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SUBMISSION FROM THE CENTRE FOR MENTAL HEALTH RESEARCH TO THE SENATE SELECT COMMITTEE ON MENTAL HEALTH

This submission is made on behalf of the Centre for Mental Health Research¹ at the Australian National University and has been authorized at the level of Director. The Director and representatives from the Consumer Research Unit at the Centre would appreciate the opportunity to address the committee. In particular they would like to outline the importance of consumer participation in research, and demonstrate the way in which technology can aid mental health delivery.

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¹ Information about the Centre for Mental Health Research at the ANU is located in Attachment 1.

EXECUTIVE SUMMARY

Our submission focuses on those terms of reference that will deliver better health for the future generations of individuals vulnerable to mental health problems. This submission addresses three terms of reference.

(n) *The current state of mental health research, the adequacy of its funding and the extent to which best practice is disseminated*

In this submission we argue that an investment in research and development will deliver significant improvements in the following areas:

- The **prevention of mental health problems:** Research will indicate how prevention can best be achieved and how these programs can be rolled out in a variety of settings including schools, families and the Internet.
- The **recognition and understanding of mental health problems**, thereby increasing the opportunity for early detection and the reduction of stigma and discrimination.
- **Early intervention in mental health problems:** Research is indicating strategies that will reduce the severity of illness and prevent the development of new cases.
- The **development of better treatments**, and
- The **use of technology to develop better and cost effective interventions.**

We argue that these developments will only be achieved if the level of funding for mental health research is increased. At present, Australia spends 3% of funding on mental health research, compared to 9% for cancer research. The 8.9% of NHMRC funds spent on mental health is small when compared to the 19.1% contribution of mental disorders to disease burden in Australia. Compared to other OECD countries, Australia spends relatively little on research. The mental health research workforce is small. Unlike areas such as HIV/AIDs where the Australian Government initiated and funded National research and policy centres, there is no Australian government funded research centre of excellence which directly addresses a spectrum of mental health research disorders. There are no specific public health training programs in mental health, and within mental health there is clearly a discrepancy between the impact of the disorders and the research funds spent on them.

The dissemination of best practice is limited to the development of practice guidelines that are distributed primarily to health professionals. Current practice does not deal with the issue of providing best practice guidance to those directly affected by mental health problems or to the families and carers who support them. A review of the dissemination of high quality health information to consumers for depression reported that the best information was disseminated by two university departments (ANU and UNSW), *beyondblue* and by a private health service (Infrapsych). The Australian Government site, Healthinsite (<http://www.healthinsite.gov.au/>), disseminated health information provided by health sites that did not match the quality of those reported above, and websites directly supported by the Australian Government, such as REACHOUT! did not disseminate high quality information (see Griffiths and Christensen, 2002).

Recommendations

- More funding needs to be directed to both projects/programs and workforce capacity building, with priority given to training, development and creation of career positions for mental health researchers, including consumer researchers.
- The **development of high quality health information** is a research function that should be supported by the Australian Government.
- There would be great benefit to Australia in establishing a **National Centre for Mental Health Research**. Such a centre could be located at the ANU developed from the existing base of the Centre for Mental Health Research (CMHR).

(p) E-TECHNOLOGY: The potential for new modes of delivery of mental health care, including e-technology.

The recent establishment of Nehta (the National E-health Transitional Authority) by the Australian Government will drive the development of e-health records and linkage across hospitals and providers. This linkage will ultimately be of benefit to health consumers, including mental health consumers, if consumer fears of lack of confidentiality and consent are addressed adequately. (Unlike other health consumers, mental health consumers are more likely to refuse consent for their health information to be provided to medical staff because of fear of discrimination). Nehta will help eventually in delivering better health outcomes for consumers.

However, Australia's e-health strategy has yet to consider new trends and new health delivery systems with proven effectiveness in reducing mental health problems. These technologies involve delivering medicine and mental health services on the Internet, directly to people who suffer mental health problems. They provide services to those not normally seeking assistance, those in remote areas, and those without access to services. Some of these services provide continuity of care which is simply unavailable in the mainstream health 'system'.

If directed at a young audience, e-technology is likely to capture a space that will become more important for the new generation of health care users. Australia is likely to lag behind other OECD countries, where developments in this field are advancing rapidly.

Recommendations

- The establishment of a **consumer-focused e mental health research and policy centre**.
- A funding model for e-health applications.
- The development of a national strategic plan to drive the development of e-solutions in mental health, especially to a young adolescent market.
- Investigations of the ethics and funding of human interaction over the web.
- The development of a **youth portal** to offer a holistic online mental health clinic.
- The development of **e-based chronic disease management systems for mental health**.

(h) The role of primary health care in promotion, prevention, early detection and chronic care management.

Although many people have their general practitioner as the primary or only provider of mental health care, over 60% of the population with mental health problems do not seek care from any health professional (Andrews & Henderson, 2000). A recent report examining Internet communities worldwide found that 49% of users who met criteria for major depression were not receiving any help, and that 35% had no contact with the medical or health services in the preceding year (Powell, McCarthy, & Eysenbach, 2003). There is also evidence that current services avert only a small amount of the burden of affective disorders (see Andrews & Wilkinson, 2002). Consequently, we strongly support the role of a range of agencies and settings in the development of prevention strategies and chronic care management.

Recommendation

- A **multi-modal approach** should be taken to the delivery of early intervention, prevention and chronic disease management.

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(n) THE CURRENT STATE OF MENTAL HEALTH RESEARCH, THE ADEQUACY OF ITS FUNDING, AND THE EXTENT TO WHICH BEST PRACTICE IS DISSEMINATED.

1.1 The current state of mental health research in Australia

1.1.a Locations for mental health research

Mental health research is conducted in a number of universities, clinical services and research institutions in Australia, in addition to research conducted under the auspices of not for profit organisations such as Lifeline, Sane, Mental Health Council of Australia, *beyondblue*, and through business investment. A list of centres which directly research mental health, and which are associated with the Australasian Society for Psychiatric Research (ASPR), is attached (Attachment 2). Program and project research funding for mental health comes largely from the National Health and Medical Research Council (NHMRC) (see below), and to a lesser extent from ARC funds, from the Rotary Mental Health Fund, and from the Victorian Centre for Excellence (grants that are provided to researchers in Victoria and funded by the Victorian government and *beyondblue*). Private funding agencies such as the Vincent Fairfax Family Foundation, Telstra and industry, including major pharmaceutical firms, provide Research & Development (R&D) support.

1.1.b Sources of mental health research funding

Mental health research funding receives approximately 3.3% of total R&D in health in Australia. According to the Access Economics Report *Exceptional Returns: the value of investing in Health R&D in Australia*, in 2000-2001 Australia spends \$1.7bn on R&D, half of which is contributed by the Australian Government. Overall, Australia ranks at the low end of OECD spectrum for health R&D funding. Cancer research is the leading recipient of funds, receiving \$125 million (9% of total R&D funds) per annum; followed by cardiovascular research, with \$88 million (6% of total); with R&D related to nervous system (6%) and infectious diseases (6%). Mental health receives \$43.7 million, which is about 3% of the total. The largest single source of R&D funding in health is provided by the NHMRC. Approximately 35% of federal funding is channelled through the NHMRC. Data from the *Exceptional Returns* report reveals that for 2002, NHMRC budgeting was \$42 million for cancer, \$30 million for cardiovascular health, \$30 million for mental health and nearly \$25 million for diabetes research (NHMRC, 2002). There are currently 5 large five-year program grants in mental health funded by the NHMRC (Attachment 3) and 8 NHMRC Research Fellows (Attachment 6).

1.1.c Quality of mental health research

Australia does not perform as well as comparable countries such as Canada and New Zealand in terms of research output in mental health. Citation of research published provides an index of the impact and quality of the work undertaken. Australia ranks fifth in the world in terms of total number of citations, but is ranked lower than Canada and New Zealand both with and without adjustment for population size. (Hickie, Christensen, Davenport & Luscombe, in press) (Attachment 4). In terms of total citations, the best performing states are NSW, Victoria, Queensland and the ACT. Twelve Australians are in the top 500 researchers in the world based on Institute for Scientific Information ISI citation rates. These figures show that the best mental health research is conducted by teams of mental health researchers and by a number of 'standout' researchers. Australia has particular recognized expertise in epidemiology, cognitive psychology, longitudinal studies, risk factor research and clinical interventions and prevention strategies (Hickie, Christensen, Davenport & Luscombe, in press).

1.1.d Distribution of mental health research relative to health care costs

The distribution of fields of research within mental health varies across the country. An important consideration is the extent to which research effort is directed at areas of mental health that are costly. The figures shown in Table 1 are based on the percentage of cost on health care within these sectors (see Jorm, Griffiths, Christensen et al., 2001) (Attachment 5).

Relative to health care expenditure, these figures show that dementia particularly is relatively under researched, with 24.8% of cost and only 14.1% of research funding.

Table 1: Comparison of the distribution of research with the distribution of health system costs.

CATEGORY OF MENTAL DISORDER	% OF COST ¹	% OF PUBLISHED RESEARCH	% OF COMPETITIVE GRANT FUNDING
Dementia	24.8	8.9	14.1
Substance use disorders	12.1	20.0	22.0
Schizophrenia & other psychosis	20.2	12.1	9.0
Affective disorders	22.3	16.7	14.1
Anxiety disorders	12.2	16.3	8.7
Personality disorders	1.8	1.3	1.8
Mental retardation	0.9	6.1	10.9
Eating disorders	0.8	4.5	1.6
Disorders of childhood & adolescence	2.5	9.8	16.2
Suicide	2.5	4.2	1.7
Total	100	100	100

¹ Note: Percentages are based only on the disorders included in this table.

1.1.e Distribution of mental health research relative to disability burden

The World Health Organization (WHO) developed the use of DALYs, or Disability Adjusted Life Years as a means of measuring the health impact of different diseases. Relative to disability burden, anxiety and depression are relatively underfunded (Attachment 5).

Table 2: Comparison of the distribution of research with the distribution of disease burden.

CATEGORY OF MENTAL DISORDER	% OF BURDEN (DALYS) ¹	% OF PUBLISHED RESEARCH	% OF COMPETITIVE GRANT FUNDING
Affective disorders	23.1	16.7	15.7
Substance use disorders	16.6	28.8	30.0
Anxiety disorders	15.8	16.3	9.7
Childhood disorders	3.9	2.4	2.5
Schizophrenia ²	3.7	12.1	10.0
Borderline personality disorder	3.4	.0	0.6
Eating disorders	2.4	4.5	1.8
Dementia	18.6	8.9	15.7
Suicide & self-inflicted injury	11.7	4.2	1.9
Mental retardation	.8	6.1	12.1
Total	100	100	100

¹ Note: Percentages are based only on the disorders included in this table.

² Unspecified psychosis has been included here because the research on psychosis was predominantly about schizophrenia.

1.1.f Distribution of mental health research relative to settings of research

More research is carried out in specialist settings (67%) than in primary care or in the community (10%). There is little research on mental health services and how to improve them (Attachment 5). In 2002, the Centre for Mental Health Research established the first Consumer Research Unit in Australia in an effort to incorporate consumer participation in mental health research. It has been apparent that stakeholder, consumer and carers' perceptions of research differ from those of researchers and granting bodies. The former group have greater interest in prevention, health services and an emphasis on early intervention. Greater resources will need to be applied to this field if it is to be successful.

1.1.g Workforce issues

The mental health research workforce is small. Of the 286 NHMRC Research Fellows in Australia in 2005, only 8 (or 3%) are mental health specialists. This contrasts with 30% in cancer diseases and public health, and 67% in the biological sciences. NHMRC Research Fellowships are prestigious fellowships awarded to the best medical researchers (see Attachment 6). There are no specific public health training programs in mental health. Nor is there a scheme to support the employment of lay or academic consumer researchers (the latter are qualified academics who have personally experienced a mental disorder).

1.2 Adequacy of funding for mental health research

1.2.a Funding relative to other health sectors

As noted above using figures from the Access Economics Report *Exceptional Returns: the value of investing in Health R&D in Australia*, in 2000-2001, around 3% of total expenditure was spent on mental health, compared to 9% on cancer and 8% on pharmaceutical treatments. Using data from our review of priorities in mental health in 2001 (Attachment 5), 8.9% of NHMRC funds were spent on mental health. The 8.9% of NHMRC funds spent on mental health is small when compared to the 19.1% contribution of mental disorders to disease burden in Australia.

1.2.b Funding on training relative to other health sectors

Compared to other sectors, little money is spent on public health training focusing on mental health. The Public Health Education and Research Program (PHERP) is an Australian Government initiative that funds public health research. During the most recent funding phase, the Government provided \$45 million in funding over 5 years (2001-2005) to various public health research bodies, including \$37 million of core curriculum funding. PHERP funding is distributed across five State-based Centres of Public Health. However, none of these Centres of Public Health undertake or fund research or training in mental health (see Attachment 7).

1.2.c Funding on Centres of Excellence or CRCs

Unlike other research sectors, the Australian Government does not support Centres of Excellence in mental health. The one exception is the Post Traumatic Stress Disorder Centre in Melbourne, which receives funding from the Department of Veterans Affairs². This contrasts with other areas of medical research in Australia where national centres have been established at times of need. An example of a Centre that has been established in response to national need is the National Centre in HIV Epidemiology and Clinical Research. There are a number of Co-Operative Research Centres for Medical Science and Technology.³ Although researchers in mental health are eligible to apply for CRC support, there are no CRCs that currently address mental health outcomes. This may be because previous mental health applications are of poor quality, or that there is a critical shortage of individuals working in what is a highly important research area.

1.2.d Funding within mental health

As can be seen in the Tables presented above, some research areas in mental health receive more funding than others. According to research undertaken in 2001, the most active research area in mental health is substance abuse disorders (25% of grant funding) with the next most active research areas being affective disorders (13%), anxiety disorders (8%), childhood conditions (15%) and dementia (13%). By contrast, anxiety disorders have the highest prevalence, affective disorders contribute the highest disease burden, and dementia has the highest health care costs (Attachment 5). There is a clear discrepancy between the impact of disorders and the research funds spent on them.

² The National Drug and Alcohol Research Centre is also funded by the Australian Government. However, its specific mission is to examine drug and alcohol problems not mental health problems such as depression, anxiety and schizophrenia.

³ CRC for Aboriginal Health; CRC for Asthma; CRC for Cellular Growth Factors; CRC for Chronic Inflammatory Diseases; CRC for Cochlear Implant and Hearing Aid Innovation; CRC for Diagnostics; CRC for Discovery of Genes for Common Human Diseases; CRC for Oral Health Science; CRC for Vaccine Technology; The Vision CRC.

1.2.e Private funding

Expenditure on health R&D is supported by business (25% of all funds expended) and other sources (13%). Mental health research is not funded by any national foundation, such as those that exist for cancer and heart disease (The Heart Foundation, The Cancer Research Foundation). Although it is impossible to judge the amount of private expenditure that may go into mental health, the absence of central focus for philanthropy represents a lost opportunity.

1.3 The extent to which best practice is disseminated

A range of strategies have been put in place to distribute best practice guidelines in mental health (based on scientific research outcomes) to general practitioners and psychiatrists. A number of clinical practice guidelines are distributed by the Australian and New Zealand College of Psychiatrists, but despite these initiatives clinical practice guidelines do not exist for social phobia and other high frequency mental health disorders. The Australian guidelines for a number of disorders depart from international recommendations.

There is very little coordinated effort expended in the provision of best practice guidance to those directly affected by mental health problems, or to the families and carers who support them. A review of the quality of high health information available to consumers on the World Wide Web reported that the best information was disseminated by two university departments (ANU and UNSW), *beyondblue* and by a private health service (Infrapsych). The Australian Government does not always employ the best quality information on its own sites or those it funds. For example, at the time of this review, Healthinsite disseminated health information provided by mental health sites that did not match the quality of those reported above. Moreover, websites directly supported by the Australian Government, such as REACHOUT! did not disseminate high quality mental health information (see Griffiths and Christensen, 2002). A second issue concerns the extent to which information found on various websites is actively sought by consumers. A measure of the popularity of a site is Google's page rank index. Below is an indication of the popularity of a number of Australian web sites. Clearly some websites are both popular and of high quality (i.e. ANU's BluePages).

Table 3: Top ranking websites in Australia for mental health organisations.

ORGANISATION	PAGE RANK
www.moodgym.anu.edu.au	6
www.blackdoginstitute.org.au	5
www.beyondblue.org.au	5
www.bluepages.anu.edu.au	5
http://www.ranzcp.org	5
http://www.psychology.org.au	5
http://www.sane.org	5
www.lifeline.org.au	5
www.kidshelp.com.au	5
http://www.infrapsych.com/root/1033/default.htm	4
www.orygen.org	4
www.depressionnet.com.au	3

Recommendations

Australia's expertise in mental health research needs to be supported and fostered to deliver to citizens benefits comparable to those enjoyed in countries such as New Zealand and Canada. Given the cost of mental health in terms of health care expenditure and disease burden, the annual rate of expenditure to mental health research from both NHMRC and other sources needs to be increased. It is clear that 3.3% of total health R&D funding is inadequate given the crisis faced in mental health research. More funding needs to be directed to both projects/programs and workforce capacity building, with priority given to training, development and creation of career positions for mental health researchers, including consumer researchers.

Research funding should be directed to research topics that are priorities in terms of health cost and disease burden. Dementia research, research into anxiety and depression, research outside of clinical settings, consumer driven research, and research into early intervention and prevention are priorities. Research into the mental health of older Australians is also an important and urgent priority given the ageing of the Australian population and other findings from Intergeneration Report:

http://www.budget.gov.au/2002-03/bp5/html/01_BP5Prelim.html

RECOMMENDATION 1: That a national Centre for Mental Health Research be established.

There would be great benefit to Australia in establishing a National Centre for Mental Health Research. The role of such a Centre would be to: strengthen research in the mental health sector; provide post graduate training (PhD and Masters) in public mental health; focus on priorities in the mental health sector such as dementia, anxiety and depression; increase the workforce of mental health researchers; provide expertise in e-health and new health care models (see (p) below); raise the profile of mental health research; provide the opportunity for Australia to lead in areas where they excel; deliver on Australian mental health policy; and provide a location for major mental health data sets.

Such a Centre could be located at the ANU developed from the existing base of the Centre for Mental Health Research (CMHR). The ANU Centre for Mental Health Research is the only centre in Australia providing mental health research from a public health perspective, with a Consumer Research Unit, and which focuses on priority areas of dementia, anxiety and depression. It currently has the largest group of NHMRC Fellows of any research institute in Australia. It also has an international reputation in areas of mental health, ageing and cognition.

However, CMHR's funding situation is tenuous. It exists entirely on competitive and other grants and the resulting infrastructure funds this generates. All of the academics at CMHR are employed on short term contracts. More importantly, CMHR's current NHMRC Program Grant, which constitutes its primary source of funding is due to expire in 2006. There is a therefore a significant risk that the CMHR will be unable to continue after this date due to lack of funding and Australia will lose a leading mental health research organisation that has been described by an overseas expert as 'an Australian national treasure.'⁴

The Centre and the ANU form a sound base from which to develop a national centre. It collaborates with, and is located in close physical proximity to the National Centre for Epidemiology and Population Health. It is also located in close proximity to Commonwealth policy makers and the Mental Health Council of Australia, the peak mental health body for the mental health sector, with which it already enjoys close ties.

⁴ Sir David Goldberg, eminent British mental health researcher.

A model for the development of such a Centre is the Government's response to the HIV/AIDS strategy, which is regarded as the most successful and innovative public health responses in the world. In the late 1980's, the government recognised the need for a prompt comprehensive plan to prevent an anticipated HIV/AIDS epidemic. Coordinated effort on a number of fronts (e.g. research, public education and treatment) was harnessed and the government took a strong leadership role in providing upfront funding. In particular, the Commonwealth provides funding to a number of national research centres, including the National Centre in HIV Epidemiology and Clinical Research, and the National Centre in HIV Social Research, both based at the University of NSW.

RECOMMENDATION 2: The development of high quality health information is a research function that should be supported by the Australian Government.

High quality health information is expensive to develop because it involves research and critical appraisal by experts. Expertise and research that delivers such material should be funded, particularly as there is evidence that such information can change attitudes and reduce mental health problems (see Jorm et al. 2004; Christensen, Griffiths and Jorm, 2004). The Australian Government should support the work of all institutions that produce high quality health information for consumers. The Government should disseminate that information. At present the costs of **developing and providing** high quality information **primarily** rests with the university sector.

RECOMMENDATION 3: Further funding for training in mental health research.

Further funding for training in mental health research is required. While the establishment of a National Centre would partially address this issue, training must also be increased throughout Australia.

(p) THE POTENTIAL FOR NEW MODES OF DELIVERY OF MENTAL HEALTH CARE, INCLUDING E-TECHNOLOGY.

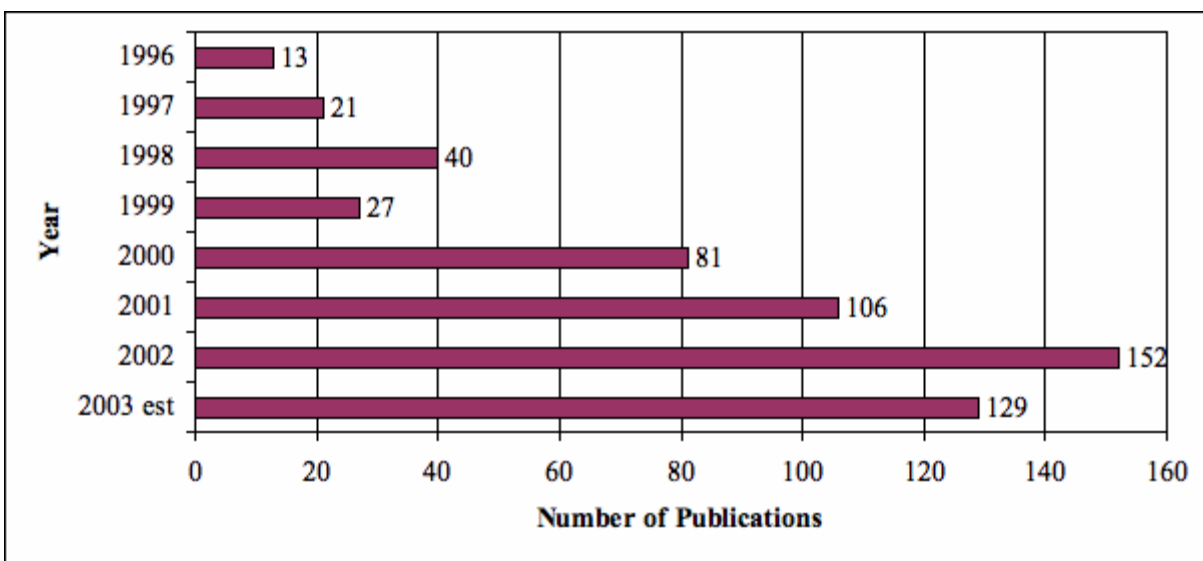
2.1 Australia's e-health strategy and the new health technologies

Australia's e-health strategy involves developing a coordinated national approach to supporting clinical care, using information to build an improved health care system, and empowering consumer and communities for better health (Health Online, 2001). Health Online projects to date have focused primarily on facilitating and improving the function of existing health care systems. These projects have included the development of tools for doctors, and systems for improving the flow of information across the health sector; the facilitation of the interoperability between health systems; management of medications; and methods for preserving privacy in a secure environment. Although these strategies will help in delivering better health outcomes for consumers, Australia's e-health strategy has yet to consider new trends and new health delivery systems which are emerging, and which are expected to transform the nature of health care in Australia and other OCED countries.

