of randomization not stated Compliance with programme 64%

Table 1 (Continued)

Author	Study design & number of participants	Comparison groups	Intervention	Outcome	Absolute change	Relative change	Quality
Winett 1999	Controlled trial (n = 180)	Internet and classroom (n = 103) vs. classroom (n = 77) in a poor US high school	Five educational modules for school health classes	Regular meals Fruits and vegetables Breads and cereals Regular sodas High fat snacks High fat dairy Fast food (calories)** Fast food fat (g)** Aerobic exercise (days/week)	0.3 points 1.1 points 1.0 point 0.4 points NS NS 261 14.2 0.8	F = 14.09 F = 15.11 F = 18.53 F = 5.25 r = 3.28 r = 4.28 F = 4.27	Not randomized or blinded due to logistical restraints Internet access was not always reliable

NS = not statistically significant ($P > 0.05$). **n = 39.

services themselves are evolving, new research methodologies may be required to identify and track users prospectively in order to obtain health outcome measurements.

From the studies we did identify, there was some evidence that Internet-based materials may provide consumers with necessary information and support in a timely manner to achieve positive health outcomes. Although the overall effectiveness of the Internet on health service utilization outcomes was not clear, the results indicate that the Internet may impact on the overall cost effectiveness of health service provision and workflow practices.

Conclusion

We need to know how and why consumers use the Internet for health-care information and services, what subsequent actions they take, and how this affects their behaviour and health status. As increasing numbers of people use the Internet the public health benefits and risks of online health-care should be examined by measuring changes in health status, health service utilization, costs, decision-making models and consumer satisfaction. Indicators such as the number of adverse events, amount of quality online health information, number of licensed online health-care providers and the implementation of online practice standards may also be used to evaluate the effectiveness of the Internet as a health-care intervention in its own right.

At present, there is almost no evidence regarding the effect of consumer Internet use on health outcomes. Well-designed controlled studies, instead of anecdotes and opinions, about the risks and benefits of using the Internet are urgently needed.

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Appendix 1

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APPENDIX 2:

CONSUMER USE OF THE INTERNET: DESCRIPTIVE STUDIES.

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APPENDIX 3: CHI-SQUARE CALCULATIONS

The following chi-square calculations demonstrate the strength of association between online health seeking behavior and demographic variables in the South Australian Health Omnibus survey.

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
INFOSEEK * AGE	3025	99.9%	2	.1%	3027	100.0%
INFOSEEK * COUNTRY OF BIRTH	3027	100.0%	0	.0%	3027	100.0%
INFOSEEK * AREA	3027	100.0%	0	.0%	3027	100.0%
INFOSEEK * EDUCATIONAL ATTAINMENT	3028	100.0%	0	.0%	3027	100.0%
INFOSEEK * MARITAL STATUS	3028	100.0%	0	.0%	3027	100.0%
INFOSEEK * GENDER	3028	100.0%	0	.0%	3027	100.0%

INFOSEEK * AGE

Crosstab

			AGE						Total
			15 - 24 years	25 - 34 years	35 - 44 years	45 - 54 years	55 - 64 years	65 years or more	
INFOSEEK	.00	Count	366	397	427	377	301	515	2383
		% within AGE	72.3%	73.7%	74.1%	73.2%	86.5%	95.2%	78.6%
	1.00	Count	140	142	149	138	47	26	642
		% within AGE	27.7%	26.3%	25.9%	26.8%	13.5%	4.8%	21.2%
Total		Count	506	539	576	515	348	541	3025
		% within AGE	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	137.640 ^a	5	.000
Likelihood Ratio	167.424	5	.000
Linear-by-Linear Association	100.403	1	.000
N of Valid Cases	3025		

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 73.86.

INFOSEEK * COUNTRY OF BIRTH

Crosstab

			COUNTRY OF BIRTH			Total
			Australia	UK & Ireland	Other	
INFOSEEK .00	Count		1807	272	305	2384
	% within COUNTRY OF BIRTH		77.8%	80.2%	83.3%	78.8%
1.00	Count		515	67	61	643
	% within COUNTRY OF BIRTH		22.2%	19.8%	16.7%	21.2%
Total	Count		2322	339	366	3027
	% within COUNTRY OF BIRTH		100.0%	100.0%	100.0%	100.0%

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	6.241 ^a	2	.044
Likelihood Ratio	6.509	2	.039
Linear-by-Linear Association	6.221	1	.013
N of Valid Cases	3027		

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 72.01.