2.2 The growth of e-technologies in mental health

It is predicted that health systems in developed countries will change radically over the next ten years, with self help and self responsibility for health forming a new tier of the health system (see Coiera, 2004). The Internet is predicted to bring about radical change in medicine and health care, with experts rating the Internet 7.8 on a scale of 0 (no change in healthcare) to 10 (radical change). Particularly in the area of mental health, it is readily apparent that 'medicine on the Internet' – eHealth – is already a significant factor in the lives of many consumers. As Forkner-Dunn (2003) has noted: "The eHealth care train has not only left the station but is rapidly moving down the track carrying tens of millions of e-patients and many possibilities for transforming patient self-management, improving health outcomes, and enhancing the patient-clinician relationship."

Figure 1: Growth of e-technologies in mental health as indicated by numbers of academic publications



Source: Wantland et al. (2004)

The above graph (Figure 1) demonstrates the growth in the e-health. It maps the number of publications that use the key term 'web therapies' as a function of year (Wantland et al., 2004). Over the past few years there has been a rapid escalation of online services for mental health. The use of these services and web applications is largely unregulated and self-directed, with most consumers accessing the sites directly and not via mainstream therapy or medical services. Online counselling is common: there are web applications for depression, anxiety, panic and eating disorders.

2.3 Australia has world leaders of health technologies in mental health

Australia has led the world in the development of e-technologies. For example, Australians have

- (i) developed and evaluated innovative online interactive mental health interventions in depression (moodgym.anu.edu.au; bluepages.anu.edu.au) (ANU); anxiety and panic (UQ; Monash; Infrapsych, WA),
- (ii) developed cutting edge online research infrastructure for conducting distal interventions and enabling networking between consumers and researchers (ANU),
- (iii) conducted studies of consumer informatics and web-site quality (ANU),
- (iv) collaborated in the development of search engine technology for identifying high quality depression websites (ANU; CSIRO),
- (v) contributed to national policy (ANU; UNSW: See Attachment 8), and
- (vi) contributed to a range of CD roms for delivering health information and treatment via personal computers (UNSW; University of Newcastle).

These technologies are consumer focussed and arisen from the needs of consumers to gain access to mental health services.

2.4 Advantages of e-technologies

2.4a Access and availability

As many as 60% of individuals with mental health problems do not seek help from the medical profession. Websites have unique potential to provide direct evidence based information and education for consumers of mental health services and their carers.

2.4.b Provision of assistance to those who would not normally seek assistance from medical system

These sites provide information and assistance to individuals who for reasons of stigma or lack of available health services seek information. Moreover, in the new environment of self-help and self management, these forms of assistances will grow exponentially.

2.4.c Provision of mental health therapies not available to those in remote areas

Web applications which are automated, such as MoodGYM provide effective online treatment in the form of cognitive behaviour therapy to those without access to affordable therapy. Chat groups and online bulletin boards provide support and assistance and information sharing. Web therapy and telepsychiatry are also available privately, or through medical benefits. Interventions with online treatment and counsellor support are also available at present – Panic Online, although the service is

not directly available to the public. The interventions developed at the ANU have been tested through rigorous randomised controlled trials.

2.4.d A consumer focus

E-technologies provide direct services to consumers who are then empowered to manage their own health more effectively.

2.4.e Capacity to assist in the provision of continuity of care

A major problem in the delivery of health care systems to consumers is the lack of continuity of care. Technology can assist in the provision of continuity of care. Mental health ‘systems’ provide poor continuity over time, so people are provided with no integrated management plan for what is a recurring and often chronic condition. There is poor continuity across service boundaries, so there is a lack of inter-sectoral collaboration: for example, relationships between GPs and psychiatrists may be poor for reasons that are based on differences in values and approaches, but also because of issues of confidentiality and lack of standardization. There is also poor continuity across settings with lack of support for recovery, and no coordination between support services such as housing, education and employment. Additionally, there is lack of support for carers in the home setting who take on the burden of responsibility for the person with a mental illness. In Australia, Infrapsych (a West Australian IT/mental health company) is currently demonstrating the feasibility of providing technological solutions to these problems. In conjunction with educators and psychiatrists, these systems can provide ‘automated case management’, with tracking and feedback to the patient, the family and the medical profession.

2.4.f Cost effectiveness

Recent models demonstrate the cost effectiveness of web-based systems. The model below (Figure 2) illustrates the cost of psychologist delivered CBT (P-CBT), GP delivered drug therapy (GP-Drug) and the automated web application, MoodGYM CBT, (M-CBT). The cost of M-CBT decelerates with high volume of users, so that it becomes highly cost effective relative to other treatments after approximately 700 patients (see Attachment 10).

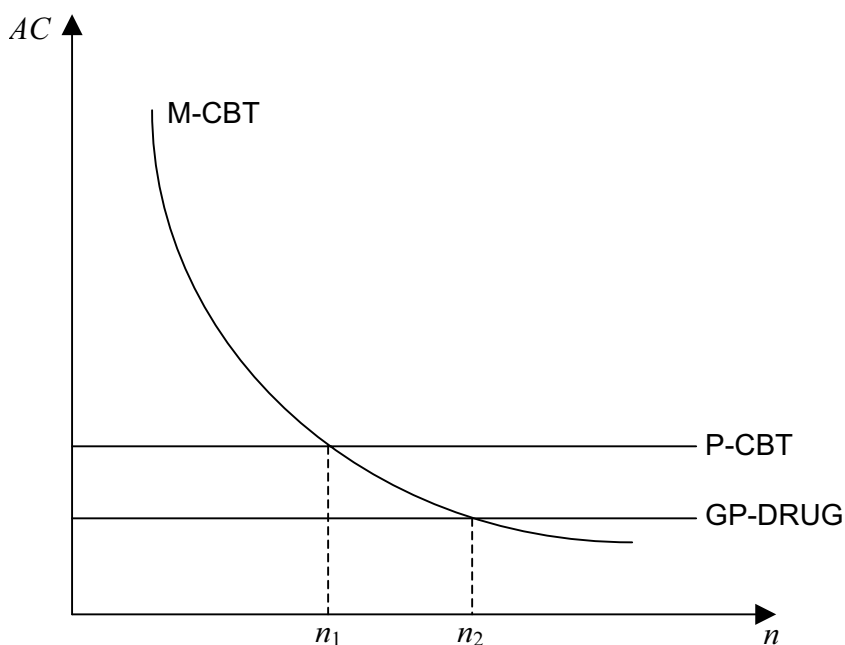


Figure 2: A comparison of the costs associated with treatments delivered by psychologists, general practitioners and MoodGYM.

2.4.g Capacity to capture young Australians who need education about mental health problems.

As noted by Viner (2005), adolescence is a critical period for engaging the population in health. Self management behaviour is also established at this time. Viner argues that it is time to “direct engagement of young people through information technology”. We believe that there is great opportunity to engage youth in health problems through entertainment, games or guessing competitions using real or ‘fabricated’ media personalities.

2.4.h Summary

These new ways of delivering mental health services are highly promising in that they are consistent with trends in the delivery of health services for the next 10 years, are cost effective, provide access for those with unmet need, are able to deliver continuity of care in a mental health care system that lacks co-ordination, are highly consumer focused, and have a high level of consumer acceptability. Possibly more importantly, if directed at a young audience, e-technology is likely to capture a space that will become more important for the new generation of health care users.

2.5 An example of a successful e-technology application in mental health

MoodGYM is an interactive software program that delivers cognitive behaviour therapy, which is an evidence-based treatment for depression (Attachment 9). Research undertaken at our Centre has demonstrated that MoodGYM, when compared to a placebo condition, is significantly more effective in reducing depression and anxiety symptoms in the community (Christensen, Griffiths & Jorm, 2004). More recent analyses of online users suggest that the effects of MoodGYM are similar to those achieved in our randomized controlled trials (Christensen, Griffiths & Jorm, 2004). Moreover, the degree of improvement appears to be of the same magnitude as that achieved in modern evidence-based face-to-face psychotherapy (CBT). We have also established the cost effectiveness of MoodGYM relative to antidepressants and face-to-face treatment in depression (see Attachment 10).

Although not formally marketed, MoodGYM has uptake of 18,000 visitors per month from 62 countries around the world. with 40% of users under 30 years of age. The current database consists of over 80,000 registrants: <http://moodgym.anu.edu.au/>. The site is currently funded by the ANU, and has not received any Australian Government financial support.

Recommendations

RECOMMENDATION 4: A centre for research into mental health informatics

The establishment of a consumer-focused eHealth research and policy centre, with primary emphasis on mental health but also extending to other chronic illnesses, is clearly indicated. This centre would investigate the use of Internet technology to provide high quality health information and evidence-based prevention and treatment programs to the Australian public. The establishment of this centre at CMHR at the ANU would build on the existing experience and success of researchers there. The group already has strong links with other relevant organizations, notably the CSIRO.

An e-health & consumer informatics program at ANU would:

- i) focus on research, development, evaluation and dissemination of evidence-based consumer tools;
- ii) be both consumer and public health focused;
- iii) be used directly by the public, and also as adjunct to usual procedures in general practice;
- iv) evaluate developed technologies in rural and remote Australia;
- v) incorporate content and database management tools that provide infrastructure for both research /evaluation activities and site maintenance.

The program would include the development of tools to:

- i) assist consumers to identify high quality website (evidence-based) information. This may also involve the development of search engine technology for the selective retrieval of high quality information on-line;
- ii) allow individuals to screen for mental health and other health conditions on-line;
- iii) encourage prevention and motivate help seeking or early treatment. Tools will include online risk assessment instruments to be used by the general public, and which are developed from mathematical models of epidemiological data;
- iv) destigmatise health conditions where barriers to help seeking are predominant;
- v) directly impact on health behaviours, such as physical activity web interventions, cognitive behaviour therapy and interpersonal therapy web interventions;
- vi) assist in the management of chronic disease (e.g., chronic disease management systems and self management education).

The program would include the maintenance of mental health services including:

- i) high quality public health information Internet sites
- ii) best practice standards for delivering mental health programs on the Internet

RECOMMENDATION 5: A funding model for e-health applications

Currently, there is no national strategic plan to drive the development of e solutions in mental health, especially to a young adolescent market. If there is no Medicare rebate or subscription available for the use of effective automated solutions, then industry innovation will cease, and Australia will lag behind development in both the UK and USA. Currently Australia's most successful e-tools have been developed through Universities but these cannot by themselves sustain the costs that are directly attributable to the success and popularity of these programs.

RECOMMENDATION 6: Investigations of the ethics and funding of human interaction over the web.

The policy document produced by the Centre for Mental Health Research, *e-mental Health in Australia: Implications of Internet and Related Technologies* makes a number of suggestions about how to create standards for ethical web interactions (see Attachment 11).

RECOMMENDATION 7: The development of a youth portal to offer a holistic online mental health clinic.

The ANU, in partnership with CSIRO, has developed proposals for such innovative and leading applications. Australia, like the UK, could become a leader in the development of new health systems. We would like to establish a young persons virtual clinic that would use the Internet to create a virtual 'home' for youth, with networks to health providers. Health provision would be available in stepped levels: access to information and prevention; recognition of the need for prevention or early intervention; self help and responsibility including the use of automated self help packages; early treatment and intervention through links to web counselling sites, and to Lifeline, and a final level of help through the provision of online tele-psychiatry, or direct referral to a face to face consultation with a health professional.

The advantages such a site would include:

- **Greater youth access to health information.** The site would be linked to a major health portal such as NineMSN. Existing evidence based sites such as MoodGYM and BluePages (both developed by the ANU), could be integrated 'seamlessly' into the site. New developments that bring together much of Australia's talent in developing Internet programs in mental health could be harnessed.
- **The rapid advancement of the new health system.** The design of this site is commensurate with projections as to how health systems will operate in 2020 (See *British Medical Journal*, May 2004). Why not accelerate these predicted health care system changes to suit youth today?
- **Availability of resources.** The budget for such a site might be derived from funds currently earmarked for e-health developments in Australia. There needs to be clear recognition by policy makers and funders that the advantages of e-health technologies are not limited to e-records in existing clinical systems, but extend to education, prevention and self care options for the general public.
- **Availability of expertise.** Australia has an international reputation for the development of e-health solutions in mental health.

RECOMMENDATION 8: The development of e-based chronic disease management systems for mental health

The development of 'virtual clinics' will be a good investment for the future. The UK is spear-heading these developments with the introduction of the e-health space for consumers.

(h) THE ROLE OF PRIMARY HEALTH CARE IN PROMOTION, PREVENTION, EARLY DETECTION AND CHRONIC CARE MANAGEMENT.

3.1 Introduction

Although many people have their general practitioner as the primary or only provider of mental health care, over 60% of the population with mental health problems do not seek care from any health professional (Andrews & Henderson, 2000). A recent report examining internet communities worldwide found that 49% of users who met criteria for major depression were not receiving any help, and that 35% had no contact with the medical or health services in the preceding year (Powell, McCarthy & Eysenbach, 2003). There is also evidence that current services avert only a small amount of the burden of affective disorders (see Andrews and Wilkinson, 2002). Because of this high level of unmet need, a multi-modal view of the delivery of mental health services is required if all Australians in need of services are to be helped, and the costs resulting from mental disorders averted. It is also important to recognize that any strategy which focuses solely on the recruitment of general practitioners to assist in the early detection or management of mental health problems is short-sighted, given the limited workforce of doctors available and the limitations on funding available to support these services even if they could be offered.

We also strongly support the role of a range of agencies in the development of prevention strategies and chronic care management. Most chronic care management involves families and not for profit organisations. These community resources such as Lifeline Australia need to be recognized and resourced.

Below, we outline a number of these important factors in the delivery of early intervention and prevention to the community.

3.2 Early detection often involves family members, not just the individual with symptoms.

Often the first identification of symptoms or early onset of a disorder arises from the observations and response within the family of the sufferer. Families and carers are often crucially involved in the management of chronic disease. Consequently, early detection methods should recognize the central role and involvement of carers. Thereafter the carers will need information and support for the management of these conditions in family members.

3.3 The focus on general practice is too narrow and a multimodal approach is required

Following from the above, it is clear that an early detection strategy really needs to be multi-modal, targeting at individual, group and community levels. Below are some ways in which this has been or is being achieved in Australia.

3.4 Workplace initiatives

Workplaces are an area where early identification and prompt intervention may be appropriate. There is evidence that Mental Health First Aid Programs increase both mental health literacy and also the likelihood that appropriate interventions occur (Kitchener & Jorm, 2002; Kitchener & Jorm, 2004).

3.5 Schools

Schools are an important setting for screening and early intervention. Studies indicate that cognitive behaviour therapy, when delivered in school classrooms, can prevent anxiety, affective and substance-abuse disorders. It is clear that early intervention with those with some symptoms can reduce the incidence of depression by almost 50% at one-year follow-up (see Andrews and Wilkinson, 2002).

3.6 Lifeline and Crisis Help Lines, Kids Help Line, etc.

Non Government Organisations (NGOs) and crisis centres are also important for screening and early intervention. A recent paper presented by Sven Silbern at The Mental Health Services Conference “Suicide, drugs/alcohol/mental health problems and prevention” reported that men with particularly severe depression problems were assisted as much by counsellors and by crisis intervention/support treatments as by GPs. There is evidence that many people with depression are managed early and (later) through their illness by Lifeline counsellors (Christensen, Hocking, & Smith, 2004). Lifeline, SANE and other NGOs and consumer groups are settings that provide the basis for the early detection and prompt referral and treatment.

3.7 Families

Parenting programs such as the Triple P program at the University of Queensland also provide opportunities for screening and assistance.

3.8 Public health education campaigns like *beyondblue*

Health promotion campaigns are capable of increasing mental health literacy and influencing attitudes to help seeking. For example, the recognition of mental health problems in the community has improved considerably over the last 10 years, and there is evidence that general education campaigns such as *beyondblue* may be causal in producing improvement in the understanding, recognition and risk factors for depression (Jorm, Christensen, & Griffiths, in press; Jorm, Christensen, & Griffiths, 2005). There is evidence that better knowledge leads to improved views of the value of help seeking. However, more evidence is required to demonstrate that the increased value of help seeking will lead to *actual* help seeking at the population level.

3.9 Internet based resources

The Internet provides opportunities for early detection through online screening tests, by delivering individuals to more formal health care (stepped care), disseminating information about chronic disease, and the providing early treatment. interest in the use of the Internet is widespread with the following areas of advantage being identified.

3.9.a Identification of disorders at an early stage

The Internet can be used to help consumers identify disorders at an early stage. Houston et al. (2001) used a screening questionnaire for symptoms of depression using the Internet. The authors concluded that: “The Internet provides a continuously available, inexpensive, easily maintained platform to anonymously screen a large number of individuals from a broad geographic area. Older adults and minorities may have less access or visit screening sites less frequently than other populations” but

uptake of the Internet is increasing in this age group. The use of electronic environments, such as *Ninemsn*, may be useful for screening purposes for adolescent groups, although this has not yet been evaluated.

3.9.b An environment to encourage referral to more formal medical services

Internet communities may promote help seeking. A recent report examining Internet communities worldwide reported that an important factor in deciding to seek medical help was exposure to the Internet community (Powell, McCarthy, & Eysenbach, 2003).

3.9.c The potential provision of risk factor information online

The use of online 'risk profile' assessments would be another highly popular way of distributing health information that would bypass the "bottle neck" of general practice, and indeed serve to make general practice more efficient.

3.9.d The provision of early treatment through psychoeducation and treatment

The Internet offers an opportunity to deliver tailored prevention interventions such as those based on cognitive behavioural therapy (CBT) to a large audience, cost-effectively, while preserving intervention fidelity and anonymity. We have established that online psycho-education (BluePages) and CBT training (MoodGYM) can effectively treat depression (for participants with mild through to moderate symptoms in a RCT). We have also established that spontaneous users of these sites report similar outcomes (Christensen, Griffiths, Korten et al., 2004).

Recommendations

RECOMMENDATION 9: A multimodal approach be taken to the delivery of early intervention, prevention and chronic disease management

A multimodal approach should be taken to the delivery of early intervention, prevention and chronic disease management. In this submission we have demonstrated the potential of emerging technology to meet the mental health needs of Australians. E-Health approaches offer a vector of opportunity by which individuals who might not otherwise do so may have their need for assistance met. It must be recognised that even within the field of e-health, different approaches will be required to meet all needs. More importantly, service delivery needs to occur across boundaries: there will be many occasions when health care professionals will need to takeover care of an individual from that provided by e-health means. Similarly, there will be occasions where referral by health professionals of persons in their care to e-health sites and facilities will be the most appropriate course of action.

ATTACHMENT 10: Research Paper Abstract: Cost-effectiveness of MoodGYM

A comparison of the costs associated with treatments delivered by psychologists, general practitioners and MoodGYM.

These figures were prepared by Dr Jim Butler, ANU National Centre for Epidemiology and Public Health.

The average cost per patient for Psychologist-CBT is \$1,830 and for GP-DRUG treatment is \$873. The development cost of MoodGYM was \$512,979 and the annual maintenance cost is \$47,810. Assuming an effective life for MoodGYM of three years, the break-even number of clients when compared with P-CBT is 359 and with GP-DRUG is 753. Actual numbers of clients completing all modules on the MoodGYM site (709 from 1 Sep 03 to 30 Nov 04) indicate that both these break-even levels will be exceeded, so the average cost per client is lower than for the comparator therapies. The efficacy of M-CBT, as demonstrated in an RCT of the program, is comparable with that of P-CBT and GP-DRUG. This cost-effectiveness analysis therefore suggests that M-CBT is dominant – it is less costly and at least equally effective as the two comparator therapies.

Acknowledgements

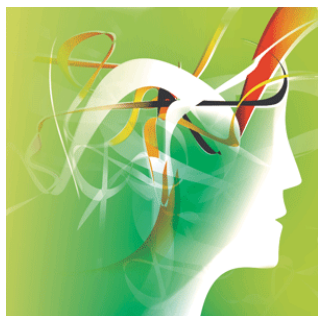
Professor Helen Christensen, Dr Kathy Griffiths, Professor Andrew Mackinnon, Ms Louise Farrer and Ms Kylie Brittliffe were involved in the preparation of this report.

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ATTACHMENT 1: Information about the ANU Centre for Mental Health Research



The Centre for Mental Health Research (CMHR) has a unique place in mental health research organisations in Australia, in that it undertakes research from a public health perspective. There are four areas of specialty: e-mental health, mental health in ageing, consumer engagement in mental health research, and welfare reform.

The Centre provides evidence-based programs and extensive doctoral and post-doctoral research training in public mental health and ageing. The Centre also contributes to government policy and research committees and councils, and engages in considerable outreach work in mental health through our Consumer Research Unit.

The Centre is funded from competitive research funding, primarily through the National Health and Medical Research Council. It also attracts research funding from other sources including the Australian Government for specific projects. All researchers including the Director and Deputy Director are employed on fixed term contracts tied to the attraction of competitive funds.

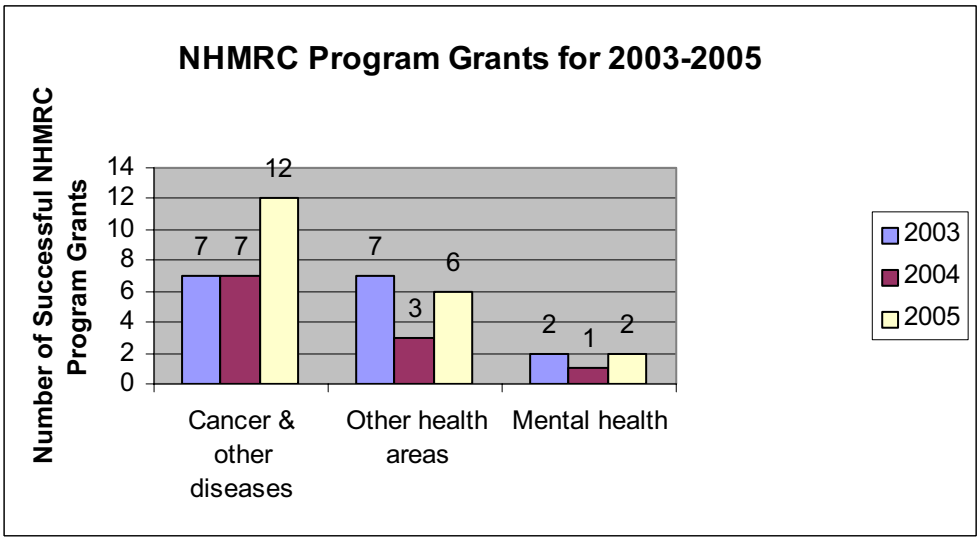
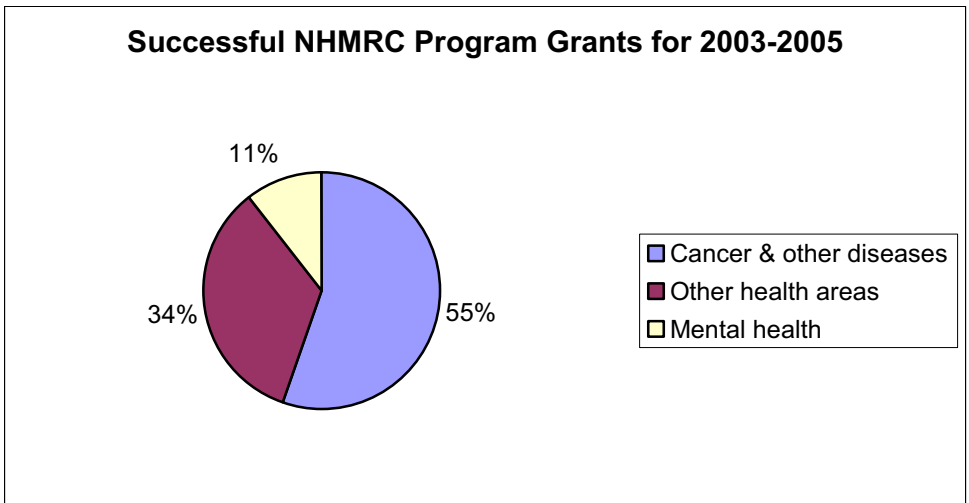
The work of the Centre is supported by AFFiRM: The Australian Foundation for Mental Health Research, which operates as an arm of the ANU Endowment within the ANU, and is currently chaired by The Hon. Margaret Reid, AO. The Foundation has supported a PhD scholarship for mental health research and engages in fundraising activities in the Canberra community, including Art for Answers and Gourmet in the Gardens.



ATTACHMENT 2: Research Centres affiliated with the Australasian Society for Psychiatric Research

Australian Transcultural Mental Health Network (http://www.atmhn.unimelb.edu.au)
Centre for Clinical Research in Neuropsychiatry (http://www.ccrn.uwa.edu.au)
Centre for Mental Health Research (http://www.anu.edu.au/cmhr)
Centre for Mental Health Studies (Newcastle, NSW) (http://www.newcastle.edu.au/centre/cmhs/)
Centre for Palliative Care (http://www.pallcare.unimelb.edu.au)
Centre for Rural and Remote Mental Health (Orange, NSW) (http://www.crrmh.com.au/)
Clinical Research Unit for Anxiety Disorders (http://www.crufad.unsw.edu.au)
Cognitive Neurosciences Laboratory at Flinders University: (http://som.flinders.edu.au/FUSA/NEUROSCIENCE/cognitive.htm)
Mental Health Research Institute of Victoria (http://www.mhri.edu.au)
Mental Health Council of Australia (MHCA) (http://www.mhca.com.au)
Mood Disorders Unit (http://www.mdu.unsw.edu.au)
Monash University, Department of Psychological Medicine (http://www.med.monash.edu.au/psychmed)
Neuropsychiatric Institute, Prince of Wales Hospital (http://www.med.unsw.edu.au/npi)
Neuroscience Institute of Schizophrenia and Allied Disorders (http://www.nisad.org.au)
Brain Sciences Institute http://www.scan.swin.edu.au/
Queensland Centre for Schizophrenia Research (http://www.qcsr.uq.edu.au)
University of Adelaide (www.psychiatry.adelaide.edu.au)
University of Auckland, Department of Psychiatry and Behavioural Science (http://www.auckland.ac.nz/pbsc/mpshome.html)
University of Melbourne, Department of Psychiatry (http://www.psychiatry.unimelb.edu.au)
University of Melbourne, Department of Psychology (http://www.psych.unimelb.edu.au/index.html)
University of New South Wales, School of Psychiatry (http://psych.med.unsw.edu.au/)
University of Qld, Department of Psychiatry (http://www.psychiatry.uq.edu.au)
University of Sydney, Department of Psychological Medicine (http://www.usyd.edu.au/su/psych)
University of WA, School of Psychiatry and Clinical Neurosciences (http://www.psychiatry.uwa.edu.au/)
University of WA, School of Psychology (http://www.psychology.uwa.edu.au/)

ATTACHMENT 3: A comparison of the number of successful NHMRC Program Grants allocated to mental health and other health areas



ATTACHMENT 4: Research Paper

Hickie IB, Christensen H and Davenport TA, Luscombe GM. Can we track the impact of Australian mental health research? *Australian and New Zealand Journal of Psychiatry* (in press).

Can we track the impact of Australian mental health research?

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ABSTRACT

Objective: Arguments are being made to increase research and development funding for mental health research in Australia. Consequently the methods used to measure the results of increased investment require review. This study aimed to describe the status of Australian mental health research and to propose potential methods for tracking changes in research output. Specifically, we describe the research output of nations, Australian states, Australian and New Zealand institutions and Australian and New Zealand researchers using citation rates.

Method: Information on research output was sourced from two international databases (Institute for Scientific Information [ISI] Essential Science IndicatorsSM and ISI Web of Science®), and the ISI list of Highly Cited ResearchersTM.

Results: In an international setting, Australia does not perform as well as comparable countries such as New Zealand or Canada in terms of research output. Within Australia, the scientific performance of institutions apparently relates to the strength of some individual researchers or consolidated research groups. Highly cited papers are evident in the fields of syndrome definition, epidemiology and epidemiological methods, cognitive science and prognostic or longitudinal studies.

Conclusions: Australian researchers need to consider the success of New Zealand and Canadian researchers, particularly given the relatively low investment in health and medical research in New Zealand. Although citation analyses are fraught with difficulties they can be effectively complemented by other measures of responsiveness to clinical or population needs and community expectations and should be conducted regularly and independently to monitor the status of Australian mental health research.

Keywords: research output, research success, citations, publications, mental health

INTRODUCTION

"The Australian public strongly supports health and medical research and believes in its benefits to quality of life. Health and medical research findings are amongst the most heavily covered issues in the Australian media, and charitable community support for health and medical research is widespread. Yet, public investment in health and medical research is low by OECD standards. Other developed nations are rapidly expanding their investment in health and medical research to gain the anticipated health, health care and economic benefits." [1, p.30]

There is intense community, government and professional interest in the current state of Australian mental health research. This is reflected not only in recent government [2], community [3, 4, 5] and scientific reports [6] but also in the priority settings of the most recent National Mental Health Plan [7]. For the first time, innovation, research and sustainability are described as critical elements of our National Mental Health Strategy [7]. The most recent report of the Mental Health Council of Australia concludes that if we are to reduce the ongoing costs of mental disorders in Australia we must develop new preventative, early intervention and sustained treatment strategies [8].

In 2003, a case was put to the Prime Minister's Science, Engineering and Innovation Council that Australia should increase its investment in research in basic and clinical neurosciences [6]. Previously, the case had been put for significant investment in early child development and family support [9] and this has now resulted in a substantial national program [10]. Specifically, the earlier expansion of treatments for depression in primary care in Australia, and the more recent work of *beyondblue: the national depression initiative*, have already produced population-based benefits [11]. On the basis of impressive trial evidence [12], arguments have now been advanced for rapid expansion of e-health based mental health information and intervention services [13].

However, when such arguments for increased funding for research and development are advanced, it is critical that we specify how we will measure potential benefits. Traditional academic markers of research success have included both measurements of inputs (e.g. increased dollar funding from both government and non-government funding sources, increased success at competitive grants through both Australian national and international funding sources) and at least some measurements of outputs (e.g. number of scientific publications, publications in high quality international journals). Until recently, the impact factor of the journal served as a proxy for the likely impact of individual articles.

With regard to these markers of output, the advent of more powerful electronic tracking methodologies has led to development of new capabilities that allow us to measure the direct impact of individual articles. Additionally, one can now trace the impact of individual researchers, groups of researchers, research institutions, or whole countries through counting the citations of published articles. Importantly, citations can be followed over time to give a reasonable indication of changes in national, institutional or individual productivity.

Our goals in this report are to describe some measures of the current status of Australian mental health research and to propose potential methods for tracking changes in research output over the next decade. Specifically, we describe the research output of nations, Australian states, Australian and New Zealand institutions and Australian and New Zealand researchers using citation rates derived from two international databases (Institute for Scientific Information [ISI] Essential Science IndicatorsSM [ESI; 14] and ISI Web of Science® [15]).

METHODS

Research outputs

Citations for countries and institutions were calculated from the ISI ESISM, while performance for particular individuals was examined using: (i) ISI ESISM; (ii) ISI Web of Science®; (iii) ISI Highly Cited ResearchersTM indices; and (iv) further examination of highly cited papers from Web of Science®.

ISI indexes academic literature across many scientific disciplines. This indexation forms the basis of the ESISM and Web of Science® databases.

ISI ESISM

The ISI ESISM database provides performance statistics for countries (top 50%; by field of research), institutions (top 1%; based on published author affiliations) and individual authors (top 1%). The ESISM database incorporates all ISI databases and ISI-indexed journals. Letters, article corrections and abstracts are omitted and ISI does not include books or book chapters. ESISM data are based on the previous 10 years and the database is updated every two months. Citations are grouped according to area of study. The four ESISM field of research categories included in the current manuscript are: ‘*psychiatry/psychology*’ (which covers 10 topics from applied, diagnosis and treatment, through to social); ‘*clinical medicine*’ (which covers 25 topics from anaesthesiology through general and internal medicine to urology); ‘*neuroscience and behavior*’ (which covers basic and clinical neurology, psychopharmacology, biobehavioural psychology, molecular psychology, cellular and molecular neuroscience, neuronal development, and neuronal function underlying higher cognitive processes); and ‘*social sciences general*’ (which covers 11 topics from communication to public health and administration to social work and social policy) [16].

ISI Highly Cited ResearchersTM

ISI also publishes information on Highly Cited ResearchersTM based on ISI citation databases. In the current manuscript, ‘highly cited researchers’ are amongst the top 250 most cited researchers within a specific research category for the period 1983 to 2002 (the most recent available data).

ISI Web of Science®

The ISI Web of Science® database enables simultaneous searches of three citation indexes: Science (which includes 150 scientific disciplines), Social Sciences (which includes 50 social science disciplines) and Arts and Humanities (which includes 6,800 major science and social science journals). These data describe only the individual citations of authors and citations to specific papers. They provide total citations across all research areas and hence are not restricted to one of the subject areas.

Highly cited papers

All manuscripts identified from the Web of Science® searches for individual authors were collated and ordered by number of citations. Results are presented for Australian and New Zealand authored manuscripts with 100 or more citations.

Comparison of research outputs

These four measures reflect general research output but vary in the exact measure of research output or the time frame over which the output is measured. It is, therefore, likely that these measures will perform differently on an individual basis. The differences in outcome for the citation systems will reflect differences in search strategies, categorisation of research categories and lack of specificity in linking individuals to specific citations. Additionally, the time frame for assessment is different. The ISI uses a 10-year (rolling) time frame for ESISM (e.g. citation rates based on papers published during 1992 to 2002) and a 20-year (rolling) time frame for Highly Cited ResearchersTM. The Web

of Science® database provides current number of citations for publications back to 1980, although other publication time frames can be selected.

Procedure

We first considered data accessed on November 1 2003 from ESISM that covered the period from January 1 1993 to August 30 2003. The top 1,500 most cited authors in the scientist world rankings in the category ‘*psychiatry/psychology*’ were reviewed to identify Australian and New Zealand researchers. This formed the basis of our sample. Authors on this list were contacted to verify their publishing details (including all initials used in publication, and author affiliations) and asked if prominent publishers within the field of psychiatry or psychology in Australia and New Zealand had been inadvertently omitted. With considerable cooperation of the many researchers who were identified in the 2003 ESISM database, we were then able to track the citations of individual researchers within the Web of Science® for the previous decade. We initially asked authors to search the Web of Science database® for the previous decade (1993 to 2003) to collect information on the total number of citations from their publications. As citations vary significantly over time (citation databases are updated weekly), and authors ran searches over a total period of six months, we repeated all Web of Science® searches on May 3 2004. The Highly Cited ResearchersTM database was searched to identify Australian and New Zealand authors in mental health related fields and was accessed at the same time. Data on highly cited papers was extracted from the Web of Science® searches.

Population estimates obtained from the GEOHIVE global statistics website [17] during November 2003 were used to calculate citations per capita. Figures for England and Wales were retrieved from the Office for National Statistics in the United Kingdom [18]. Population estimates for Australian States and Territories were obtained from the Australian Bureau of Statistics demographic figures for December 2003 [19].

RESULTS

Indicators for countries and institutions

For the decade January 1 1994 to June 7 2004, the top 15 countries by citations in the research category ‘*psychiatry/psychology*’ were identified. Australia was ranked number five. For those 15 countries, we then compared standings for citations per paper and citations per capita. New Zealand and Canada advanced in ranking in these comparisons (Table 1).

{Insert Table 1 here}

With the 2003 ESISM country ranking data, we repeated the same exercise for the category ‘*neuroscience and behavior*’. Here there is little difference between Australia and New Zealand, but both countries rank significantly below Canada (Table 2). These rankings increased once citations per paper and citations per capita were considered. Within Australia and New Zealand, we then sought to identify the strengths of various states and academic institutions (Table 3). Here, population distribution and institutional resources vary considerably and may have marked effects. Relative to its population, the strength of Victoria in ‘*neuroscience and behavior*’ and ‘*clinical medicine*’ is notable, while the performance of the Australian Capital Territory in ‘*psychiatry/psychology*’ and ‘*clinical medicine*’ is also noteworthy. The strengths of the University of New South Wales and Macquarie University in ‘*psychiatry/psychology*’ are notable, while in ‘*neuroscience and behavior*’ and ‘*clinical medicine*’ the performance of the University of Sydney stands out. Within Victoria the strength of work within the ‘*neuroscience and behavior*’ category at the University of Melbourne draws attention.

{Insert Tables 2 and 3 here}

Indicators of performance for individual researchers

The performance for particular individuals was examined using four indices: ESISM, Web of Science® citations, Highly Cited ResearchersTM and highly cited papers (from Web of Science® searches). Tables 4a and 4b describe the performance of individual researchers. ESISM rankings based on citations in ‘*psychiatry/psychology*’ are reported for 2004 in Table 4a while Table 4b reports rankings in 2004 using Web of Science® citations.

{Insert Tables 4a and 4b here}

ISI ESISM rankings

Importantly, no Australian researcher appears in the top 100 of world rankings, though one New Zealander does (DM Fergusson; Table 4a). In 2004, 12 Australian researchers appeared in the top 500 world ranked researchers and 26 were in the top 1,000. Of the top 30 researchers in 2004, 10 were from universities in New South Wales, five were from The Australian National University, five were from universities in Victoria and four from institutions in Queensland. From the University of New South Wales, six researchers were associated with the Mood Disorders Unit; and from The Australian National University all five listed researchers were part of the Centre for Mental Health Research. A small number of researchers were not only listed in the ‘*psychiatry/psychology*’ ESISM category in 2004 but were also significantly listed in the ‘*social sciences general*’ or ‘*clinical medicine*’ categories.

ISI Web of Science® rankings

This led to the generation of Table 4b for researchers. The Web of Science® system generally resulted in more citations for individual researchers as it brings all their publications together into one grouping. It shows some considerable differences from the ESISM system. For individual papers, it is clear that Australia has had considerable strengths in clinical syndrome definition (e.g. Fukuda *et al.* – 847 citations [20]), epidemiology and epidemiological methods (e.g. Ormel *et al.* – 283 citations [21]), cognitive sciences (e.g. Coltheart *et al.* – 464 citations [22]), phenomenology (e.g. Yehuda and McFarlane – 171 citations [23]) and risk factor research (e.g. Jones *et al.* – 337 citations [24]) but less impact in clinical trials or clinical neuroscience.

Highly cited individual researchers for the last 20 years

The Australians who appear in this list for the category ‘*psychology/psychiatry*’ are AF Jorm, HW Marsh, G Parker and for ‘*social sciences general*’ WD Hall.

DISCUSSION

This presentation of citation rates for the last 10 years provides some important insights into the current national and international standing of Australian mental health research. Before over-interpreting between and within country differences, the amount of resource investment in research and many other contributing factors need to be considered. The Wills report [1] noted “*With 0.3% of the world’s population, Australia produces about 2.5% of the world’s health and medical research output.*” (p.5). However, “*In 1995, Australia spent 0.115% of GDP or \$28 per capita on health and medical research and development. The GDP-weighted OECD average for developed nations was significantly higher at 0.174% or \$66 per capita.*” (p.7). For that period, public expenditure on health and medical research was highest in Switzerland (0.315%), the United States was mid-ranking (0.211%) and New Zealand was lowest (0.051%).

More recent evidence [25] suggests that Australia’s total public expenditure in health-related R&D was 0.12% of GDP during 2002 and that the comparisons with other countries had not changed significantly. Of the four major OECD countries, public expenditure was highest in the United States

(0.25%), France was mid-ranking (0.20%) while the United Kingdom and Germany were relatively low (0.13% and 0.11%, respectively) [25]. Research investment in mental health in Australia (both public and private expenditure) is low by comparison with other major health areas (2000-01: mental health comprised around 3% of total expenditure, compared with cancer at 9%, and pharmaceutical treatments at 8%) [26].

While citation systems are only one measure of research output, there is evidence that they do relate to real world health impacts. For example, in a recent review of the most cited articles ever published in the *Medical Journal of Australia*, Dr John Cade's 1949 description of the therapeutic effects of Lithium Carbonate led the field (888 citations) [27]. Consequently, having taken account of the resources, issues and Australia's generally high ranking in overall medical research performance, several comparisons in mental health are notable.

First, on a number of key measures we do not perform as well as comparable countries such as Canada or New Zealand. Given the relatively low level of national investment in research, the very high impact of a small number of New Zealand researchers should be the subject of active discussion. Their performance may simply reflect the quality of those individuals or it may reflect their capacity to pursue longer-term, high value and internationally collaborative projects.

There is a very high degree of variability in performance between our major research institutions, and performance in mental health research is not strongly tied to the overall scientific performance of the home institution. Instead the major factors appear to be the strength of some individual researchers, their national or international networks, and/or the strength of certain consolidated research groups over a sustained period. Among the individual researchers, NG Martin, at Queensland Institute of Medical Research working in association with the Australian Twin Registry and his network of international genetic and genetic epidemiology colleagues is notable. Other notable performers include M Coltheart and RM Rapee working in cognitive sciences and psychology at Macquarie University and RA Bryant in psychology at the University of New South Wales. The consolidated research groups of AF Jorm and colleagues at the Centre for Mental Health Research, The Australian National University (H Christensen, AE Korten, B Rodgers), G Parker and his colleagues at the Black Dog Institute (formerly the Mood Disorders Unit), University of New South Wales (P Mitchell, K Wilhelm, D Hadzi-Pavlovic, previously P Boyce and I Hickie) and PD McGorry at University of Melbourne and ORYGEN Youth Health (HJ Jackson, C Pantelis) stand out.

While it may be argued that consolidated research groups simply inflate citation rates through double-counting (as each author receives credit for each paper published), it is important to note the extent to which the contributions of these groups have also been recognised through other mechanisms (eg. NHMRC Program Grant awards) or the extent to which they have led important international movements. Moreover, the citations of consolidated research groups reflect the collective work of younger researchers and PhD students, whose performance reflects the capacity building associated with these research centres. For the Centre for Mental Health at The Australian National University stand out publications have highlighted epidemiological aspects of ageing, mental health literacy, e-health services and the lead researchers (AF Jorm, H Christensen) have high citation per paper ratios. Similarly, for the University of Melbourne and ORYGEN Youth Health team standout publications (and high citations per paper) have highlighted the effects of clinical interventions in early or prodromal psychosis, as well as the neuroimaging changes that accompany transition to psychosis (PD McGorry).

The extent to which our research efforts might be more strategic and obviously responsive to population need or community expectations needs to be articulated [2,3]. The most recent overview of Australian mental health research highlighted important differences between current investigator-driven activity and both community expectation and population health burden [28, 29].

Consequently, other potential markers of success now need to be considered. At the input end we might consider more closely responsiveness to community priorities, targeting of population-health burden, consumer and carer participation and broadening of non-government agency support. From an output perspective, factors such as impacts on population health or health service delivery are deserving of greater attention. Development of specific metrics for each of these constructs is challenging. Some key processes such as the NHMRC Program Grant assessment procedures have attempted to operationalise these perspectives, placing weight not only on quantitative measures of productivity but also peer-assessed notions of international and national impact [30]. Indirect measures of public health penetration or impact in the community might be achieved through Internet searches. These might reveal the extent to which applications have been picked up and transmitted beyond academic research publication.

Can we set realistic goals for Australian mental health research? In our view, we should at least aspire to match New Zealand and Canada in terms of per capita citation rates for our key specialty areas. Both these countries appear to derive great benefit from their international collaborative programs. Second, we need to back those individuals, and those groups of researchers, that add real value to the Australian research environment. Some have access to unique resources (e.g. Australian Twin Registry and international twin collections) while others have pursued internationally leading paradigm shifts in epidemiology, cognitive sciences, mental health literacy, e-health, interventions in first episode psychosis or primary care psychiatry.

We need to point to the limitations of our empirical data. Citation tracking exercises are fraught with difficulties (31). In the ESISM system particularly, there are issues related to a lack of capacity to distinguish between common names, variability in use of first and second initials (e.g. C Nemeroff vs CB Nemeroff) and allocation of researchers and their citations to various categories. For example, one of Australia's most productive researchers WD Hall is listed as a citation classic in '*social sciences general*' but not '*psychiatry/psychology*'. Further, the citation rates vary considerably between categories with citations for those who appear in '*psychiatry/psychology*' generally being much lower than those who appear in '*clinical medicine*'. Individual researchers may not be highly ranked in the ESISM if their work is shared between subject areas. Nevertheless, we maintain that these citations are of value but may best be pursued by an independent body working in close association with active researchers. We would suggest that this process be conducted on a regular basis (e.g. biannually) and overseen either by an appropriate collegiate body such as the Australasian Society for Psychiatric Research or an administrative arm of our National Mental Health Strategy.