INFOSEEK * AREA

Crosstab

			AREA		Total
			Metropolitan	Country	
INFOSEEK .00	Count		1631	753	2384
	% within AREA		78.5%	79.3%	78.8%
1.00	Count		447	196	643
	% within AREA		21.5%	20.7%	21.2%
Total	Count		2078	949	3027
	% within AREA		100.0%	100.0%	100.0%

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	.287 ^b	1	.592		
Continuity Correction ^a	.238	1	.626		
Likelihood Ratio	.288	1	.592		
Fisher's Exact Test				.632	.314
Linear-by-Linear Association	.286	1	.593		
N of Valid Cases	3027				

a. Computed only for a 2x2 table

b. 0 cells (.0%) have expected count less than 5. The minimum expected count is 201.59.

INFOSEEK * EDUCATIONAL ATTAINMENT

Crosstab

			EDUCATIONAL ATTAINMENT						Total
			Still at school	Left before 15 yrs	Left after 15 yrs	Trade quals	Certificate / Diploma	Bachelor Degree	
INFOSEEK .00	Count		96	450	823	356	458	201	2384
	% within EDUCATIONAL ATTAINMENT		63.2%	93.0%	82.4%	84.6%	72.1%	59.6%	78.7%
1.00	Count		56	34	176	65	177	136	644
	% within EDUCATIONAL ATTAINMENT		36.8%	7.0%	17.6%	15.4%	27.9%	40.4%	21.3%
Total	Count		152	484	999	421	635	337	3028
	% within EDUCATIONAL ATTAINMENT		100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	187.025 ^a	5	.000
Likelihood Ratio	189.164	5	.000
Linear-by-Linear Association	76.235	1	.000
N of Valid Cases	3028		

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 32.33.

INFOSEEK * MARITAL STATUS

Crosstab

			MARITAL STATUS				Total
			Married / De facto	Separated / Divorced	Widowed	Never Married	
INFOSEEK .00	Count		1425	201	207	552	2385
	% within MARITAL STATUS		78.0%	79.8%	96.3%	75.1%	78.8%
1.00	Count		401	51	8	183	643
	% within MARITAL STATUS		22.0%	20.2%	3.7%	24.9%	21.2%
Total		Count	1826	252	215	735	3028
		% within MARITAL STATUS	100.0%	100.0%	100.0%	100.0%	100.0%

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	46.050 ^a	3	.000
Likelihood Ratio	61.648	3	.000
Linear-by-Linear Association	.010	1	.919
N of Valid Cases	3028		

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 45.66.

INFOSEEK * GENDER

Crosstab

			GENDER		Total
			Male	Female	
INFOSEEK .00	Count		1197	1187	2384
	% within GENDER		80.7%	76.9%	78.7%
1.00	Count		287	357	644
	% within GENDER		19.3%	23.1%	21.3%
Total		Count	1484	1544	3028
		% within GENDER	100.0%	100.0%	100.0%

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	6.464 ^b	1	.011		
Continuity Correction ^a	6.240	1	.012		
Likelihood Ratio	6.477	1	.011		
Fisher's Exact Test				.011	.006
Linear-by-Linear Association	6.462	1	.011		
N of Valid Cases	3028				

a. Computed only for a 2x2 table

b. 0 cells (.0%) have expected count less than 5. The minimum expected count is 315.62.

Dear Internet pharmacist

The Internet potentially provides positive opportunities to empower consumers by providing innovative health information and services. Online pharmacies provide consumers with convenient and timely access to competitively priced medicines and professional pharmacy services but some may fail to protect consumers from harmful medicines, improper prescribing or dispensing and poor quality health information.

My name is Tracey Bessell and I am doing research under the supervision of Professor Chris Silagy, Director of the Institute of Health Services Research, towards a PhD at Monash University, Australia.