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Table 1: Ranking of top 15 countries by total number of citations, citations per paper and citations per capita 'psychiatry/psychology' as of June 7 2004.

Ranking of country by total citations	Total numbers of citations	Ranking of country by citations per paper	Citations per paper	Ranking of citations p
1. United States	935,529	1. United States	8.85	1. Wales
2. England	152,391	2. Wales	8.83	2. Canada
3. Canada	111,705	3. England	8.24	3. New Zea
4. Germany	66,485	4. Scotland	8.09	4. Scotland
5. Australia	47,588	5. Canada	8.03	5. United S
6. The Netherlands	46,086	6. New Zealand	7.56	6. England
7. France	23,359	7. Finland	7.51	7. Israel
8. Italy	21,532	8. The Netherlands	7.23	8. The Neth
9. Israel	18,610	9. Italy	7.15	9. Finland
10. Sweden	17,205	10. Sweden	6.56	10. Austral
11. Scotland	16,849	11. Australia	6.18	11. Sweder
12. New Zealand	13,362	12. Israel	5.59	12. German
13. Wales	12,821	13. Germany	5.52	13. France
14. Finland	12,699	14. France	5.36	14. Italy
15. Japan	12,150	15. Japan	3.47	15. Japan

Note: These data cover the period January 1 1994 – April 1 2004.

**Table 2: Ranking of top 10 countries by total number of citations, citations per paper and citations per capita
'neuroscience and behavior' as of November 1 2003.**

Ranking of country by total citations	Total numbers of citations	Ranking of country by citations per paper	Citations per paper	Ranking of country by citations per capita
1. United States	2,261,215	1. United States	20.34	1. Switzerland
2. England	380,521	2. Switzerland	19.12	2. Sweden
3. Germany	343,926	3. England	18.60	3. Canada
4. Canada	274,793	4. Canada	16.96	4. United States
5. Japan	272,594	5. Sweden	16.10	5. England
6. France	228,058	6. Germany	15.56	6. The Netherlands
7. Italy	160,843	7. New Zealand	14.51	7. Germany
8. Sweden	116,473	8. France	14.43	8. Australia
9. Switzerland	102,270	9. Australia	13.20	9. France
10. The Netherlands	88,172	10. The Netherlands	12.90	10. New Zealand
11. Australia	75,892			
22. New Zealand	14,927			

Note: These data cover the period January 1 1993 – August 30 2003.

Table 3: Total number of citations in the areas of ‘psychiatry/psychology’, ‘neuroscience and behavior’, ‘clinical general’ by Australian and New Zealand institutions as of November 1 2003.

<i>Academic institution by state or territory (population, '000)</i>	<i>Total number of ‘psychiatry/psychology’ citations</i>	<i>Total number of ‘neuroscience and behavior’ citations</i>	<i>Total ‘clinical general’ citations</i>
New South Wales (6,716.3)			
Macquarie University	3,298	-	2
University of New South Wales	7,839	5,056	2
University Newcastle†	1,328	-	1
University of Sydney	3,798	11,044	4
NSW TOTAL	16,263	16,100	8
Queensland (3,840.1)			
University of Queensland	6,269	6,813	2
Queensland Institute of Medical Research	-	-	1
QLD TOTAL	6,269	6,813	4
Victoria (4,948.0)			
La Trobe University	2,065	-	4
University of Melbourne	5,579	14,129	3
Monash University	3,299	5,696	3
VIC TOTAL	10,943	19,825	7
Australian Capital Territory (322.6)			
The Australian National University	3,194	-	9
South Australia (1,531.4)			
University of Adelaide	-	-	9
Flinders University	1,539	4,822	9
Western Australia (1,969.0)			
University of Western Australia	2,361	-	2
New Zealand (3,969.4)			
University of Auckland	2,438	7,831	2
University of Canterbury	1,627	-	1
University of Otago	4,861	4,912	1
NZ TOTAL	8,926	12,743	3

Note: †Could also be University of Newcastle, England.

Table 4a: 2004 ESISM ranking of Australian and New Zealand academics in the top 1,000 in the World by to

Rank in Australia or NZ	Rank in the World	Surname INITIALS	Total number of citations	Citation
1	96	Fergusson DM	1,537	2
2	111	Silva PA	1,429	4
3	133	Jorm AF†	1,336	1
4	146	Joyce PR	1,291	1
5	162	Martin NG	1,218	1
6	199	McGorry PD	1,115	1
7	201	Bryant RA	1,111	1
8	291	Parker G†	951	
9	299	Dunn J	939	1
10	338	Christensen H‡	893	1
11	374	Rapee RM	850	1
12	404	Mulder RT	823	1
13	405	Mitchell P	822	8
14	420	Korten AE‡	803	1
15	439	Lynskey MT	779	2
16	458	Terry DJ‡	772	1
17	573	Mullen PE	692	2
18	574	Henderson AS	691	1
19	600	Ames D	675	1
20	656	Pantelis C	644	1
21	678	Andrews G	634	1
22	700	Jackson HJ	623	23.96
23	711	Marsh HW†	619	1
24	744	Wilhelm K‡	603	8
25	813	Hadzi-Pavlovic D	574	9
26	815	Dadds MR	573	2
27	850	Rodgers B	563	1
28	852	MacLeod C	562	3
29	915	Hickie I	541	1
30	949	Coltheart M	530	1

Notes: This table includes academics working in Australia and New Zealand as at December 2003. *Academic institution represents current institution. †Denotes the academic is male. ‡Denotes the academic is female. Abbreviations used: ANU = Australian National University; MQ = Macquarie University; Monash = Monash University; QCF = Queensland Cancer Fund; QIMR = Queensland Institute of Medical Research; UoM = University of Melbourne; UNSW = University of New South Wales; UOtago = University of Otago; UQ = University of Queensland; UWA = University of Western Australia; UWS = University of Western Sydney.

Table 4b: 2004 Web of Science® (WOS) ranking of Australian and New Zealand academics by total number

Rank in Australia and New Zealand using WOS	Rank in Australia and New Zealand using ESISM 2004	Surname INITIALS	Total number of citations (WOS)	Citations p (WO
1	5	Martin NG	3,339	11.3
2	3	Jorm AF	2,915	16.6
3	1	Fergusson DM	2,760	20.1
4	29	Hickie I	2,585	17.2
5	2	Silva PA	2,554	30.7
6	4	Joyce PR	2,049	15.4
7	14	Korten AE‡	2,037	19.7
8	15	Lynskey MT	1,974	18.9
9	10	Christensen H‡	1,863	17.5
10	18	Henderson AS	1,701	17.1
11	6	McGorry PD	1,612	8.1
12	13	Mitchell P	1,422	8.7
13	30	Coltheart M	1,390	17.6
14	8	Parker G	1,352	6.8
15	7	Bryant RA	1,334	12.4
16	> 30#	Mackinnon A	1,286	14.4
17	27	Rodgers B	1,285	20.4
18	17	Mullen PE	1,216	18.7
19	23	Marsh HW	1,184	12.0
20	> 30#	McFarlane AC	1,133	16.1
21	11	Rapee RM	1,128	20.1
22	> 30#	Brodaty H	1,113	9.4
23	20	Pantelis C	1,068	7.2
24	> 30#	McGee R	1,066	14.4
25	N/A†	Copolov D	1,024	6.2
26	> 30#	Sachdev P	1,021	7.2
27	12	Mulder RT	1,009	12.6
28	24	Wilhelm K‡	993	10.1
29	21	Andrews G	972	9.5
30	16	Terry DJ‡	947	15.2
31	25	Hadzi-Pavlovic D	943	11.3
32	26	Dadds MR	885	17.7
33	> 30#	Boyce P	873	10.1
34	22	Jackson HJ	792	14.9

Rank in Australia and New Zealand using WOS	Rank in Australia and New Zealand using ESI SM 2004	Surname INITIALS	Total number of citations (WOS)	Citations per year (WOS)
35	19	Ames D	781	7.8
36	N/A†	Patton GC	778	11.7
37	9	Dunn J	728	13.4
38	> 30#	Austin MP‡	624	12.7
39	> 30#	Forgas JP	611	19.0
40	> 30#	Prior M‡	592	11.8
41	> 30#	King NJ	564	7.8
42	28	MacLeod C	535	53.5
43	> 30#	Spence SH‡	535	13.3
44	> 30#	Barrett PM‡	531	16.0
45	N/A†	Paxinos G	523	16.3
46	N/A†	Michie PT‡	479	5.6
47	N/A†	Ward PB	459	6.0
48	N/A†	Sawyer MG	439	7.3
49	N/A†	Jablensky A	437	4.6
50	N/A†	Carr V	424	6.6
51	N/A†	Kavanagh DJ	284	5.2
52	> 30#	Lee C‡	277	7.9
53	N/A†	Sanders MR	275	10.1

Notes: This table includes academics working in Australia and New Zealand as at December 2003. *Academic institution represents current institution. #>30 indicates the academic was in the top 1,500 in the World according to ESISM (but not the top 1,000). †N/A indicates the academic was not in the top 1,000 according to ESISM. Abbreviations used for academic institutions: ANU = The Australian National University; Griffith = Griffith University; MQ = Macquarie University; QCF = Queensland Cancer Fund; QIMR = Queensland Institute of Medical Research; UAdelaide = University of Adelaide; UNB = University of Newcastle; UNSW = University of New South Wales; UOtago = University of Otago; UQ = University of Queensland; USydney = University of Sydney; UWA = University of Western Australia; UWS = University of Western Sydney.

ATTACHMENT 5: Research Priorities in Mental Health

Research Priorities in Mental Health: A report commissioned by the Mental Health and Special Programs Branch of the Commonwealth Department of Health and Ageing, November 2001.

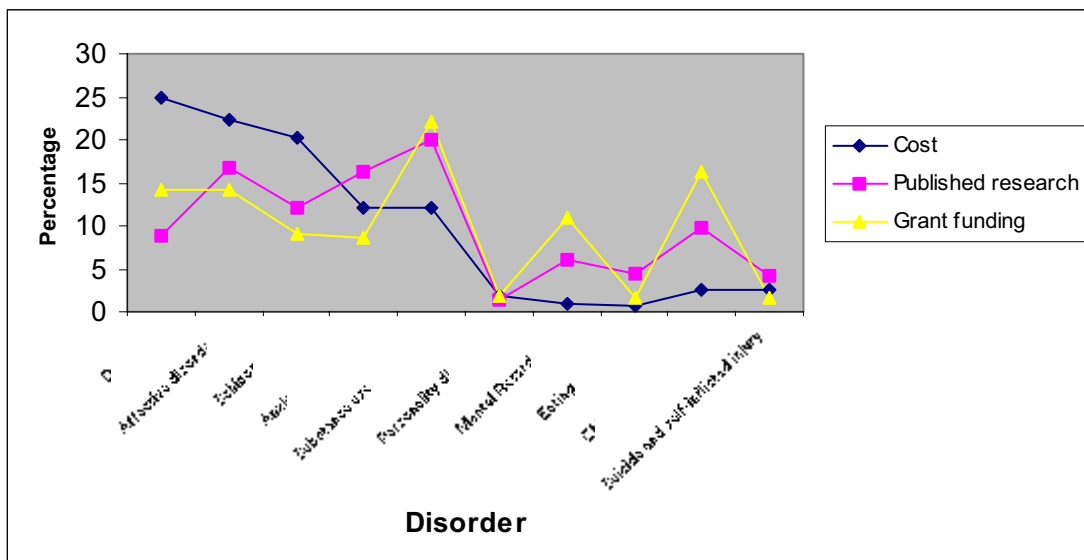
(a) Relative to Health Care expenditure, dementia is relatively under researched: Compared to other categories of mental disorders, dementia accounts for the greatest cost (24.8%) in terms of health care expenditure, yet shares in only 14.1% of competitive grant funding, and 8.9% of published research (see Table 5.1 and Figure 5.1). Substance use disorders, however, account for only 12.1% of cost, yet receive 22% of competitive grant funding, and 20% of published research.

Table 5.1. Comparison of the distribution of research with the distribution of health system costs.

CATEGORY OF MENTAL DISORDER	% OF COST ¹	% OF PUBLISHED RESEARCH	% OF COMPETITIVE GRANT FUNDING
Dementia	24.8	8.9	14.1
Substance use disorders	12.1	20.0	22.0
Schizophrenia & other psychosis	20.2	12.1	9.0
Affective disorders	22.3	16.7	14.1
Anxiety disorders	12.2	16.3	8.7
Personality disorders	1.8	1.3	1.8
Mental retardation	0.9	6.1	10.9
Eating disorders	0.8	4.5	1.6
Disorders of childhood & adolescence	2.5	9.8	16.2
Suicide	2.5	4.2	1.7
Total	100	100	100

¹ Note: Percentages are based only on the disorders included in this table.

Figure 5.1: Comparison of the distribution of research and grant funding with the distribution of health system costs.



(b) Relative to disability burden, anxiety and depression are relatively under-researched:

Compared to other categories of mental disorders, affective disorders (e.g. depression, bipolar disorder), and anxiety disorders account for a high degree of burden in terms of years of life lost due to premature mortality and years lost due to disability (DALYs) (Table 5.2 and Figure 5.2). However, these disorders share in only 15.7% and 9.7% of grant funding respectively. The amount of published research in affective disorders (16.7%) is also disproportionate to the level of disability burden the disorder creates. Substance use disorders, however, receive a much greater amount of both published research (28.8%) and competitive grant funding (30.0%).

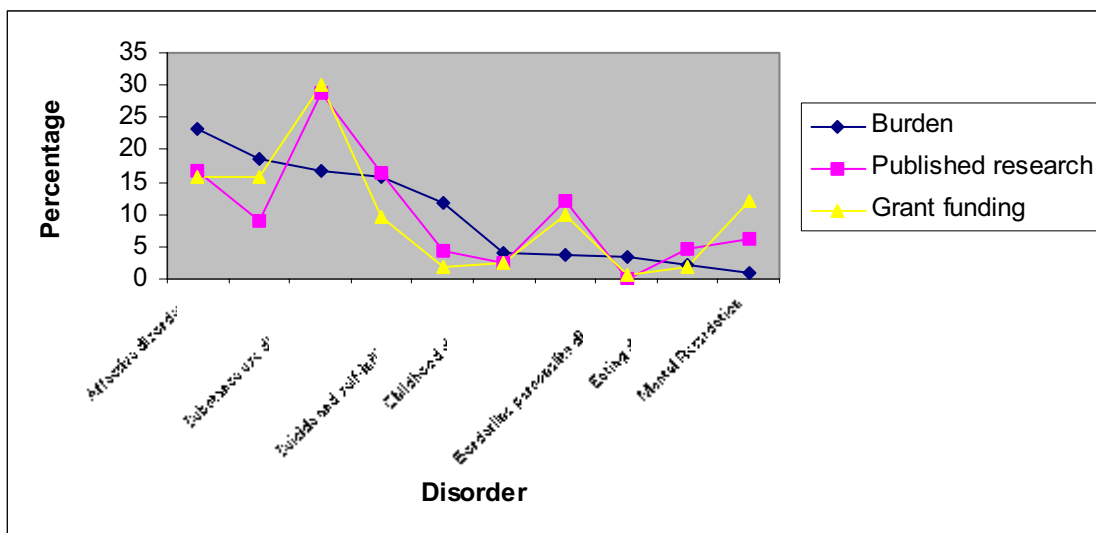
Table 5.2: Comparison of the distribution of research with the distribution of disease burden.

CATEGORY OF MENTAL DISORDER	% OF BURDEN (DALYs) ¹	% OF PUBLISHED RESEARCH	% OF COMPETITIVE GRANT FUNDING
Affective disorders	23.1	16.7	15.7
Substance use disorders	16.6	28.8	30.0
Anxiety disorders	15.8	16.3	9.7
Childhood disorders	3.9	2.4	2.5
Schizophrenia ²	3.7	12.1	10.0
Borderline personality disorder	3.4	0	0.6
Eating disorders	2.4	4.5	1.8
Dementia	18.6	8.9	15.7
Suicide & self-inflicted injury	11.7	4.2	1.9
Mental retardation	.8	6.1	12.1
Total	100	100	100

¹ Note: Percentages are based only on the disorders included in this table.

² Unspecified psychosis has been included here because the research on psychosis was predominantly about schizophrenia.

Figure 5.2: Comparison of the distribution of research with the distribution of disease burden and grant funding.



(c) More research is carried out in specialist settings (67%) than in primary care (10%): Table 5.3 shows that the majority of mental health research is conducted in specialist settings. A lower amount of research is done in the general community, and very little research is carried out in primary care.

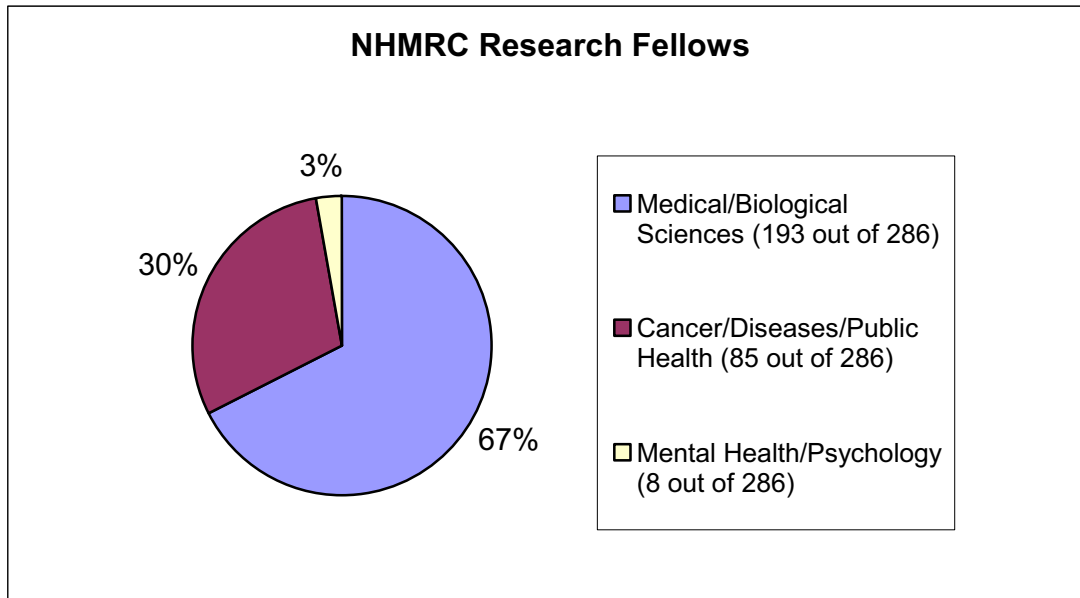
Table 5.3: Percentage of research carried out in various settings.

SETTING	NUMBER OF ARTICLES (WEIGHTED)	% OF ARTICLES (WEIGHTED)	FUNDING (\$ WEIGHTED)	% OF FUNDING (\$ WEIGHTED)
Patients in hospital or other specialist settings	273	66.6	18,272,348	69.1
Patients in primary care	14	3.4	1,157,958	9.7
People in the general community	123	30.0	2,542,206	21.2
Total	410	100	11,972,512	100

ATTACHMENT 6: NHMRC Research Fellows

The mental health research workforce is small: Only a small percentage of NHMRC Research Fellows (3%) conduct research in mental health (Figure 6.1).

Figure 6.1: Comparison of the percentages of NHMRC Research Fellows in mental health with the medical/biological sciences and diseases/cancer/public health.



ATTACHMENT 7: PHERP Funding

PHERP Funding

The Public Health Education and Research Program (PHERP) is an Australian Government initiative that funds public health research. During the most recent funding phase, the Government has provided \$45 million in funding over 5 years (2001-2005) to various public health research bodies, including \$37 million of core curriculum funding. PHERP funding is distributed across five State-based Centres of Public Health:

1. Sydney Public Health Consortium – University of Sydney and the University of New South Wales.
2. Victorian Consortium for Public Health – Monash University, University of Melbourne, La Trobe University and Deakin University.
3. Queensland Centre for Public Health – Griffith University, Queensland University of Technology and the University of Queensland.
4. Western Australian Centre for Public Health – University of Western Australia and Curtin University of Technology.
5. South Australian Centre for Public Health – Adelaide University and Flinders University.

PHERP funding is also allocated to:

- The School of Public Health and Tropical Medicine at James Cook University of North Queensland.
- National Centre for Epidemiology and Population Health – Australian National University.
- Australian Centre for International and Tropical Health and Nutrition – University of Queensland and the Council of the Queensland Institute of Medical Research.
- Centre for Clinical Epidemiology and Biostatistics – University of Newcastle.

None of these national centres of excellence conduct research in mental health. Some of these research centres have been set up in response to national need, for example, the National Drug and Alcohol Research Centre (NDARC), which was formed as part of the National Drug Strategy. However, there is no national centre of excellence that conducts mental health research, despite the fact that mental health is one of the Government appointed National Health Priority Areas. The Review of Phase III of PHERP has begun, and is a mechanism through which to stipulate a national initiative to fund mental health research.

The quality and accessibility of Australian depression sites on the World Wide Web

Kathleen M Griffiths and Helen Christensen

IT HAS BEEN ESTIMATED that 6.4 million Australian adults — almost half the adult population — accessed the Internet during 2000.¹ Reportedly, more Internet users search the Web for information on depression than any other health condition.² This is not surprising given the high level of disability associated with depression in the community³ and the fact that the Web provides a convenient, anonymous means of obtaining information about the problem. However, much of the depression information on the Web is of low quality⁴⁻⁶ and originates in the United States. If Australian consumers are to benefit from Web-based media, they need to know which sites are of high quality and appropriate to local needs.

Because consumers are more likely to trust information on a website that is recommended by their doctor,⁷ general practitioners are uniquely placed to advise people about which depression websites to visit.⁷ However, there are currently no systematic guides to Australian depression websites on which GPs can base their advice.

Another way that consumers or non-specialist healthcare providers might judge the quality of sites is by indirect indicators that do not rely on specialist knowledge. Although many such indicators have been proposed, their validity as markers of content quality has not been established.^{4,8} Recently, the DISCERN scale⁹ has generated considerable interest as a potential indicator of website quality. In particular, the scale is intended to assist people without content expertise assess the quality of written health treatment information by systematically rating a number of attributes of a publication, such as the extent to which it describes treatment alternatives and their risks and benefits; the degree to which the information appears balanced and unbiased; and whether the publication documents areas of uncertainty. To our knowledge, there have been no studies of the validity of DISCERN as an indicator of the content accuracy of Web-based or other written health material.

Here we intend to:

- provide information for consumers and healthcare providers about Australian depression sites and the quality (accuracy and comprehensiveness) of their content;
- explore the validity of the DISCERN system as an indicator of the quality of treatment content; and
- determine the accessibility of Australian depression websites.