The aim of this research project is to determine whether Australian consumers can obtain non-prescription and complementary medicines via the Internet in safe and appropriate manner. The Australian Commonwealth Department of Health and Aged Care are funding this project, which will inform consumers, pharmacists and policymakers about the characteristics of online pharmacies and the public health issues of obtaining medicines via the Internet.

We recently surveyed your online pharmacy using a standard case scenario and are pleased to present you with a copy of the results. We surveyed and ordered pharmaceuticals from a total of 104 online pharmacies, around the world. The combined survey results will be emailed to participating online pharmacies in November 2001. This will enable you to compare your website with the other 103 pharmacies. Prior consent was not sought from online pharmacies because the consenting pharmacist may not be the same person delivering the service. Furthermore this ensures that your results are not biased by preferential pharmacy service.

My supervisors and I will have access to the original data, which will be stored for five years as prescribed by the university regulations. **All data will be coded and no results that could identify any individual websites or participants will be published in the combined survey results, reports or papers.**

If you require further information, wish to comment on or withdraw your website's case study results (participation is voluntary) please email Tracey Bessell at tracey.bessell@med.monash.edu.au. To participate in this survey no action is required.

Thank you

Tracey Bessell BPharm MPH
PHD Candidate

Should you have any complaint concerning the manner in which this research (project number 2000/125) is conducted, please do not hesitate to contact The Standing Committee on Ethics in Research Involving Humans at the following address:

The Secretary
The Standing Committee on Ethics in Research Involving Humans
Monash University
Wellington Road
Clayton Victoria 3800
Telephone (03) 9905 2052 Fax (03) 9905 1420
Email: SCERH@adm.monash.edu.au

Website Name	
1 URL	
2 Country of origin	

Where are the following displayed?	Home-page	Rest of Website	Not displayed
3a Name of Pharmacist /Company Owner			
3b Physical Address			
3c Toll free telephone number			
3d Telephone			
3e Fax			
3f Email			
3g Date of website Update			
3h Consumer feedback/evaluation of site			

4 How many hours per day is a pharmacist is available?	Not displayed	0 to 12	12< to 24
---	----------------------	----------------	---------------------

Can you search the website by?	Y	N	U
5a Product names eg Sudafed, Nurofen			
5b Therapeutic substances eg pseudoephedrine, ibuprofen			
5c Therapeutic class eg cough & cold, analgesic			
5d No search function			

Can the following medicines (containing single therapeutic agents) be ordered from this website?	Y	N	U
6a Codeine 20-50mg Tabs/ Caps			
6b Sildenafil 50-100mg Tabs			
6c Amoxycillin 250-500mg Tabs/Caps			
6d Clotrimazole 1-3% Vaginal Cream			
6e Pseudoephedrine 30-120mg Tabs			
6f St Johns Wort 100mg+ Tabs/Caps			

If the following can be ordered, is a prescription ordered by a registered medical practitioner required to purchase these medicines? (These medicines are scheduled prescription only in Australia)	Y	N	U
7a Codeine 20-50mg Tabs/ Caps			
7b Sildenafil 50-100mg Tabs			
7c Amoxycillin 250-500mg Tabs/Caps			

8 Are online consultations with a registered medical practitioner available from this website?	Y	N	U
---	----------	----------	----------

9 Which of the following are displayed on the website?	
Help screen	
Site Map	
Menu	
None of the above	

10 Which of the following pharmacy services promoted on the website?	
Pharmacists advice	
Medication reviews	
Compounding	

11 Which of the following pharmacy/health quality seals are displayed on the website?	
Verified Internet Pharmacy Practice Sites (VIPPS)	
Quality Care Pharmacy Program (QCPP)	
Health on the Net (HON)	
Other quality indicator (name)	
None	

12 Which of the following policies are displayed on the website?	
Privacy policy regarding personal medical information	
Information disclaimer	
Quality of care disclaimer	
Returns policy	
None of the above	

13 Which products are advertised on the website?	
Prescription Medicines	
Non-Prescription Medicines	
Complementary medicines	
General goods ie health & beauty	
No products	

14 Which types of information are displayed on the website?	
Medicines information (inc dose, frequency, interactions, potential adverse effects)	
Disease/condition specific	
Lifestyle	
Testimonials	
None of the above	

Q15 - 17 Quality of information (DISCERN instrument www.discern.org.uk)

15 Is the website reliable?	No 1	2	Part 3	4	Yes 5
Are the aims clear?					
Does it achieve its aims?					
Is it relevant?					
Is it clear what sources of information were used to compile the publication (other than author or producer)?					
Is it clear when the information used or reported in the publication was produced?					
Is it balanced or unbiased?					
Does it provide details of additional sources of support and information?					
Does it refer to areas of uncertainty?					

16a How good is the quality of information on treatment choices? eg St Johns Wort for depression	No 1	2	Part 3	4	Yes 5
Does it describe how each treatment works?					
Does it describe the benefits of each treatment?					
Does it describe the risks of each treatment?					
Does it describe what would happen if no treatment were used?					
Does it describe how the treatment choices affect the overall quality of life?					
Is it clear that there may be more than one possible treatment choice?					
Does it provide support for shared decision-making?					
Nil information available					

16 b How good is the quality of information on treatment choices? eg Sudafed for nasal congestion.	No 1	2	Part 3	4	Yes 5
Does it describe how each treatment works?					
Does it describe the benefits of each treatment?					
Does it describe the risks of each treatment?					
Does it describe what would happen if no treatment were used?					
Does it describe how the treatment choices affect the overall quality of life?					
Is it clear that there may be more than one possible treatment choice?					
Does it provide support for shared decision-making?					
Nil information available					

17 Overall Rating of the Medicines Information on the Website.	Low		Mid		High
--	-----	--	-----	--	------

18 Which types of external links are displayed on the website?	
Online doctor consultation	
Health Insurance Company	
Peer-reviewed medical journals	
Evidence-based practice sites	
Government	
Online medical libraries eg MEDLINE	
Pharmaceutical Manufacturers	
Pharmacy Banner/Marketing Groups	
Consumer health/support groups	
Hospital or Community Health Centres	
Other	
Nil	

18 Where does the website deliver?	
Local	
National	
Global	

Case study

Place an order for Sudafed® (preferred brand) or pseudoephedrine HCl (30-120mg) (single therapeutic ingredient), quantity 10-60 capsules/tablets and St John's Wort 100mg+, quantity 10-60 (no preferred brand) from an online supplier of scheduled medicines. Choose the cheapest Sudafed® or St John's Wort product if multiple options are available

The Sudafed® or pseudoephedrine HCl product is for your own use. You have had a runny nose for a couple of days and a friend suggested you try it - you have not used this product before or tried anything else to treat the problem. The St John's Wort is also for your own use. You have been feeling really flat and low and you read about St John's Wort in a magazine - you have not used this product before. You have taken Prozac (fluoxetine) for depression for the past 3 months after being in a car accident. You are not taking any other medications and have no other illnesses.

Ordering

19 Were you required to register a user name and password?	Y	N	U
--	---	---	---

Did the pharmacy staff collect the following information?	Y	N	U
20a Have you used the product before?			
20b Who was the medicine for?			
20c What are the symptoms?			
20d How long have you had the symptoms?			
20e What have you already tried to treat the condition?			
20f What other medicines are you taking?			
20g What other medical conditions do you have?			

Did the pharmacy staff or website provide the following information:	Y	N	U
21a How to use the product ie dose and frequency			
21b How long to use the product			
21c Potential adverse effects			
21d Potential interactions with other medicines			
21e What to do if you do not feel better			
21f Lifestyle changes eg smoking cessation, exercise.			

22 Were other products recommended to you?	Y	N	U
22a If yes name			
22b Generic			
22c Add on sale			

23 Were you cautioned about buying either of the products?	Y	N	U
23a If yes, which product?			
23b Why?			

24 Were you referred to a health professional?	Y	N	U
24a If yes, why?			

25 Was an electronic payment transaction via a secure server link (SSL)?	Y	N	U
---	----------	----------	----------

Delivery Advice	Y	N	U
26a Was electronic confirmation of your order sent to you?			