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ABSTRACT

Objectives: To provide information about Australian depression sites and the quality of their content; to identify possible indicators of the quality of site content; and determine the accessibility of Australian depression web sites.

Design: Cross-sectional survey of 15 Australian depression web sites.

Main outcome measures: (i) Quality of treatment content (concordance of site information with evidence-based guidelines, number of evidence-based treatments recommended, discussion of other relevant issues, subjective rating of treatment content); (ii) potential quality indicators (conformity with DISCERN criteria, citation of scientific evidence); (iii) accessibility (search engine rank).

Results: Mean content quality scores were not high and site accessibility was poor. There was a consistent association between the quality-of-content measures and the DISCERN and scientific accountability scores. Search engine rank was not associated with content quality.

Conclusions: The quality of information about depression on Australian websites could be improved. DISCERN may be a useful indicator of website quality, as may scientific accountability. The sites that received the highest quality-of-content ratings were beyondblue, BluePages, CRUFAD and InfraPsych.

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Methods

The methodology used in this study is an extension of that described in our previous study of the quality of “popular” international depression sites.⁴

Identification of Australian depression sites

Potentially relevant Australian depression sites were identified (November to December 2001) by entering the query term “depression” into each of 17 Australian search engines and six major search and metasearch engines that permit searches restricted to the Australian domain.^{10,11} Only sites appearing in the top 200 results of a search engine list and containing at least eight internal Web pages focusing on depression were included. Three additional, newly released sites not returned by the search engines were also included.

Twenty-seven sites were found. Of these, 12 (clearing house, bipolar disorder, postnatal depression, web-based cognitive therapy) were excluded from formal analysis, leaving 15 sites (Appendix).

Site assessment

Each author independently rated the sites in terms of site characteristics and coverage, quality of content and potential quality indicators using a standard protocol sheet. Disagreements between item ratings were resolved through discussion (except for the DISCERN and global subjective judgements).

Site characteristics and coverage

Site characteristics (eg, ownership structure, scope, privacy policy, registration required) and coverage of symptoms/diagnosis, self-assessment screening, treatment, prevention, risk factors, prevalence, resources, and specific groups were rated for each site.

Quality of content

Guideline score

The total guideline score was the number of items (maximum, 20) for which site information agreed with depression guidelines produced by the Centre for Evidence Based Mental Health (CEBMH) at Oxford.¹² Items covered antidepressants and associated management issues, St John's wort, psychotherapy, counselling, bibliotherapy, and exercise.

Evidence-based and non-evidence-based scores

The number of evidence-based treatments (evidence+) (maximum, 8) and the number of non-evidence-based treatments (evidence-) (maximum, 26) (Box 1) that were recommended as effective were calculated for each site. Evidence-based treatments were defined as those interventions that are supported by a systematic review of the evidence as effective.¹³ Non-evidence-based interventions were those which, on systematic review of the available evidence, do not seem to be effective or which have been the subject of little or no appropriate research.¹³

Global score

Each author provided an independent, global, subjective rating (out of 10) of the quality of the treatment information on each site.

Potential quality indicators

Scientific evidence score

Interventions were typically not accompanied by a reference to scientific evidence. We therefore classified each site according to whether it always, or almost always, cited scientific evidence to support claims (rating, 3); provided scientific evidence to support more than three but not the majority of claims (rating, 2); provided evidence to support between one and three of the claims (rating, 1); or never cited supporting scientific evidence (rating, 0).

DISCERN score.

Each judge independently rated the sites using the 15-item, five-point DISCERN scale.⁹ A DISCERN score was calculated by summing the 15 scores across the scale for a site. An additional item referred to the overall quality of the treatment information and was analysed separately.

1: Evidence-based and non-evidence-based treatments counted in assessing the websites¹³

Evidence-based treatments

Antidepressants	Bibliotherapy
Cognitive behaviour therapy	Electroconvulsive therapy
Exercise	Interpersonal therapy
Light therapy (seasonal affective disorder)	St John's wort

Non-evidence-based treatments

Alcohol for relaxation	Caffeine avoidance
Chocolate	Colour therapy
Dance therapy	Fish oils
Ginkgo biloba	Ginseng
Glutamine	Homoeopathy
Hypnotherapy	Lemon balm
Meditation	Music
Natural progesterone	Painkillers
Pets	Phenylalanine
Pleasant activities	Selenium
Sugar avoidance	Supportive counselling
Tranquillisers	Vervain
Vitamins (other than folate)	

Accessibility of sites on search engines

The rank order of appearance of each site on each search engine result was recorded and the number of search engines retrieving a site in first place, and in the first 10 and first 200 places, noted.

Results

Site characteristics and coverage

The site characteristics are summarised in Box 2. All sites provided information for consumers. Significantly, only a third of the sites had an editorial board. All sites published some treatment information and most included information about symptoms and diagnosis (14 sites), prevalence (13 sites), stigma reduction (11 sites), risk factors (11 sites), and resources (10 sites). Half the sites provided a self-assessment screening test on the site. Only four sites included information on prevention and only four had information on specific groups. Four sites included a bulletin board and two had chatrooms, but none provided online counselling or psychotherapy.

Quality of content

Guideline score

On average, sites contained correct information for less than half of the guideline items (mean, 7.5 out of 20; SD, 4.8; range, 0–14). This was often due to omission of relevant material rather than inclusion of inaccurate information. With respect to the guideline items, most sites acknowl-

edged that antidepressants are effective (14 sites) and non-addictive (11 sites). However, only three sites clearly specified that a trial of six weeks is required before discontinuing a particular antidepressant, and only six indicated that antidepressants should be continued for at least four to six months after improvement or that a discontinuation syndrome can occur with abrupt cessation of antidepressants. Few sites (two) indicated that problem solving might be an effective treatment for depression. Finally, of the 11 sites that mentioned counselling, only two warned that counselling is not by itself an effective intervention.

Evidence-based score

On average, sites recommended more than half of the eight evidence-based treatments (mean, 4.7 out of 8; SD, 2.4; range, 0–8) but few of the non-evidence-based treatments (mean, 1.4 out of 26; SD, 0.8; range, 0–3). Antidepressants were recommended most often (14 sites), followed by ECT (11 sites), exercise (10 sites), interpersonal therapy (9 sites), and cognitive behaviour therapy (8 sites). Of the non-evidence-based treatments, supportive counselling was most often recommended (9 sites).

Issues score

The average issues score was 11.8 out of 22 (SD, 4.0; range, 4–18). Positive features were that all sites promoted speaking to healthcare professionals and stated the risk of suicide. Most indicated that depression can (14 sites) and should (13 sites) be treated, and provided details of contact organisations (12 sites). Most sites also acknowledged that treatments other than antidepressants are effective and that psychological therapy can be effective in its own right. On the other hand, 13 sites failed to indicate the relative effectiveness of different treatment options compared with antidepressants. Only six sites indicated that psychological therapy (cognitive behaviour therapy or interpersonal therapy) is as effective as antidepressants for mild to moderate depression. About half the sites failed to mention side effects, dangers and contraindications of antidepressants, and few (4 sites) mentioned the drawbacks of non-antidepressant treatments (for example, lack of availability of individual cognitive behaviour therapy).

Global score

As there was a high correlation between ratings of the two judges ($r = 0.92$; $P < 0.001$), the scores for the two judges were averaged. The mean global score was 4.6 out of 10 (SD, 2.5). Individual ratings ranged from 1 to 8.5, suggesting that the quality of the treatment information was variable but that some sites were of high quality.

Potential quality indicators

Scientific evidence score

The mean scientific evidence score was 0.9 out of 3 (SD, 0.9; range, 0–3). Only one site consistently referred to the level of scientific evidence in support of claims and only two other sites referred to evidence for three or more recommended treatments. Of the remaining sites, half did not refer to any scientific evidence.

2: Site characteristics of Australian depression information websites ($n = 15$)

	Characteristic	Number (%) of sites
Ownership structure	Individual	3 (20%)
	Organisation	11 (73%)
	Unknown	1 (7%)
Scope	Specific (mental health)	12 (80%)
	Broad (health)	3 (20%)
Editorial board	No	10 (67%)
	Yes	5 (33%)
Healthcare professional involved	No	5 (33%)
	Yes	10 (67%)
Promotion of products/services	No	10 (67%)
	Yes	5 (33%)
Privacy policy	No	6 (40%)
	Yes	9 (60%)
Disclaimer	No	1 (7%)
	Yes	14 (93%)
Feedback mechanism	No	1 (7%)
	Yes	14 (93%)
Collects personal information	No	6 (40%)
	Yes	9 (60%)
Register to access all information	No	10 (67%)
	Yes	5 (33%)

DISCERN score

The total DISCERN scores for the two judges were significantly correlated ($r = 0.88$; $P < 0.001$), as were the “overall rating” scores ($r = 0.65$; $P < 0.01$). The judges’ ratings were therefore averaged for each measure. The mean DISCERN score was 44.1 out of 60 (SD, 12.1; range, 26.5–62). The mean score on the overall rating DISCERN item was 2.9 out of 5 (SD, 1.0; range, 1–4.5), which suggests that on average the sites had significant shortcomings.

Accessibility of sites on search engines

On average, search engines returned 1.7 (SD, 1.2; range, 0–4) sites in the top 10 results list, and 4 (SD, 2.5; range, 0–10) sites in the top 200 list. DepressioNet was the most accessible site, being returned first and in the top 10 results by 11 and 17 search engines, respectively. No other site was returned in top place. beyondblue and Climbing the Cliffs of Depression were the next most frequently returned top 10 and top 200 sites. The well-known Reach Out! site received few hits.

Associations between content quality, potential quality indicators, and accessibility

Box 3 shows the intercorrelations between each of the content and potential quality indicator scores. With one exception (evidence–), all content scores (guideline, issues, evidence+) were significantly correlated with each other and with the DISCERN “overall rating” score. There was also a

significant correlation between the extent to which sites mentioned scientific evidence in support of treatments (scientific score) and scores on all content measures except evidence-.

There was no relationship between the accessibility of a site (as judged by the number of search engines retrieving it in the top 10 or the top 200 results) and the quality of the site (as judged by any of the content or other measures and excluding the new sites *InfraPsych* and *BluePages*, which would not have been indexed by public search engines at the time of the study).

Discussion

We have systematically identified Australian websites that provide information about depression. On average, scores on measures of content quality were relatively low, a result that is broadly consistent with the conclusions of previous studies that, overall, the quality of depression information on the Web is not high.⁴⁻⁶

Nevertheless, there was considerable variability in the comprehensiveness and the quality of sites, and all sites had strengths as well as weaknesses. The consistently best-scoring sites included two university-based sites (*BluePages* and *CRUFAD*), the site of the National Depression Initiative (*beyondblue*) and the privately owned site *InfraPsych* (Box 4). These sites had the best average ranks across the four main content measures (guideline, issues, evidence+, global), and achieved top scores on the evidence-based guideline scale and top ratings on at least three of the content measures. Other specific advantages of these sites are summarised in Box 4.

Several other sites were notable in providing useful information with respect to particular aspects of depression. These were *Depression doctor.com* (offers extensive information about depression management and methods of coping with antidepressant side effects), *myDr* (includes a searchable *MIMS* database), and *DepressioNet* (provides consumer support and networking, extensive lists of sources of help). *Dark Side of the Mood* stands out for its accessible and concise presentation of above-average quality of content.

Despite their limitations, all sites provided useful information. The fact that all or most sites indicated that depression can be treated, encouraged patients to seek expert advice, attempted to destigmatise depression and indicated that antidepressants are effective and non-addictive treatments is likely to encourage help-seeking and facilitate treatment compliance. Providing information about symptoms, as most sites did, might facilitate correct diagnosis, as patients who self-label as depressed are more likely to receive an appropriate diagnosis.¹⁴

On the other hand, there is a clear need to improve the coverage and the accuracy of content in a number of areas, including details of the recommended duration of antidepressants to avoid relapse, the time needed to trial an antidepressant and the importance of ceasing antidepressants slowly to avoid discontinuation effects. This information could improve compliance, lessen the likelihood of relapse and premature abandonment of effective treatments, and, by avoiding discontinuation symptoms, improve the

3: Intercorrelations* between content measures and potential quality indicators

	Issues	Evidence+	Evidence-	Global	DISCERN	Scientific
Guideline	0.85 [†]	0.75 [†]	0.26	0.96 [†]	0.92 [†]	0.71 [†]
Issues		0.85 [†]	-0.07	0.85 [†]	0.89 [†]	0.67 [†]
Evidence+			0.17	0.86 [†]	0.76 [†]	0.66 [†]
Evidence-				0.26	0.12	0.38
Global					0.91 [†]	0.78 [†]
DISCERN						0.85 [†]

*Results are based on Pearson rho correlations, except for results involving Evidence+, Evidence- and Scientific, which are based on Spearman rho correlations. Evidence+ = number of endorsed evidence-based treatments. Evidence- = number of endorsed non-evidence-based treatments. †P<0.01.

4: Consumer guide to Australian depression websites

Recommended sites overall (alphabetical order)

beyondblue <<http://www.beyondblue.org.au>>
BluePages <<http://bluepages.anu.edu.au>>
CRUFAD <<http://www.crufad.unsw.edu.au>>
InfraPsych <<http://www.infrapsych.com.au>>

Recommended subsections or aspects of sites (alphabetical order of features)

Accessible and above-average quality	<i>Dark Side of the Mood</i>
Antidepressants	
management of depression	<i>depression doctor.com</i> , <i>InfraPsych</i>
side effects	<i>myDr</i>
ways of coping with side effects	<i>depression doctor.com</i>
Cognitive behaviour based strategies*	<i>beyondblue</i> , <i>CRUFAD</i>
Evidence-based information about treatments	<i>BluePages</i>
Focused search of other depression sites	<i>BluePages</i>
Online consumer support	<i>DepressioNet</i>
Online depression screening	<i>BluePages</i> , <i>CRUFAD</i> , <i>InfraPsych</i>

* A cognitive behaviour therapy module is under construction on *InfraPsych*.

likelihood that patients will be willing to take antidepressants in the future. Sites also need to provide more information about the relative effectiveness of different treatments (eg, that cognitive behaviour therapy is as effective as antidepressants for mild to moderate depression). Currently, many sites recommend "counselling" as a treatment for depression, although supportive therapy is not by itself an effective intervention for depression. More generally, sites should ensure that they consider the consumer perspective, both with respect to content and style.

Finally, there is a need to provide comprehensive, high quality information about depression for adolescents. Currently, no site adequately fulfils this role.

Indicators of site quality

One aim of our study was to identify possible indicators of quality of treatment content. This is an important issue for all health sites, not just those concerned with depression. We found that ratings on the DISCERN instrument and specifying an evidence base were consistently associated with the quality of site content. The advantage of DISCERN is that it can be administered by people with no content knowledge in an area. It seems unlikely that the typical consumer or carer seeking depression information would take the time or be sufficiently motivated to learn how to apply the instrument. Nevertheless, DISCERN might assist people who are constructing lists of or links to recommended resources (eg, government portals such as HealthInsite, HealthySA) and for people who are developing health content for the Web.

Accessibility

The other aim of this study was to determine how accessible Australian depression sites are to people not already aware of their existence. We found that local sites are not easily found with search engines, even using search strategies designed to limit the search to Australian sites. It has been reported that few people search beyond the first 10 links in a search engine list. Apart from DepressionNet and, to a lesser extent, beyondblue and Climbing the Cliffs of Depression, the depression sites we reviewed rarely, if ever, appeared in the first 10 results. Significantly, there is no association between the quality of the content of a site and the order in which it appears on the search engines.

Detailed consideration of how high-quality sites can be accessed more readily by the Australian public is beyond the scope of this article. However, it would be helpful if such sites could be promoted by high-traffic government and other portals. At the time of writing, the government-owned quality portal HealthInsite listed only one of the sites reviewed in this study (myDr) and none of the four "recommended" sites.

Study limitations

Our study has a number of limitations. First, we are the joint authors of one of the sites (BluePages) and this might have influenced our judgements. In addition, one of the measures (evidence+) is based on a review of which we were co-authors and which forms the basis for the treatment section of the BluePages.¹³ However, the general pattern of the results does not change if BluePages is excluded from the analysis.

A second limitation of this study is that the judges rated the sites on both content and potential quality measures. Future studies using different raters for these measures and a larger sample size are needed.

In addition, this study did not incorporate evaluations by consumers. We plan to conduct further studies using DISCERN and other ratings produced by consumers and non-technical assessors.

We also acknowledge that websites are rarely static and that no account was taken of information on linked external sites.

A final limitation of this study is that it is confined to depression information. Online counselling is becoming increasingly popular. DepressionNet alone claims to attract more than 1 000 000 visits per quarter. Clearly, the next challenge will be to develop methods for assessing the quality of online counselling services and online support groups.

Competing interests

Kathleen Griffiths and Helen Christensen were co-authors of the depression website BluePages, which was included in this review. They are also co-authors of a review of the effectiveness of interventions for depression¹³ on which one of the quality-of-content measures was based.

Acknowledgements

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Appendix: Descriptions of Australian depression sites (November–December 2001)

Included sites

1. beyondblue: the national depression initiative

<http://www.beyondblue.org.au/>

This is the official site of beyondblue, a national initiative designed to increase community awareness of depression. The site provides online screening tests for depression, describes “the causes” and course of depression and provides information about psychological and medical treatments for depression. It includes self-help psychological techniques (activity planning, stress reduction, managing sleep–wake cycle, maintaining assertiveness), a bulletin board and resources (eg, downloadable video, patient education leaflets, links, bulletins, research reports). There is no readily available information about sponsorship on the site, nor is there any information about the site editorial board.



2. BluePages

<http://bluepages.anu.edu.au/>



Developed by the Centre for Mental Health Research at the Australian National University, this site provides evidence-based treatment information about the medical, psychological and alternative treatments for depression.

Other features include a facility for focused searching of other Australian and international depression sites, online assessment of depression and anxiety, a downloadable relaxation tape and an extensive list of State and national resources.

3. Climbing the cliff of depression: Finding footholds for peers

<http://www.climb.webcentral.com.au/>

This small site is intended primarily for teenagers and provides advice about how to recognise and help a depressed or suicidal person. The site describes antidepressant therapy, but does not indicate that other therapies may be the preferred first-line treatment for teenagers.

4. Clinical Research Unit for Anxiety and Depression (CRUfAD)

<http://www.crufad.unsw.edu.au>

This site is the official site of CRUfAD, a facility jointly owned by the University of New South Wales and St Vincent's Hospital. The site is subdivided into three sections: a “Self Help Clinic”, “Support for Professionals” and “Research”. The site provides an online depression quiz, and information about effective treatments, including concrete suggestions for activity scheduling and problem solving, a list of potentially pleasant activities and a detailed list of cognitive behaviour therapy materials and links. The site is supported by the sale of CRUfAD-produced books, videos and CDs.



5. Dark side of the Mood

<http://abc.net.au/health/depression/>

This comprehensive site has been prepared by ABC specialist health reporter Rae Fry and is a stand-alone sub-site on ABC Online's Health Matters. The site discusses a range of medical, psychological, physical and alternative treatment options and includes a very clear summary of the side effects and risks of conventional antidepressants and St John's wort. This site presents useful information in a form and style that is likely to be highly appealing and accessible to the lay reader.



6. depression doctor.com

<http://www.depression.com.au/>

Written by Dr David Horgan (psychiatrist),



depression doctor.com provides information on the nature, diagnosis, epidemiology, treatment, and prevention of depression and the relationship between depression and various medical conditions. Considerable detail is provided about different types of antidepressants and their side effects, as well as management strategies and treatments to counteract common side effects (eg, weight gain, sexual problems, sweating).

7. depressionadvice.com.au

<http://depressionadvice.com.au/>

Owned by the pharmaceutical company Pfizer, this site provides information for the general public (“General depression advice”) as well as “patient depression advice” (password required) and advice for registered medical practitioners (password required). Our review was confined to the general public section of the site,



which briefly summarises treatments and includes an online quiz, resources and links, and some advice for carers. Although antidepressants are described as an effective treatment for depression, the different types of antidepressant and the potential side effects of medication are not addressed in this section of the site.

8. DepressioNet

<http://depressioNet.com.au>



This site, owned by DIRS Pty Ltd, was established and initially wholly funded by Leanne Pethick, a consumer. It has recently received sponsorship from a number of pharmaceutical companies, Blackmores, the Australian Psychological Society and others. The most distinctive aspect of the site is the support available to visitors through its chat room (moderated by consumer staff) and bulletin board (closed at the time of access due to lack of funding). DepressioNet also includes information about symptoms and diagnosis, types of depression, sources of help by State, treatment options, incidence, and risk factors. Other features include contributor stories; poems and quotes; relevant news items from the Australian press; information about books, websites, conferences and events; and summaries of relevant research studies.

9. Feeling Down?

<http://www.feelingdown.org.au>

This site has been prepared by a psychiatrist (Dr David Horgan). The emphasis in the treatment section is on antidepressants and their side effects. Feeling Down? refers the user to Dr Horgan's more extensive site depression doctor.com.

10. Good Medicine

http://www.lifestyle.ninemsn.com.au/goodmedicine/Factsheets/cat_mental.asp

Good Medicine is a subsite of Microsoft- and ecorp-owned online publisher ninemsn (which claims to be the most accessed website in Australia, with five million visitors a month). The site obtains its revenue through online advertising. This site may provide the casual visitor with some preliminary information, links/contacts and online advice. However, it is not an integrated, comprehensive source of information on depression.



11. InfraPsych

<http://www.infrapsych.com.au>

This website is owned by InfraPsych, a company established by Australian psychiatrist Dr Dennis Tannenbaum. At the time of access, the site was in a trial phase. Information was presented primarily in a Question and Answer format and the topics covered included symptoms, "causes", epidemiology, depression management, sources of help and medical and psychological options. Side effects of medications were discussed in detail and the site featured an online depression assessment tool. Even in its early trial form this is a comprehensive source of depression information for consumers. However, the relatively formal writing style may not be ideal for some consumers.



12. Mood Disorders Unit (MDU), University of New South Wales

<http://www.mdu.unsw.edu.au>

This site is the official website of the Mood Disorders Unit at the Prince of Wales Hospital, Sydney (Director, Professor Graham Parker). In addition to describing the Mood Disorders Unit services and research, the site provides general information about the nature and types, risk factors and epidemiology of depression. The site also provides some information on the treatment of depression, but the major sections were still under construction at the time of access.



13. myDr

<http://www.mydr.com.au/default.asp?Section=mentalhealth>

myDr provides health information for Australian consumers, including information about depression. The site is owned by MediMedia Australia, which also produces the drug reference text *MIMS* and the weekly tabloid *Medical Observer*. In addition to provid-



ing information about symptoms and treatment of depression, the site provides a facility for searching for medications by name over the *MIMS* Australia database and to search for healthcare professionals by specialty, particular interest and region. The major treatment emphasis is on medications and there is minimal information about psychotherapy.

14. Reach Out!

<http://reachout.asn.au/>

An initiative of the Inspire Foundation, Reach Out! is supported financially by both government and non-government agencies, including the Commonwealth Department of Health and Ageing and the Macquarie Bank, and aims to provide information and referral for young people. Across a range of issues, there is an emphasis on destigmatisation and community involvement. Specific information about depression is very limited. Acupuncture, naturopathy and eating well are recommended in the management of depression, in addition to evidence-based treatments such as exercise and medication. Cognitive behaviour therapy is not mentioned specifically.



15. True Blue Friends

<http://www.truebluefriends.au.com/>



This small consumer-run site is primarily aimed at offering a platform for mutual consumer support. It includes a bulletin board and features a weekly chatroom. There is a list of best and worst things to say to a depressed person, some self-help "tried and tested methods by depressives for depressives!", but no description of evidence-based treatments.

Excluded sites

1. Auseinet

<http://auseinet.flinders.edu.au/>

Auseinet aims to inform, educate and promote "good practice" in mental health promotion, prevention, early intervention and suicide prevention. Supported by the Commonwealth Department of Health and Ageing, run by a management committee and owned by Flinders University of South Australia, the site targets both the community and health professionals.



2. Mental Health and Wellbeing

<http://www.health.gov.au/hsdd/mentalhe/index.htm>

Owned by the the Mental Health and Special Programs Branch of the Commonwealth Department of Health and Ageing, this site provides government mental health information, crisis and support contacts, access to publications, information on suicide and other special programs. Information can be obtained about the Depression Action Program and the National Youth Suicide Prevention Strategy. The site targets both consumers and the media, and serves to direct visitors to more information about government policy, initiatives, education programs and legislation.



3. Fyreniyce

<http://members.iinet.net.au/~fractal1/fhello.htm>

This Western Australian site, subtitled "Australia's premier bipolar website", is a consumer site which provides an email support group (visitors subscribe to an email group), and an on-line support group facility (these facilities were not tested).

**4. Healthinsite**

<http://www.healthinsite.gov.au/>



A Commonwealth initiative, this site aims to provide a single entry point to quality health information from information providers, such as peak healthcare organisations and government agencies. Resources for depression comprise a list of links to depression information published on other depression sites (Better Health Channel and myDr).

5. Healthy SA

<http://www.healthysa.sa.gov.au/>

This large clearinghouse site, owned by the South Australian Department of Human Services, provides information on a range of health issues, including mental illness, and depression specifically. Summaries with Web links are provided for a range of topics, including postnatal depression, treatments, support and anti-depressant medication. Many of these Web links are to other sites such as beyondblue and SANE Australia.

**6. Medical Journal of Australia Mental Health Information Centre**

<http://www.mja.com.au/public/mentalhealth/course/contents.html>

This site is an online publishing feature of *eMJA*, and is owned by the *Medical Journal of Australia*. The Mental Health Information Centre incorporates a number of short courses for depression and these link to recent *MJA Practice Essentials* articles.

**7. Mood Disorders Association (SA) Inc**

<http://homepages.picknowl.com.au/mda/>

Mood Disorders Association (SA) Inc is the website of an incorporated association supported by the South Australian Health Commission and run by a team of community workers and volunteers. Details are provided about the real-life support group meetings in Adelaide. Information about the nature and treatment of depression is patchy.

8. Moodgym

<http://moodgym.anu.edu.au>

Moodgym is a free interactive website which offers "training" for the public in the prevention of depression using cognitive behaviour therapy. The website was developed by the Centre for Mental Health Research at the Australian National University. It differs from all other sites in that it provides an interactive learning environment.

9. PaNDa

<http://home.vicnet.net.au/~panda/>

Specifically designed for women and their families, PaNDa is the Victorian website of a not-for-profit self-help organisation. The site provides basic information about postnatal depression, practical advice, subscription to a newsletter, resources (including videos and educational kits for sale) and contacts for telephone advice and real-life support group meetings.

**10. PaNDSI**

<http://www.pandsi.org.au>



This small site provides information and support for mothers with postnatal or antenatal depression.

11. RACGP

<http://www.racgp.org.au/>

This site is owned by the Royal Australian College of General Practitioners and provides information about issues of relevance to GPs, resources, and access to member services. The site targets GPs rather than consumers, and provides ready access to sources of relevance to GP practice, but the material is not organised into topic areas.

**12. The Better Health Channel**

<http://www.betterhealth.vic.gov.au/bhcv2/bhcsite.nsf>

This site, established by the Victorian Government's Department of Human Services, aims to provide information to the community that is "quality assured, reliable, up-to-date [and] locally relevant". Like Healthinsite, the Better Health Channel has established recognised partners who provide content that is reviewed by Victoria's Chief Health Officer. Mental health information is summarised under alphabetical listings, with information provided by organisations such as the Australian Psychological Society, DepressioNet, and SANE. Most information specifically about depression was provided by DepressioNet. □



Working out MoodGYM :

a user's guide



Working out MoodGYM: a user's guide

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1. Introduction and overview

What is MoodGYM?

MoodGYM is a free, interactive internet-based program designed to prevent and decrease symptoms of depression.

MoodGYM aims to teach you how you can feel less stressed, depressed and anxious, and better able to cope with your life. From MoodGYM we hope you will learn helpful ways of thinking about problems, how to improve your self-esteem, and how best to relate to others (and to be more assertive). You will also learn how to increase the pleasure in your life, how to relax and how to cope with a relationship breakup.

MoodGYM consists of a number of interactive modules. These are designed to be completed in order, as each module builds upon material covered in earlier modules. As you move through the program, you will be presented with information, animated demonstrations, quizzes and 'homework' exercises. Your answers to the exercises are recorded in your own personal MoodGYM Workbook. The Workbook is important as it helps you track your progress as you move through the modules.

Think of MoodGYM as an interactive self-help book. There are many books about how to improve your mental health. The advantage of MoodGYM is that it can give you feedback about your mental health, and you can use the online exercises to work out how to handle life's challenges better.

How to access MoodGYM

MoodGYM is located at <http://moodgym.anu.edu.au>. The site opens with the homepage shown below.

1. Before entering MoodGYM, you will need to register as a new user. To do this, click on the New User link on the homepage. This will take you to a page containing MoodGYM's Terms of Use and Information about Privacy. This is important information that you must read carefully before proceeding. To accept the terms of use, click the I agree link.



The MoodGYM homepage

2. You will then be asked to complete the registration form shown on the right. Choose a USERNAME and PASSWORD that you will use each time you log onto MoodGYM. **Make sure you keep a record of your username and password for future reference.** (If you provide an email address, an automated email will be sent to you confirming your user details.) **Please do not enter your real name—instead use a pseudonym or a made-up username.**



The registration page

3. After entering your details, hit the Add User button. This will take you to a screen titled the MoodGYM training program shown right. This is the MoodGYM 'Main page' You can return to the main page at any time during your MoodGYM session by hitting the Main link at the bottom of the screen.



The MoodGYM training program page

Getting started

To get started, go to the navigation bar at the bottom of the main page and click on one of the following links:

- [What is MoodGYM?](#)
- [Begin the training program](#)
- [Interactive extras](#)
- [Disclaimer](#)
- [Feedback](#)

We suggest that you begin by clicking on the what is MoodGYM? link. This will open a new page that contains further links to information about MoodGYM, such as how the website was developed and the techniques used in the program.



The What is MoodGYM? page

To begin the training program, click on the begin the training program link that appears at the bottom of the main page. This will open a page that contains information about the MoodGYM exercises and quizzes, the Workbook, and how to navigate the site. It is a good idea to familiarise yourself with this information before you go further into the program. (But remember, as you move through MoodGYM, you will become familiar with how it works).



The Begin the training program page

You are now ready to start the program!

Before you begin the first module

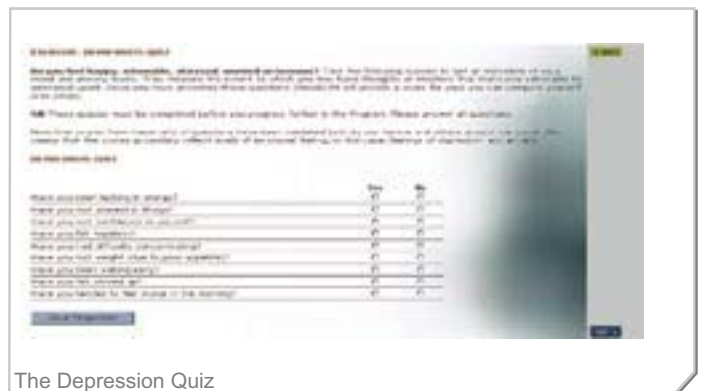
1. Once you are ready to begin, click the NEXT button at the right of the screen. This will open the [Meet the characters](#) page, where you will be introduced to MoodGYM's six characters. Find out about each character by clicking on the relevant icon. ▶
2. When you hit the NEXT button after meeting the characters, you will be asked to complete the first [Depression and Anxiety Quizzes](#). To enter your answers to the quizzes, just use your mouse to click in the circle for either 'yes' or 'no', then click on the SAVE RESPONSES button. Your answers will be saved into your Workbook, which you can view at any time by clicking on the OPEN WORKBOOK link at the bottom of the screen. When you have completed the quizzes you will receive immediate feedback about your results. ▶

You will be asked to take a couple of minutes at the beginning of each MoodGYM module to complete the Depression and Anxiety quizzes. These quizzes give you an indication of how you are feeling as you progress through MoodGYM. In the Workbook, there is a graph that displays your results on the Depression and Anxiety quizzes. This is useful for monitoring your progress throughout the program.

3. After you have completed the Depression and Anxiety quizzes, you will be asked to complete the first [WarpY Thoughts Quiz](#). This quiz gives you an indication of your typical patterns of thinking. For each statement, use your mouse to select a response ranging from 'strongly agree' to 'strongly disagree'. Click the SAVE RESPONSES button to save your answers and move onto the next page. There are 7 different pages to complete, and once you have finished, a graph will display your typical thought patterns. To move to the next page, click the [Next – View the characters' results](#) link that appears above the graph. This will take you to a page where you can click on the icons of the characters to see their WarpY Thoughts patterns. ▶



The *Meet the characters* page



The Depression Quiz



The *WarpY Thoughts* graph page

Feelings module

Once you have met the MoodGYM characters and completed the first series of quizzes, it is time to start the first module: Feelings. A Feelings link will appear on the right of the screen, and you will see the page shown right. ▶

Click on the ENTER icon on the screen, or the NEXT button to begin the module.

The Feelings module takes about 20 minutes to complete. In this module you will:

- Find out about negative thinking patterns, biased perceptions of situations, and negative views about the future;
- Discover if you have biased views of the future or of yourself;
- Learn about how the way you think influences the way you feel (also known in MoodGYM as 'WUTIWUF'); and
- Reflect on how you tend to respond to day-to-day challenges.

There are four exercises for you to complete in this module. We strongly suggest that you complete all of the exercises if you can. Your answers are recorded in your Workbook, and some of them are kept for you to use later in the program.

You will notice that the final exercise of the Feelings module (Three Encounters of an Emotional Kind) involves an exercise where you record events that occur over the next 3 days. Although it is possible to start the next module without completing this exercise, we recommend that you complete it first. ▶

The very last page of the module is a summary page that reviews what was covered in the module, and shows you your results from the exercises. There is also a place for you to record your personal goals for the week. We suggest you print out this page as a record of your activity. ▶

Once you have reached the end of the Feelings module, a link for the next module will appear at the right of the screen. To begin the module, click on this link, then click



The entry page for the *Feelings* module



The WUTIWUF page



The link to the final exercise of the *Feelings* module, Three Encounters of an Emotional Kind



The *Feelings* module summary page

Thoughts module

The **Thoughts** module takes about 25 minutes to complete. The module begins with the Depression and Anxiety quizzes. After completing these, you will:

- Learn to identify biased or 'warpy' thoughts that lots of people have.
- See if you can identify these warpy thoughts in yourself.
- Learn how to challenge and contest your warpy thoughts—they may not be accurate!
- Find out the areas where you are most vulnerable: Is it the need for approval, the need to be loved, the need to succeed, the need to be perfect...or something else?
- Start learning about self-esteem and how to improve it.

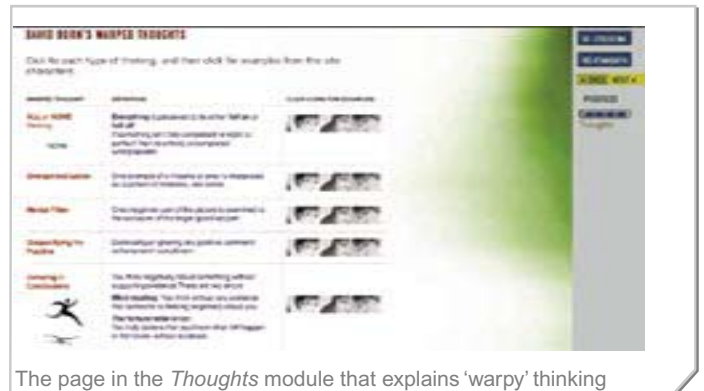
Note that some of the exercises in this module use 'Flash Player'. Look carefully at each of the pages to make sure that you haven't missed any of the interactive exercises. (See the *Frequently Asked Questions and Troubleshooting* section for how to get Flash Player if you don't have it).

The last exercise of this module (**Being nice to myself for a change**) involves keeping a 'diary' of nice things you do for yourself during the next week. You can start the next module without completing this exercise, but it is a good idea to complete it first.

When you get to the end of the module, remember to print out your summary page.



The entry page for the *Thoughts* module



The page in the *Thoughts* module that explains 'warpy' thinking

Unwarping module

The **Unwarping** module takes at least 30 minutes to complete. After completing the Depression and Anxiety quizzes, you will:

- Learn ways of changing your thinking—for example, taking the role of the reporter, increasing positive thinking, setting up thought experiments, trying new ways of responding, being your own coach and mental biofeedback... Try them all and see which works best for you!



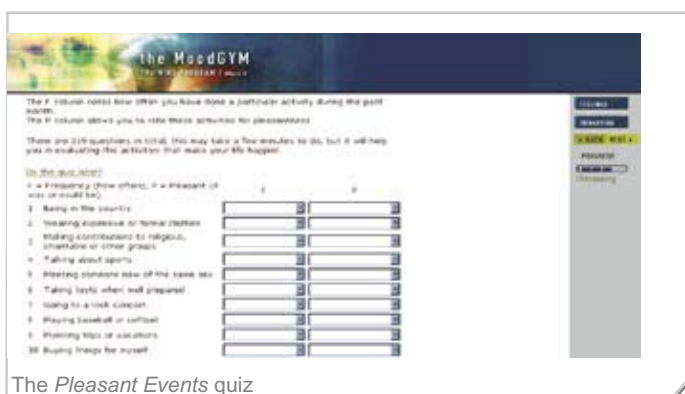
The entry page for the *Unwarping* module

- Work on improving areas where you may be at risk. Based on your responses to the first Warpy Thoughts Quiz, the program will identify your areas of vulnerability. On the menu page (shown to the right), click on these areas for specific suggestions. You will return to this menu page after completing each of these suggestion sections. You can visit all sections if you wish, or just focus on your particular areas of vulnerability.
- Get a chance to identify what sorts of activities you like in the [Pleasant Events](#) quiz. This assessment is lengthy (it has 319 questions!) BUT at the end you will find out how frequently you do things you enjoy (maybe completing long questionnaires is not one of them!). You will also find out how you compare to other people. Do you engage in as many enjoyable activities as others? Are there things that you enjoy doing that you aren't doing at the moment? Keep at it... it will be worthwhile when you finish!

Don't forget to print out your Unwarping module summary page.



The menu page in the *Unwarping* module that provides you with different information and exercises for different types of vulnerability



The *Pleasant Events* quiz

De-stressing module

The De-stressing module is designed to help you relax and cope with stress better. The module starts with the Depression and Anxiety quizzes. Once you have completed these quizzes, you will:

- Start learning about stress and how it works.
- Find out about the stressors in your life and how they might affect you.
- Do a questionnaire that lets you know if you are vulnerable because you have been exposed to many stressful events in your life recently.
- Try out some relaxation exercises that can help you deal with stress. There are three relaxation tapes and each can be downloaded free by clicking on the links. However, this may take some time. Try to download them from a computer that has a 'broadband' connection. This will be much quicker!
- Examine your relationships with your family, particularly with your parents (try the [Mum and Dad](#) quiz). Although it is written from the perspective of the young person, this section provides information that is useful for both parents and children.



The entry page for the *De-stressing* module



MoodGYM has three different types of downloadable relaxation tapes which are available from this page

- Find out more about relaxation in the [Relaxfest](#), the relaxation game-show! Remember to click on the small red NEXT button at the bottom of the picture (not the larger NEXT button at the side of the screen, otherwise you will miss the Relaxfest altogether!).

Don't forget to print out your summary page at the end of the De-stressing module.



The Relaxfest page

Relationships module

The [Relationships](#) module is the shortest MoodGYM module. Relationships can be a source of great distress when they go wrong. This module aims to help you cope with and grow after a relationship breakup. The module also describes simple, but highly effective problem-solving strategies.

After completing the Depression and Anxiety quizzes, you will learn about:

- The thoughts and feelings that are common in different stages of relationship breakups. Do any of these sound familiar to you? (This section uses Flash; take care that you don't miss the small red NEXT buttons in the middle of the screen.)
- How to contest your warpy thoughts so that you can cope better with relationship breakups.
- A simple problem solving strategy.

Don't forget to print out your summary for the Relationships module.



The entry page for the Relationships module



The relationship breakup page



The problem-solving page

After the last module

Once you have completed the MoodGYM modules, there is one final set of quizzes to complete – the final Depression and Anxiety quizzes, and the final Warpy Thoughts quiz. Once you have done these quizzes, have a look at the graph in your Workbook and see if your scores have changed since you first completed these.

After completing the quizzes, you will see a [Wrapping it up](#) page. This page provides a run-down of the topics covered in MoodGYM.

You can then submit feedback about what you thought of MoodGYM. Were there particular parts that worked well for you? Were there parts that you didn't like? We welcome all feedback about MoodGYM, good or bad. (The feedback form is also accessible at any time by clicking on the [Feedback](#) link at the bottom of the page).

FINALLY, on the very last page of MoodGYM, you will be awarded a [Certificate of Completion](#), which you can print out.

CONGRATULATIONS ON COMPLETING THE MOODGYM PROGRAM!!



The certificate of completion

2. Frequently asked questions & troubleshooting

Next time you visit MoodGYM

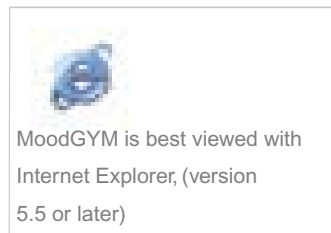
Once you have registered as a MoodGYM user, in future visits to MoodGYM you should click on the [Registered Users](#) link on the homepage (<http://moodgym.anu.edu.au>), then enter your username and password to log on.

What can I do if my connection is too slow?

If you find the site too slow you may prefer to use a computer with a fast connection (broadband access). You can find computers with broadband access in libraries and internet cafés.

How can I get Internet Explorer?

MoodGYM is designed to work best using Internet Explorer version 5.5 or later. If you don't have it installed on your computer, you can download it for free at www.microsoft.com/windows/ie. However, unless you have broadband access, this may take a long time. Fortunately, you can get the latest version of the browser from computer magazines that offer it as a free promotion.

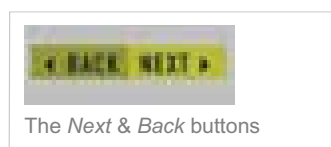


Why are some of the screens blank?

Many of the pages in MoodGYM use 'Flash Player' to display graphics and animations. If you see a page that doesn't seem to be loading properly, you probably don't have Flash installed on your computer. You can download Flash for free at <http://www.macromedia.com/downloads/>.

How do I navigate around MoodGYM?

Use the NEXT and BACK buttons to the right of the screen to navigate your way within the modules. (You may need to scroll across to see the NEXT and BACK buttons.)



The *Next* & *Back* buttons

How does the Workbook work?

When you save your answers to a quiz or exercise, your answers are stored in your Workbook. If you open your Workbook before you have completed any of the exercises, you will find that the exercise names appear in **white** text, and you won't be able to click on the exercises to open them. To complete an exercise, you need to exit the Workbook (by clicking on the EXIT WORKBOOK button at the right of the screen), and use the NEXT and BACK buttons to navigate through the module to reach the exercise.

Once you have completed and saved an exercise, it will appear as a **blue** hyperlink in the workbook. Exercises that you have saved but not completed in full will appear as **yellow** hyperlinks. You can click on the hyperlinks to open the exercises. As you progress through MoodGYM, you can use the workbook as a 'road-map' to see which exercises you have done, and which you haven't.

Also stored in your Workbook is a graph showing your results in the Depression and Anxiety quizzes that you have completed (click on the link [Your Depression and Anxiety Quiz Results](#) on the Workbook contents page). As you progress through MoodGYM and complete the Depression and Anxiety quizzes, your results will be added to the graph, so that you can compare your quiz results across the MoodGYM program.

You can open your Workbook at any time by clicking on the OPEN MY WORKBOOK link at the bottom of the screen (then click on the ENTER icon on the screen). To leave the workbook and go back to the page you were on, click on the EXIT MY WORKBOOK button at the right side of the screen.

Can I skip a module and move onto the next one?

You will find that MoodGYM has been designed so that you can only move through the site in sequence. This means that you cannot skip a module and move onto the next module: you must finish a module before you can access the next module.



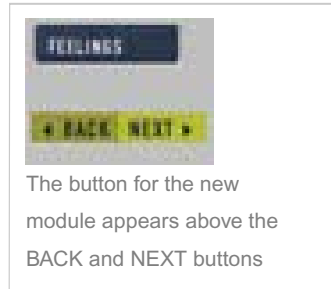
The Workbook entry screen



The Workbook Contents Page

How do I start a new module?

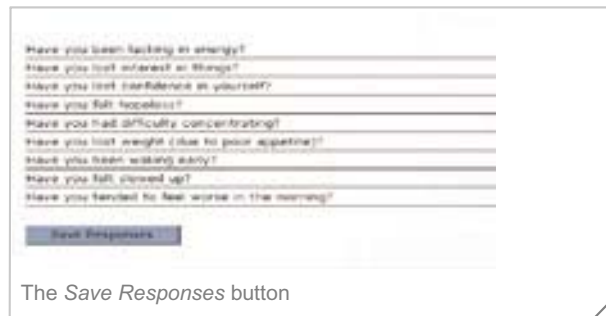
When you have finished a module, you will see the next module button appearing on the right of the screen, above the BACK and NEXT buttons. Click on the module button, then NEXT to begin the next module.