Delivery

27 Which method of delivery was used?		
Post		
Registered Post		
Courier		
Other		
Inspected by customs	Y	N
Package type	Box	Envelope
Bubble wrap or similar	Y	N

28 Was a signature required to receive delivery?	Y	N	U
--	---	---	---

29 Which of the following were received upon delivery?	
Written medicines information	1
Advertising (products)	2
Advertising (pharmacy services)	3
Pharmacist contact details	4
Service summary sheet provided	5

Q30-35 Quality of information (DISCERN instrument www.discern.org.uk)

30 Is the written medicines information delivered with the product reliable? Eg Sudafed	No 1	2	Part 3	4	Yes 5
Are the aims clear?					
Does it achieve its aims?					
Is it relevant?					
Is it clear what sources of information were used to compile the publication (other than author or producer)?					
Is it clear when the information used or reported in the publication was produced?					
Is it balanced or unbiased?					
Does it provide details of additional sources of support and information?					
Does it refer to areas of uncertainty?					

31 How good is the quality of information on treatment choices?	No 1	2	Part 3	4	Yes 5
Does it describe how each treatment works?					
Does it describe the benefits of each treatment?					
Does it describe the risks of each treatment?					
Does it describe what would happen if no treatment were used?					
Does it describe how the treatment choices affect the overall quality of life?					
Is it clear that there may be more than one possible treatment choice?					
Does it provide support for shared decision-making?					
Nil information available					

32 Overall Rating of the written medicines information delivered with Sudafed.	Low 1	2	Mid 3	4	High 5
--	----------	---	----------	---	-----------

33 Is the written medicines information delivered with the St Johns Wort product reliable?	No 1	2	Part 3	4	Yes 5
Are the aims clear?					
Does it achieve its aims?					
Is it relevant?					
Is it clear what sources of information were used to compile the publication (other than author or producer)?					
Is it clear when the information used or reported in the publication was produced?					
Is it balanced or unbiased?					
Does it provide details of additional sources of support and information?					
Does it refer to areas of uncertainty?					

34 How good is the quality of information on treatment choices?	No 1	2	Part 3	4	Yes 5
Does it describe how each treatment works?					
Does it describe the benefits of each treatment?					
Does it describe the risks of each treatment?					
Does it describe what would happen if no treatment were used?					
Does it describe how the treatment choices affect the overall quality of life?					
Is it clear that there may be more than one possible treatment choice?					
Does it provide support for shared decision-making?					
Nil information available					

35 Overall Rating of the written medicines information delivered with St Johns Wort.	Low 1	2	Mid 3	4	High 5
--	----------	---	----------	---	-----------

Were the products received:	Y	N	U
Product Name 1(pseudoephedrine), Strength, Quantity			
Batch No:			
Expiry Date			
36a The same as ordered			
36b In original packaging			
36c Squashed			

Product Name 2(St Johns Wort), Strength, Quantity.			
Batch No:			
Expiry Date			
36e The same as ordered			
36g In original packaging			
36h Squashed			

37 Delivery Time (n days)	
----------------------------------	--

Cost	AUS \$	
38a Cost of medicines (1=Pseudoephedrine, 2= St Johns Wort)	1	2
38b Delivery charge		
38c Other charges		
38d Total cost		

39 Did the pharmacist provide individual follow-up?	Y	N	U
39a If yes, how many days after order received?	(days)		
39b If yes, by email			
39c If yes, by other method (name)			

Feedback	Y	N	U
40a Did the pharmacist seek feedback or evaluation of the service provided?			

Interaction between fluoxetine and SJW	Y	N
41a Was the interaction detected?		
41b Was appropriate advice provided?		

Thank you for taking the time to consider these results. I hope you find them an accurate and useful evaluation of your website.

Tracey.

APPENDIX 5: THE ONLINE SURVEY OF CONSUMERS WHO BOUGHT MEDICINES VIA THE INTERNET

MONASH HOME > MONASH INFO > NEWS & EVENTS > CAMPUSES & FACULTIES >
★ FACULTY OF MEDICINE, NURSING & HEALTH SCIENCES



Monash Institute of Health Services

Project Title: The influence of the Internet on the Quality Use of Medicines

My name is Tracey Bessell and I am doing research under the supervision of Associate Professor Jeremy Anderson at the Monash Institute of Health Services Research, towards A PhD at Monash University.

The aim of this research is to determine the influence of the Internet on the Quality Use of Medicine. It is being funded by Commonwealth Department of Health And Aged Care. I hope that the findings of this research project will inform consumers, health professionals and policymakers about the benefits and risks of buying medicines via the Internet.