The button for the new module appears above the BACK and NEXT buttons

How do I save my answers into my Workbook?

To save your exercise answers in the Workbook, click on the SAVE RESPONSES button that appears at the bottom of the exercise. You can open your Workbook at any time by clicking on the WORKBOOK link at the bottom of the page.



The Save Responses button

In some of the quizzes, you will notice that the NEXT button is red instead of yellow. This means that for this quiz, you need to answer all the questions, and press the SAVE RESPONSES button before you can move onto the next page.

What happens if I don't answer all the questions?

Some of the MoodGYM exercises must be completed in full before you can move onto the next page. Other exercises do not need to be completed. However, we recommend that you complete all of the MoodGYM exercises. By doing this you will get much more out of the program than if you simply read the material presented. Also, in some exercises, the answers you give are used in later exercises, so if you have skipped over some of the early questions, you may not find later exercises as interesting or useful.

How do I know how much further I have to go in a module?

When you begin a module, a progress meter will appear at the right of the screen. As you move through the module, the number of blue 'blocks' in the progress meter will increase. This lets you know how much of the module you have completed, and how much further you have to go.



The Progress Meter

Can I go back to earlier modules?

Yes, you can go back to an earlier module by clicking on the relevant module button that appears at the right of the screen, above the BACK and NEXT buttons.

'Pop-up' windows

There are many links to pop-up windows throughout MoodGYM. Most of these windows have a CLOSE WINDOW label at the bottom of the text, which you can click on to take you back to the page you were on. If they don't, click on the small box with a cross in it, in the top right hand corner to close the window.

Exiting MoodGYM

To exit MoodGYM, you can simply close your browser, or click on the [Log Off](#) button at the bottom of the screen.

Next time I use MoodGYM, can I go back to the last page I was on?

Yes. On the main page, there is an option to return to the last page you worked on. Hit the [Click here](#) link to return to that page.

What are the 'characters' in MoodGYM for?

Throughout MoodGYM you will see references to the characters, Elle, Noproblemos, Moody and others. These characters help to illustrate the important information and techniques in MoodGYM. By clicking on these characters you will see the different ways each reacts to different situations.

Can I get personal feedback?

Unfortunately MoodGYM doesn't have the resources to give users individual feedback. If you would like to find out how to get personal feedback to any questions you may have, go to the [what is MoodGYM](#) link (on the main page), and click

on the [personal feedback](#) option at the top of the screen. This will take you to a page that has some links that you may find useful.

Are my answers confidential?

The information that you enter into your workbook is collected in our database and can be accessed by a small number of researchers involved with MoodGYM. This information is only identified by your username and not by your name. These data are treated with the strictest confidence. To further protect your privacy, **please use a pseudonym or a made-up username when you register.**

Detailed information about confidentiality can be found by clicking on the [Disclaimer](#) link at the bottom of the MoodGYM screen.



The [Click Here](#) link will take you back to the last page you worked on

3. Technical information about MoodGYM

About the development of MoodGYM

Authors

The concept for MoodGYM and the content of the site were developed by the Centre for Mental Health Research (CMHR) at the Australian National University (www.anu.edu.au/cmhr).

Design

Young people from the community provided feedback about the look of the site, its content and ease of navigation. The graphics and layout for MoodGYM were designed by Minh Dang Nathan Bayliss and Mick Carney at Silverscope. Database assistance and design was provided by Corporate Information Systems at the ANU and 110.com. The original music and voice for the progressive relaxation and meditation programs were provided by Candie Argento and Nathan Vincent. The 'Relaxation by musical composition' original track is the work of Nick Hulscamp.

MoodGYM users

MoodGYM was originally designed as a **prevention** program for depression for youth aged between 15 and 25 years. However, data from over 19,000 individuals who have registered at the MoodGYM site over the last two years indicates that individuals who use MoodGYM directly through the Internet have elevated anxiety and depression scores relative to those in the general community. The average age of users is about 35 years. Approximately two thirds of users are women, reflecting the higher prevalence of depression in women. This pattern of usage suggests that individuals at **most ages** and with relatively **high symptoms** of anxiety and depression may find MoodGYM useful. Please note, however, that the MoodGYM program recommends that all individuals who score highly on the

depression screening instruments seek the advice and help of a health professional.

Cognitive Behaviour Therapy (CBT) ¹

MoodGYM is designed to deliver cognitive behaviour therapy (CBT), an evidence-based psychotherapy commonly used in clinical practice. The cognitive therapy component is designed to change dysfunctional beliefs and thoughts thereby lowering emotional distress. The behaviour component, which includes relaxation training, problem solving, and activity scheduling, is designed to identify factors in the environment that could change behaviours.

People who are depressed tend to have distorted thinking patterns. They see themselves and their situation more negatively than others see it. CBT teaches people how to replace their unhelpful thinking styles with helpful thinking patterns.

CBT has been shown to be an effective treatment for people with mild to moderate depression. In fact, CBT is as effective as antidepressant drugs for these people. Unlike antidepressants, CBT works as well for adolescents as for adults. Another advantage is that unlike antidepressants, CBT helps people learn skills that may prevent them from becoming depressed in the future. CBT may not be suitable for severely depressed people because they may be too depressed to learn the new thinking skills.

¹. Source: Jorm AF, Christensen H, Griffiths KM, Korten A, Rodgers B. *Help for Depression: What Works (and What Doesn't)*. Centre for Mental Health Research: Canberra, 2001. This is an evidence-based review of a range of medical, psychological and alternative 'treatments' for depression. The book can be purchased from PANDANAS Books, ANU. (Ph. 02 6125 3269; Fax: 02 6125 9975; website: (<http://rspas-bookshop.anu.edu.au>)). See also MoodGYM's sister site BluePages (<http://bluepages.anu.edu.au>).

CBT resources

CBT is generally provided by a specially trained clinical psychologist or counsellor. CBT is also sometimes available from therapists employed in hospitals or government-funded clinics. There are also self-help books on CBT, which can be bought in most bookshops. Some examples are:

- Feeling Good. The New Mood Therapy. David D Burns (Morrow, 1999).
- Beating the Blues. S Tanner & J. Ball (Doubleday: Sydney, 1989).
- Control your depression. PM Lewinsohn, RF Munoz, R.F., MA Youngren, & AM Zeiss. (Englewood Cliffs, NJ: Prentice-Hall, 1986; 2nd edition)

Publications about MoodGYM

Below is a list of articles and publications about MoodGYM for those who are interested in reading more about the program:

- Griffiths KM & Christensen H. MoodGYM and BluePages. In *Openmind: The Mental Health Magazine.* Issue 121: May/June 2003.
- Christensen H, Griffiths KM & Korten A. (2002). Web-based cognitive behaviour therapy: Analysis of site usage and changes in depression and anxiety scores. Journal of Medical Internet Research. February 15; 4(1): e3.
- Christensen H, Griffiths KM & Jorm AF. Delivering depression interventions using the Internet: positive results from a large randomized controlled trial. (submitted)

Acknowledgements

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Greg Battye (Division of Communication and Education, University of Canberra)
 David Hawking (Mathematical and Information Sciences, CSIRO)
 John Hearn (Deputy Vice Chancellor (Research), Australian National University)
 Robin Stanton (Pro Vice Chancellor, Australian National University)

Manuals

Chloe Groves, Kathy Griffiths, Helen Christensen



e-Mental Health in Australia: Implications of the Internet and Related Technologies for Policy



Helen Christensen | Kathleen M Griffiths | Kimberley Evans

CENTRE FOR MENTAL HEALTH RESEARCH
THE AUSTRALIAN NATIONAL UNIVERSITY





e-Mental Health in Australia: Implications of the Internet and Related Technologies for Policy

May 2002

Helen Christensen | Kathleen M Griffiths | Kimberley Evans

CENTRE FOR MENTAL HEALTH RESEARCH
THE AUSTRALIAN NATIONAL UNIVERSITY



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Papers published as part of the Information Strategy Committee Discussion paper series are not meant to be prescriptive and do not represent any official Government, National Mental Health Working Group, or Information Strategy Committee position. They are intended to stimulate discussion on a range of mental health information development and outcome measurement issues. The views expressed in these papers are not necessarily the views of the Commonwealth Government or any particular State or Territory government.

Suggested citation:

Christensen H, Griffiths KM, Evans K. 2002. e-Mental Health in Australia: Implications of the Internet and Related Technologies for Policy. ISC Discussion Paper No 3. Commonwealth Department of Health and Ageing, Canberra.

Additional copies of the report can be obtained from:

Mental Health and Special Programs Branch
Commonwealth Department of Health and Ageing
GPO Box 9848
Canberra ACT 2601
Phone: 1800 066 247
Facsimile: 1800 634 400
Website: <http://www.mentalhealth.gov.au>

Previously published ISC Discussion papers

Discussion Paper No. 1 (Out of Print)

Morris-Yates, A & Andrews, G (1997)

Local Area Information Systems for Mental Health Services:
General Principles and Guidelines

Discussion Paper No.2 (Out of Print)

Report of the National Indigenous Mental Health Data
Workshop (1998)

Designed by Fusebox Design

Printed by National Capital Printing

Publications Approval number: 3184

Foreword



This report revives the ISC Discussion Paper series issued under the auspices of the Information Strategy Committee of the AHMAC National Mental Health Working Group. Access to quality information is essential to achieve the objectives of the National Mental Health Strategy. The series provides a vehicle for generating debate about how quality information may be defined, gained and used. As such, the series takes a broad view of the term information, similar to that in the report, *Mental Health Information Development: National Information Priorities and Strategies under the Second National Mental Health Plan 1998-2003 (First Edition June 1999)*, where it is used in a management intelligence sense enabling effective planning, resourcing, management and delivery of mental health services that best meet community need. Innovations in information and communications technology provide compelling opportunities to underpin improvements in information management and service delivery.

As the third paper in the ISC Discussion Paper series, this report addresses the important emerging area of electronic mental health and aims to generate discussion about these developments as well as highlighting possible strategic areas for action by governments and other interested parties.

Rapid developments are occurring in the broad field of electronic health, including the use of new and emerging information and communications technologies to provide better health services to Australians who require them. Electronic mental health service provision is at the leading edge of these developments.

Within Australia, national activity in electronic health is being guided by *Health Online: A Health Information Action Plan for Australia*, endorsed by Australian Health Ministers, and the *National Telehealth Plan for Australia and New Zealand*. Under these plans, governments, consumers, health care providers and others are working on a range of projects and activities to harness the new technologies to improve the range and quality of health services and information available to the Australian public.

Activity in the area of electronic mental health needs to take account of the wider electronic health agenda, but also contribute to and extend that agenda. This report, accompanied by a targeted consultation process, is an important step in this direction, and will help inform the mental health policy agenda and strategic ways forward.

Dr Peggy Brown
Chair, Information Strategy Committee
Australian Health Ministers' Advisory Council
National Mental Health Working Group

Dermot Casey
Assistant Secretary
Mental Health and Special Programs Branch
Department of Health and Ageing

Acknowledgments

Special thanks are due to Professor Tony Jorm who chaired the 26 June 2001 meeting in Canberra, to Ms Claire Kelly for producing the reference list and for organisation, research and secretariat support and to Dr Ruth Parslow and Ms Chloe Groves for their assistance with the report. We also wish to thank Ms Helen Catchatoor for her many helpful comments on the manuscript.

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Executive summary



The Internet and other technologies have the potential for delivering better mental health information, improved and cost effective mental health services and greater opportunities for prevention of mental health disorders. There is now a need to take stock of the impact of the technology, to consider the advantages and difficulties associated with its use and to develop strategies and policies to improve the practice of Internet mental health.

In recognition of this need, under the National Mental Health Strategy, the Mental Health and Special Programs Branch of the Commonwealth Department of Health and Aged Care (now the Commonwealth Department of Health and Ageing) commissioned the Centre for Mental Health Research at the Australian National University to convene a national workshop to provide input about the use and national policy implications of Internet technology in mental health. The workshop, which was held on 26 June 2001, involved a range of stakeholders including consumers, researchers, e-mental health service providers, policy makers, technology experts, mental health practitioners, and representatives from rural and culturally diverse backgrounds from around Australia.

The aim of the workshop was to identify:

- the advantages of Internet based technologies;
- the key obstacles to the use of Internet technology in mental health;
- possible means by which these obstacles could be overcome;
- the roles of government, the private sector, universities, health professional groups, consumers and affiliated organisations; and
- ways in which consultation among the participants and with the Commonwealth could continue.

The content and scope of the report

This report is based on lectures delivered by experts and tasks completed by participants at the workshop, a subsequent online survey of participants and other interested stakeholders who were unable to attend the workshop, and a review of the current literature on Internet mental health. The report summarises the outcome of these activities and presents a total of ten suggestions and associated strategies aimed at assisting policy makers to frame future national mental health policy.

In this report we use the term 'e-mental health' to refer to mental health services and information delivered or enhanced through the Internet and related technologies. The focus in the report is on the use of the Internet in mental health delivery, education and health promotion and illness prevention. In particular, it focuses on the use of World Wide Web technologies, the exchange of information via email, and the use of chat groups and data transfer. However, many of the suggestions and issues addressed in the report are relevant to other technologies (eg call centres). In addition, although the report is explicitly

concerned with mental health policy, we acknowledge that any work in the area must be considered and implemented in the context of national e-health developments and plans, particularly those relating to Health Online (NHIMAC, 2001).

Outcomes

Advantages of the Internet in mental health

Workshop participants identified five main advantages of the Internet in mental health:

a) Cost reduction

The Internet can reach a wide audience cost effectively and may thereby help manage health delivery costs. Targeting consumers at an early stage using the Internet may prevent symptoms from developing into disorders that require more expensive treatment. Technology may also decrease the burden associated with routine procedures. Consistent with this suggestion, there is some evidence from the literature that technology based disease management designed to improve self management of health is cost effective.

b) Facilitation of conventional service delivery

Services, particularly those relating to prevention strategies, could be integrated within the established health and community sectors, community groups could be linked to e-mental health services and e-mental health resources could be developed through partnerships between the traditional health sector and the community sector. Recent evidence suggests that the Internet is acceptable to patients, doctors and the general community, and that online support groups are popular and associated with a high degree of participant satisfaction.

c) Introduction of innovative services

The Internet is able to offer individually tailored (customised) help that may not be achievable in the timeframe provided in typical service delivery. It can facilitate the development of new networks and partnerships that would be impossible without a suitable communication infrastructure. Information can also be delivered consistently, accurately and comprehensively, treatments can be delivered with fidelity, and the Internet can facilitate the storage and rapid location of relevant information. Information delivery is inherently self paced and available at all times, and the user can obtain confidential access to a broad range of treatment and services.

d) Democratisation of health care and facilitation of consumer empowerment

The Internet makes possible the widespread dissemination of accurate mental health information. It leads to a more informed and hence a more empowered community. This increased mental health literacy may improve health outcomes for the entire society. The technology also increases the capacity of the broader community to be involved in the development of mental health services. There is evidence that self help on the Internet is prevalent overseas. It is likely that self help on the Internet is also prevalent in Australia.

e) Improved access

There is growing use of the Internet for the delivery of mental health interventions in Australia and a recognition that the Internet may be a useful means of providing for 'unmet' need. Arguably, Australia is one of the leading countries in the development of e-health and e-mental health initiatives. The workshop participants were confident that the Internet could assist in addressing some critical issues of relevance to certain disadvantaged groups, particularly those living in rural and remote areas. It was also felt that the level of computer literacy in the community, and particularly among young people, is growing and that over time the accessibility of Internet mental health programs will increase.

Barriers to the use of Internet technology in mental health

Workshop participants identified five main barriers to the implementation of e-mental health initiatives. These included:

a) The lack of established funding models in conjunction with high development and continuing maintenance costs

Participants expressed considerable concern over the high cost of the new technologies, both with respect to development and maintenance costs. It was felt that some areas (eg telepsychiatry, 'Web counselling') were likely to develop more quickly than others (eg community education, consumer to consumer support) due to differences in the potential for putting funding models in place.

b) Increased short term costs associated with increased uptake of conventional and other services

There was concern that increased awareness due to Internet promotion might lead to an increased demand on an already overburdened health system. There is no systematic empirical evidence relevant to this question.

c) Issues relating to ethical responsibility and liability

It was felt that some health provider resistance to the use of the Internet may arise from fear of legal liability. Problems might arise if information offered over the Internet is misconstrued or used inappropriately. Liability issues also concern non professional practice and information posted on the Internet. It is unclear if professionals and Web developers are ethically or legally obliged to respond to requests for help on their Websites. International evidence suggests that professional and non professional e-mental health practice is inconsistent and unstructured.

d) Privacy issues

The perception that privacy is protected is crucial to the uptake and use of e-mental health services. However, there is a basic tension between the need for access to health records and the need for security of those records. The new technologies raise important questions in relation to regulation and control of record access and the authentication of users in situations where it is not easy for each party to verify the identity of the other. The issue of the possible inappropriate use of data collected on information, prevention and consumer sites was also raised.

e) Poor quality of information

There were concerns that information may be inaccurate, that it is often not referenced, and that sponsors or potential conflicts of interest are often not declared. It was noted that there is no external regulation of Internet sites, and that there are no intelligent search engines that can retrieve only information that is accurate and consistent with evidence based standards. Consumers are not necessarily in a position to judge the validity of Internet material. Consistent with these views, there is research evidence that the quality of information on the Web is variable and that many mental health Websites produce low quality information for mental health consumers.

f) Lack of evidence of efficacy or effectiveness

Although participants believed that the Internet could and should play an important role in the delivery of mental health services, there was a concern about the lack of evidence about the effectiveness of Internet delivered services. Our own review of the literature on e-health and e-mental health sites largely supports these concerns. However, there is some evidence in support of the use of health care education, treatment and prevention of eating disorders, professionally mediated support groups, and the use of the Internet for the collection of data in epidemiological surveys.

g) Lack of uniformity of access

Australians do not have equal access to the Internet. Those who most need access to health care are often those least equipped to bridge the digital divide. In our community there is a self perpetuating cycle of low education, low health literacy, low income, and poor health. In addition, many sites are designed without sufficient input from the end user. Websites are therefore less accessible to the groups for whom they are primarily intended.

h) Limitations to the availability of optimal technologies

Despite the government policy of universal service obligation, few Australians have access to high bandwidth. This can result in a frustratingly slow service. It places serious limits on the use of state of the art technology by the majority of Australians and on the provision of Internet based psychiatry services into the home. In addition, the current telecommunication pricing structure (which depends on distance) limits technological take up. A further barrier is the lack of a suitably trained workforce for creating applications (eg hypertext, streaming, and multimedia) and failure to use the full potential of the Internet in designing applications.

Moving forward: Overcoming barriers and capitalising on advantages

From the workshop discussion, five major areas requiring action were identified. These are described below:

a) Access

It was felt that government should play an important role in implementing strategies to bridge the information divide.

Suggested schemes for facilitating access to Internet terminals included the use of resources of commercial and public organisations 'out of hours'; the more effective subsidisation of access by disadvantaged Australians; and seeking deals with Internet Service Providers to gain discounted rates for viewing health sites. It was also considered that access would be improved if all members of the community are sufficiently 'information literate' to use the new technologies, and if the end users (both professionals and consumers from different backgrounds) are involved in the design of the sites. It is also important to understand consumer needs, values and preferences so that we know what information is most desired and useful to consumers. Finally, there is a need to invest in service supply and remote system technology in Australia.

b) Ethical issues

There is an urgent need to develop a position on the role of professionals and others in e-mental health service delivery in Australia (eg to develop procedures for conducting professional to consumer relationships using the Internet). These procedures should be developed by professional organisations in consultation with government and consumers.

Confidentiality and privacy guidelines need to be developed with the involvement of all relevant stakeholders: providers of e-mental health services including consumer providers; mental health

consumer and carer representatives; research bodies, including NHMRC; and relevant statutory authorities. Some respondents felt that it was possible to rely on the provisions of the *Privacy Amendment (Private Sector) Act 2000* to protect patient information. Other participants advocated the gradual introduction of e-mental health services, and the associated generation of online data on consumers, to allow time to understand and develop solutions to confidentiality and privacy issues.

It was felt that there must be the capacity with any medical record database to mask and unmask components of the record depending on who logs on. Policies, and administrative, technological and legal infrastructures must also be established that ensure that any security breaches are detected and penalties applied. The use of passwords, fingerprints, smart cards, or biometrics were some possible solutions to the need for authentication of users. In addition, some information might be made available only when the patient and the doctor act jointly.

c) Quality and effectiveness

Workshop participants considered that the duty of care and the standards of care afforded across the Internet should not differ from more traditional service provider models. Sites providing consumer information needed to meet appropriate standards, to make explicit their basis for advice and endorsements, and to identify site authors and note the dates of revisions. Another strategy may be to educate the consumer to become more discerning. However, there is a need to identify valid indicators of site or service quality that do not require content expertise. The government could play an important role in promoting quality assurance. In the future, initiatives such as the MedCERTAIN project (Griffiths, Lecture 2.5) may prove helpful in providing consumers with evaluative information about the quality of Websites. The development of intelligent search engines which automatically return high quality mental health sites also offer a potential means for facilitating consumer access to high quality information.

Workshop participants and the online survey respondents considered it imperative that e-mental health services be evaluated, and that the nature of consumer interactions with e-mental health services be examined empirically.

d) Technology

If all Australians are to have access to health services over the Internet, prices must be capped at a reasonable level. Current pricing appears to reflect pricing policy rather than the real costs incurred by the communication carriers.

In addition to a greater expansion of digital technology, more people must be trained to use the technology and to produce software and applications for the technology. Sites and software must be designed that go beyond the linear text sites currently favoured, and target a wider range of users. Collaborative projects and skills sharing should be encouraged. The role of government might be to facilitate partnerships and an open process and to fund demonstration projects.

e) Funding

It was felt that models of funding for some Internet health care technologies could be developed within the Medicare Benefits Scheme and through the health funds. Health promotion and prevention were not considered to be sustainable through private or Medicare sources and might therefore require government funding. Possible funding arrangements include grants, industry support, and user pay arrangements. An e-mental health Cooperative Research Centre may be viable and partnership grants through industry and the Commonwealth may be a suitable model for funding. There is a need to fund e-expertise infrastructure both technologically and in mental health areas.

Towards an e-mental health policy

The Commonwealth is positioned to take a leading role in developing e-mental health policy. The suggestions and strategies outlined below are intended to provide a basis for developing a coherent e-mental health plan for Australia. A number of these strategies should be implemented immediately (eg Suggestion 1). Other strategies can be implemented once e-mental health is established as a priority area in the Third National Mental Health Plan. Suggested timing for implementing the strategies appears at the end of this report (section 4.2).

GENERAL

Suggestion 1: e-Mental health should be a priority area in mental health policy planning.