Being part of this research will involve participating in an online survey about your views and experiences of buying medicines via the Internet. These medicines include prescription-only, pharmacy or complementary medicines.

If you would like to participate please read the information below then hit the consent button.

- I declare that I have bought medicines via the Internet.
- I currently live in Australia and I am at least 18 years of age.
- I understand that agreeing to take part means that I am willing to voluntarily medicines via the Internet.
- The information I provide cannot be used except for this project. All survey responses will be stored for five years as prescribed by the university regulations. My supervisors and I will have access to this data.
- I understand that any information I provide is confidential (including my email address), and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party unless required by law.
- I also understand that my participation is voluntary, that I can choose not to participate in part of all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.

If you have any queries or would like to receive a summary of the project findings, please contact Tracey Bessell: telephone: 03 9594 7525 or email Tracey.

Should you have any complaint concerning the manner in which this research (project number 2000/125) is conducted, please do not hesitate to contact The Standing Committee on Ethics in Research Involving Humans at the following address:

The Secretary
The Standing Committee on Ethics in Research Involving Humans
Monash University
Wellington Road
Clayton Victoria 3800
Telephone: (03) 9905 2052 Fax (03) 9905 1420
Email: SCERH@adm.monash.edu.au

I agree to take part in the above Monash University Project. I have read the above information and will keep a copy of this information for my records.

I Consent

Thank you.

Tracey Bessell
PhD Candidate

I consent

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APPENDIX 5 CONTD: Net Medicines Survey

These questions are about your views and experiences of buying medicines via the Internet. This includes any medicines available from pharmacies such as prescription, pharmacy and complementary (herbal, vitamins etc) medicines.

1. What prompted you to buy medicines via the Internet? (50 words or less)

2. Describe how you selected the website(s) you bought medicines from? (50 words or less)

For example, did you search the web using a search engine eg Google and the name of the medicine, see it on television or did a friend recommend it to you?

3. List up to 5 medicines you have bought via the Internet. Please fill in the table below.
Use the example as a guide.

Name, Strength & Formulation	Website	Country (if known)	Were you required to provide a prescription written by an Australian doctor? Yes or No	Did you undertake an online medical consultation? Yes or No
Lasix 40 mg tablets	www.netmeds.com.nz	NZ	No	No

4. What are the benefits of buying medicines via the Internet? (50 words or less)
Consider why you would buy medicines via the Internet instead of the local pharmacy?

5. What are the risks of buying medicines via the Internet? (50 words or less)
Consider whether buying medicines via the Internet is as safe as buying medicines at the local pharmacy?

6. How can you tell if a website will deliver safe and effective products and services? (50 words or less)
Consider what website features or information would you look for prior to buying a medicine.

7. Do you have a positive or negative experience regarding the Internet and medicines that you would like to share with us for the benefit of others? (100 words or less)

8. How did your experience(s) of buying medicines via the Internet compare with your experiences at your regular pharmacy? (50 words or less)
Consider the levels of service, information and advice offered.

9. Would you recommend buying medicines from Australian websites to your family and friends? Please give reasons. (30 words or less)
Consider safety, privacy and security issues etc.

10. Would you recommend buying medicines from non-Australian websites to your family and friends? Please give reasons. (30 words or less).
Consider safety, privacy and security issues etc.

11. Where would you seek advice if you were unsure about the authenticity of a product received via the Internet? (20 words or less)
Consider a product where the packaging and shape of the tablets looked different from your usual product but the name and strength were the same.

The following questions below are about you. They are required for population health purposes only. (Drop down boxes with no preselections except postcode).

Postcode

Age (years)

Gender

Do you speak language(s)
other than English at home?
If yes which language(s)?

In which range is your total household income
(before tax)?

(You have the option not to disclose this
information if you wish)

\$0 - \$19,999

\$20,000-\$39,999

\$40,000 - \$59,999

\$60,000 - \$79,999

\$80,000 - \$99,999

\$100,000 or more

do not wish to disclose

Would you like to receive a summary of the project results by email?

Your email address is

Thank you. Your participation in this survey is greatly appreciated.

Tracey Bessell

Submit