Strategies:

- Establish a national Reference Group comprising representatives from key stakeholder groups to:
 - advise on e-mental health policy issues;
 - convene, establish the terms of reference for, and oversee relevant working parties;
 - provide input into the consultation process for developing the Third National Mental Health Plan; and
 - present the case that e-mental health should be a priority area within the Plan.

Suggestion 2: e-Mental health initiatives should be integrated effectively into current mental health programs.

Strategies:

- Undertake a comprehensive review of what e-mental health services are currently available. To avoid duplication, this review should take into account other initiatives currently in progress and coordinated by the National Health Information Management Advisory Council and other key groups. The review should document:
 - current Internet mental health information sites as a function of type of intervention strategy and funding source, including a description of services, who provides them, the modes of delivery, the target groups and the users of such services;
 - telemedicine mental health services including Web-counselling, Web-psychiatry and Internet and other e-technology assisted therapy, in particular, Web based ‘call centres’ which offer online advice and counselling;
 - available and emerging e-mental health technologies;
 - Internet crisis services, support groups and chat groups in Australia;
 - initiatives that aim to provide physical access to the Internet and to other e-mental health services for those with mental health symptoms;
 - the attitudes and expectations of consumers and doctors about the role of e-mental health; and
 - the full range of different types of interactions that occur online. This may also include a review of interactions that occur via electronic technology.

- Undertake an analysis of potential methods for integrating Internet services into current mental health programs. Without proactive analysis, Internet services may be disproportionately driven by market forces rather than by consumer or national needs. Delivery systems other than the Internet should also be considered. This analysis of potential methods should draw on:
 - strategies adopted overseas and in Australia;
 - the views of experts in e-mental health and mental health;
 - work in progress occurring at the national level in relation to improving the practice and outcomes in other health areas. Strategies include the use of e-technologies for improving and speeding up communications, coordinating and integrating communication between people within and between disciplines and sectors, and providing more effective diagnostic and prescribing tools;
 - results from prototypical interventions and test cases;
 - the funding and development of demonstration models for how the new technology might work. The latter will depend to some extent on which models are funded under Networking the Nation program and the National Communications Fund, two initiatives set up by the Commonwealth Department of Communications, Information Technology and the Arts; and
 - develop training and continuing education programs targeting medical schools and existing health care provider services to encourage and educate future and existing practitioners to integrate e-mental health initiatives into their practices.

ACCESS

Suggestion 3: Investigate strategies for improving access to information on the Internet for those not currently served by the technology.

Strategies:

Taking into account relevant national strategies developed under the auspices of the National Health Information Management Advisory Council:

- Identify the factors such as lack of physical access, lack of interest and lack of information literacy that contribute to the ‘digital divide’ among mental health stakeholders and serve as barriers to Internet use within Australia. Include in this strategy current literature on the nature of the ‘digital divide’ in Australia. A relevant publication may be that of Hellwig and Lloyd (2000).
- Together with relevant government, non government and practitioner organisations, plan and devise strategies for education and training of mental health consumers, carers and providers in mental health technologies.
- At a national level, identify methods for removing barriers and increasing equity of access to the Internet. Improve Internet content for communities not yet served through the development of local content, catering for lower levels of literacy, and through the involvement of local communities, consumers and carers. Individuals with mental health problems who are older, from a culturally or linguistically diverse background or of Aboriginal and Torres Strait Islander

background should be provided with the opportunity to contribute to the content of mental health sites. Moreover, these individuals should be supported in these endeavours through the development of appropriate guidelines.

- Ensure that health professionals and consumers are given the opportunity to provide input to all government mental health information sites.

QUALITY AND EFFECTIVENESS

Suggestion 4: Develop guidelines that encourage and promote high quality mental health information on the Internet in Australia.

Strategies:

- Under the direction of the proposed e-mental health Reference Group, establish a national working party with representation from major stakeholders with responsibility for:
 - developing a protocol for evaluating mental health Websites;
 - reviewing and ratifying mental health Websites with representation from major stakeholders;
 - reviewing the strategy used by Health*Insite* to develop high quality information;
 - developing strategies to educate consumers about evaluating the quality of information on mental health Websites; and
 - developing strategies for educating mental health Web producers about the importance of high quality information.

Suggestion 5: Promote the development of useful and effective mental health Websites.

Strategies:

- Assess all submissions and tenders for Commonwealth/State/Territory/local government funded Websites against an agreed assessment protocol and agreed standards.
- Assess all submissions and tenders for government funded Websites for inclusion of an appropriate evaluation protocol.
- Ensure that government funding of Internet applications is contingent on these sites developing suitable process and outcome evaluations.

ETHICAL ISSUES, CONFIDENTIALITY AND PRIVACY

Suggestion 6: Under the auspices of the National Health and Medical Research Council (NHMRC), develop and implement guidelines for mental health research activity on the Internet in Australia

Strategies:

- Establish a mechanism by which the research community in cooperation with the NHMRC can develop guidelines for conducting ethical research on the Internet.
- Develop strategies for implementing the guidelines, ensuring particularly that other ethical guidelines both within and outside the NHMRC are upgraded to incorporate guidelines for Web based research.

Suggestion 7: Develop guidelines for the professional practice of online therapy and other e-mental health therapy.

Strategies:

- Encourage professional organisations to develop guidelines and future training and accreditation requirements for the practice of professional online therapy and other e-mental health therapy.
- Use available service guidelines and standards to assist in this process and in the development of future guidelines and standards.
- Extend current initiatives to develop training and support activities for general practitioners, as outlined in Health Outline (NHIMAC, 2001), to psychiatrists, clinical psychologists and psychiatric nurses.

Suggestion 8: Promote the highest standard and ethical code of conduct in all e-mental health interactions.

Strategies:

- Under the direction of the proposed e-mental health Reference Group, establish a national working party to:
 - facilitate the development, implementation and monitoring of ethical guidelines and standards for e-mental health intervention; and
 - identify and examine relevant legal issues, and in particular, professional liability issues associated with online delivery.
- Use developments in broader areas of health (eg from Health Online (NHIMAC, 2001)) to inform this process.
- As part of the guideline implementation process, encourage relevant health professional bodies to integrate guidelines with the existing codes of professional behaviour that govern the conduct of their members.

Suggestion 9: Protect confidentiality and privacy of e-mental health interactions while improving accessibility and continuity of care through the use of e-records.

Strategies:

- Continue current initiatives with respect to medical records (*HealthConnect*), and include and be informed by current developments in the broader health sector.
- Identify any legal issues associated with confidentiality and privacy that are specific to the area of mental health.

FUNDING MODELS

Suggestion 10: Identify means by which the development and provision of innovative e-mental health applications and infrastructure can be funded.

Strategies:

- Review the roles of industry, community and government stakeholders in funding innovative e-technologies. In particular, review:
 - current initiatives in broader areas, such as developments in establishing a research and development agenda by the Office of Rural Health of the Commonwealth Department of Health and Ageing, and findings of a working party set up by the New South Wales Department of Health to investigate telehealth financing;
 - the suitability of different levels of intervention (prevention, early intervention, raising mental health literacy, treatment) to funding from each sector. For example, the former interventions are likely to be highly suitable to the new technologies and cost effective. However, they may not prosper without government funding due to the absence of alternative funding mechanisms. Treatment such as psychotherapeutic interventions may be more amenable to a fee for service approach and may therefore be more suitable to private sector funding;
 - the costs and benefits of funding innovative e-health technologies for each level of intervention and conduct an economic analysis of the costs of the Web interventions and counselling relative to face to face service delivery;
 - the means by which existing public funding arrangements for mental health could be changed to integrate the new technologies;
 - mechanisms for joint State and Territory funding of nationally accessible e-mental health developments; and
 - strategies to develop e-mental health infrastructure and in particular to encourage the development of e-mental health technologies and e-mental health expertise. It is clear that high quality sites and useful health information require input from mental health professionals and consumers with expertise in e-mental health.

Section 1: Background



1.1 Background to the report

The Internet is the fastest growing technology in the world, with 50 million users achieved in only four years. It has been estimated that there are 20,000 Websites dedicated to medical care worldwide (Dyer, 2001) and that over 36% of Australians have Internet access in their homes (ABS, 2000). Many more have access from work.

This rapid growth, combined with the potential of the Internet to impact broadly, will affect increasingly the everyday lives of all Australians. In particular, the Internet and other health technologies provide a new platform with the potential of delivering better mental health information, improved and cost effective mental health services and greater opportunities for prevention. However, there are many challenges associated with the use of this technology. The rapid expansion in technology has outpaced the development of standards and guidelines for Internet use, and there is now a need to take stock of the impact of the technology, to consider the advantages and difficulties associated with its use and to develop strategies to improve the practice of Internet mental health.

The Mental Health and Special Programs Branch of the Commonwealth Department of Health and Aged Care (now the Department of Health and Ageing) sought advice about the use of and national policy implications for Internet technology in mental health. Accordingly, a national e-mental health workshop was convened in conjunction with the Centre for Mental Health Research at the Australian National University in June, 2001. The workshop involved a range of stakeholders including consumers, researchers, e-mental health service providers, policy makers, technology experts, mental health practitioners, and representatives from rural and culturally diverse backgrounds from around Australia. Although the workshop focused on the effect of the Internet and Internet supported technologies in the delivery of mental health services, other forms of electronic communication were also considered. The workshop was chaired and facilitated by Professor Tony Jorm from the Centre for Mental Health Research.

This short report is based on three activities that occurred as part or as a consequence of this workshop. These activities were:

- a series of lectures delivered at the workshop by experts involved in developing or evaluating Website developments in Australia;
- tasks completed by stakeholders at the workshop; and
- an online survey of researchers, consumers and developers of Websites from within Australia including attendees at the workshop and other interested stakeholders who had been unable to attend the workshop.

These activities and this report were funded by the Mental Health and Special Programs Branch of the Commonwealth Department of Health and Ageing.

The lectures

Each of the experts was asked to speak on an Internet issue of relevance to a particular area of mental health delivery. The areas of interest were prevention (Dr Helen Christensen), community education (Professor Gavin Andrews), primary care (Professor Ian Hickie), specialist care (Professor Ken Kirkby), the private sector (Dr Dennis Tannenbaum); and international perspectives on Website quality (Dr Kathy Griffiths). John Payne from the Department of Health and Aged Care described a Commonwealth initiative in the area. Edited versions of these talks are presented in Section 2.

The workshop

Appendix A lists the attendees at the workshop. The aim of the workshop was to:

- identify the advantages of Internet based technologies;
- identify the key obstacles to the use of Internet technology in mental health; and
- consider possible means by which these key obstacles could be overcome.

In particular, the workshop attendees were asked to consider the roles of government, the private sector, the universities, health professional groups, consumers and affiliated organisations in this process. The workshop also aimed to develop ways in which consultation among the participants and with the Commonwealth could continue. The present report is an attempt to give forward momentum to this process.

The online survey

Following the workshop, attendees and those who had earlier expressed an interest in attending the event but who had been unable to come, were asked to complete an open ended survey conducted by email. The survey participants are listed in Appendix B.

Survey questions were based on issues identified as important by the workshop attendees and were as follows:

1. Do you believe that e-mental health should be integrated into future mental health policy planning?
2. Can you specify one important means of overcoming barriers and moving the e-mental agenda forward in each of the following areas: (a) resources, (b) quality assurance, (c) privacy/confidentiality, (d) technology, and (e) access.

Responses to this online survey, input from the workshop itself and a review of the literature form the basis for Section 3.3 which addresses how the e-mental health agenda can be moved forward.

Recommendations

The final section of this report contains a list of suggestions and strategies of relevance to mental health policy and strategic planning. These suggestions are based on the outcomes of the workshop and online survey, and on an analysis of the e-mental health literature. These recommendations consider the roles of government, Web developers, professional organisations and consumers in the development of e-mental health policy. A critical success factor is likely to be the interest, commitment and participation of a range of stakeholders.

1.2 The context

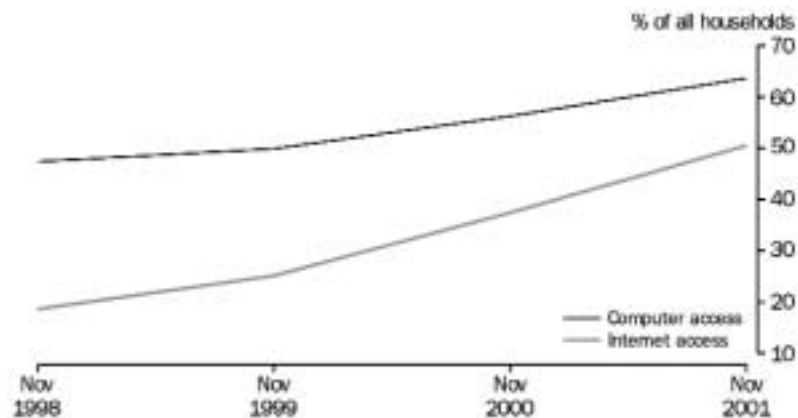
Before describing the lectures, the workshop outcomes and responses to the survey, it is appropriate to briefly outline the growth of the Internet in Australia, to provide definitions and descriptions of the Internet and of e-mental health, to sketch a useful way of conceptualising mental health delivery, and to outline some of the e-mental health initiatives in Australia.

The growth of the Internet in Australia

A new study released on 20 November 2001 from the UN Conference on Trade and Development (<http://zdnet.com/zdnn/stories/news>) (Last accessed 22 November, 2001) reported that even the suicidal airliner attacks on New York on 11 September had made little impact on Internet usage. The report noted that there were 513 million Internet users, likely to reach a billion by the end of 2004. This future growth is predicted to occur mainly in Asia, where, for example, now, patient records are being transcribed in Bangladesh from voice files for US doctors.

Closer to home, in Australia, recent Australian Bureau of Statistics figures (ABS, 2001) indicate that over half (56%) of all Australian homes have a computer, and the number with access to the Internet has risen to 2.7 million (37% of all homes). The rate at which Australians are taking up the Internet is increasing relative to the rate at which computers are entering Australian households (see Figure 1).

Figure 1: Increasing rates of computer and Internet use in Australian households



(Source: ABS 2001. Reprinted by permission)

There is now clearly a need to develop models as to how Internet and other technologies will fit in or produce departures from the normal health service delivery arrangements, to identify the advantages and disadvantages of the Internet, and to explore how barriers to the use of this technology might be overcome. These models need to take into account differences in legal, regulatory and accountability requirements in different states and countries.

e-Health policy context in Australia

In 1998, the Australian Health Ministers established the National Health Information Management Advisory Council (NHIMAC) to advise on options to promote more effective information management (including the application of information and related technology) within the health sector. NHIMAC first released *Health Online: A Health Information Action Plan for Australia* in November 1999 to provide a national strategic framework and action plans for better management and use of health information. The second edition of Health Online was released in September 2001 (NHIMAC, 2001). As part of the Health Online strategy, NHIMAC produced the action paper, *National Telehealth Plan for Australia and New Zealand*, December 2001 (NHIMAC, 2002).

NHIMAC currently has two subcommittees which address specific aspects of health information policy. The National Health Information Standards Advisory Committee (NHISAC) has been established as a national coordinating body for health information standards. The National Electronic Decision Support Taskforce has recently been established to provide advice to Health Ministers on how to achieve a nationally coordinated approach to the development of electronic decision support systems for clinicians in Australia.

Other relevant national policy groups report to the Australian Health Ministers' Advisory Council (AHMAC). These are: the National Health Information Management Group, the HealthConnect Board, the AHMAC Privacy Working Group, the Australian New Zealand Chief Information Officers Forum, and the National Health Supply Chain Reform Taskforce. Another key national group is the General Practice Computing Group.

Scope of the report

In this report, we focus on the use of the Internet in mental health delivery, education and health promotion. We consider the use of World Wide Web technologies, the exchange of information via email, and the use of chat groups and data transfer. We focus less on older technologies such as interactive video and telephones. The definitions used in the present report are narrower than those employed in some other policy papers concerned with e-health (eg NHIMAC, 2002; Mitchell, 1999). Nevertheless, many of the recommendations of the report are relevant to the use of older technologies. Moreover, they are also of relevance to emerging technologies which will pose related policy and service challenges.

Definitions

In this section we define the term 'Internet', examine the definition and attributes of e-mental health, and attempt to establish a framework for examining the role of the Internet in mental health services and delivery.

The Internet

The Internet has been defined as:

a worldwide network of computer networks that use the TCP/IP network protocols to facilitate data transmission and exchange

(Source: WordNet)

Initially, use of the Internet was confined primarily to universities, but since the introduction of the World Wide Web in 1990, it has rapidly expanded its reach to become:

an almost-ubiquitous aspect of modern information system... Its original spirit of cooperation and freedom have, to a great extent, survived this explosive transformation with the result that the vast majority of information available on the Internet is free of charge.

While the Web (primarily in the form of HTML and HTTP) is the best known aspect of the Internet, there are many other protocols in use, supporting applications such as electronic mail, Usenet, chat, remote login, and file transfer.

(Source: Free Online Dictionary of Computing)

The Internet is 'governed' by standards set out by the World Wide Web Consortium (W3C) (<http://www.w3.org/>) and the Internet Engineering Task Force (IETF) (<http://www.ietf.org>).

e-Mental health

The term e-mental health is yet to enter the scientific literature. The recently coined term e-health, however, has been listed 87 times in PubMed, the major international database of medical research abstracts (<<http://www.ncbi.nlm.nih.gov:80/entrez/query.fcgi?CMD=search&DB=PubMed>>; searched 14 November 2001).

Gunther Eysenbach, editor of the *Journal of Medical Internet Research* has defined e-health as follows:

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.

(Source: Eysenbach, 2001)

Directly based on this definition, we define e-mental health as that form of e-health which deals with mental health and mental health disorders. Thus, the term e-mental health refers to mental health services and information delivered or enhanced through the Internet and related technologies.

Eysenbach describes the characteristics of e-health, and these are outlined in Box 1. This conceptualisation acknowledges the importance of the Internet (and other related technologies) in improving access to evidence based information and decision making by professionals and consumers. It also highlights the importance of promoting equal access, an issue that is raised later in this report.

BOX 1: EYSENBACH'S CONCEPTUALISATION OF E-HEALTH

1. **Efficiency** – one of the promises of e-health is to increase efficiency in health care, thereby decreasing costs. One possible way of decreasing costs would be by avoiding duplicative or unnecessary diagnostic or therapeutic interventions, through enhanced communication possibilities between health care establishments, and through patient involvement.
2. **Enhancing quality of care** – increasing efficiency involves not only reducing costs, but at the same time improving quality. e-health may enhance the quality of health care for example by allowing comparisons between different providers, involving consumers as additional power for quality assurance, and directing patient streams to the best quality providers.
3. **Evidence based** – e-health interventions should be evidence based in a sense that their effectiveness and efficiency should not be assumed but proven by rigorous scientific evaluation. Much work still has to be done in this area.
4. **Empowerment of consumers and patients** – by making the knowledge bases of medicine and personal electronic records accessible to consumers over the Internet, e-health opens new avenues for patient-centered medicine, and enables evidence-based patient choice.
5. **Encouragement of a new relationship between the patient and health professional**, towards a true partnership, where decisions are made in a shared manner.
6. **Education of physicians** through online sources (continuing medical education) and consumers (health education, tailored preventive information for consumers).
7. **Enabling information exchange and communication** in a standardized way between health care establishments.
8. **Extending** the scope of health care beyond its conventional boundaries. This is meant in both a geographical sense as well as in a conceptual sense. e-health enables consumers to easily obtain health services online from global providers. These services can range from simple advice to more complex interventions or products such as pharmaceuticals.
9. **Ethics** – e-health involves new forms of patient-physician interaction and poses new challenges and threats to ethical issues such as online professional practice, informed consent, privacy and equity issues.
10. **Equity** – to make health care more equitable is one of the promises of e-health, but at the same time there is a considerable threat that e-health may deepen the gap between the “haves” and “have-nots”. People, who do not have the money, skills, and access to computers and networks, cannot use computers effectively. As a result, these patient populations (which would actually benefit the most from health information) are those who are the least likely to benefit from advances in information technology, unless political measures ensure equitable access for all. The digital divide currently runs between rural vs urban populations, rich vs poor, young vs old, male vs female people, and between neglected/rare vs common diseases.

Source: Eysenbach 2001. Reprinted by permission

Mental health delivery

The role of the Internet is likely to be very different for different levels and sectors of mental health delivery. The role of government and each of the stakeholder groups is also likely to vary as a function of the service delivery sector, as is the case now in nonInternet supported service delivery. We predict that there will be a disproportionate growth in consumer driven Internet interventions such as chat groups, Web counselling and consumer sites. It is also likely that expert system or technology supported interventions which facilitate self help will be growth areas. This growth in consumer driven interventions is likely to extend the scope of health care, produce more informed patients and clients, enable the more efficient use of health care provider time and expertise, and encourage the development of more sophisticated health communication systems.

A number of useful distinctions may provide a framework for discussion about e-mental health services using the Internet (see Box 2). The role of the Internet will vary depending on the *type of intervention*. It may also vary as a function of *volume and cost*. Compared to hospital and specialist care, prevention and promotion is less expensive per individual and directed at a mass audience. Public health interventions are therefore well suited to Internet delivery. A third distinction, overlapping to some extent with the first two, is based on the *type of interaction* between communicators, whether this is between consumer and health care provider (eg doctor, psychologist, social worker) or between consumers and consumers or between health care provider and health care provider (eg GP and specialists). A final distinction relates to the timeliness of the intervention and in particular, whether mental health care is required urgently or whether it is a longer term need. Because the Internet is accessible 24 hours a day, the Internet may be a first point of call in emergencies.

BOX 2: USEFUL DISTINCTIONS FOR MENTAL HEALTH DELIVERY USING THE INTERNET

Type of mental health intervention (Mrazek & Haggerty, 1994)

- Promotion
- Prevention
- Early intervention
- Treatment
- Relapse prevention
- Rehabilitation

Volume and cost structure for these sorts of delivery services

- Prevention and promotion
- Community care
- Primary care
- Specialist care
- Hospital care

Type of interaction

- Consumer/Professional: interactions using email, Web counselling
- Consumer/Consumer: interactions using email, chat groups, bulletin boards
- Consumer/other: advice from non professionals
- Professional/Professional: interactions for peer review, specialist consultation
- Consumer/information: the download of information from the Internet
- Consumer/interactive technology: interactions with a computer program/system
- Professional/information: information targeted at professionals
- Professional/interactive technology: training/ continuing education using interactive systems

Urgency of interaction

- Crisis intervention
- Routine information and care

Clearly, many more sub-distinctions can be made within each of these categories. For example, a further distinction for the type of interaction has been clearly articulated by the International Society for Mental Health Online (<http://ismho.org>) which listed the following types of interventions that are possible using the Internet:

- face to face therapy cases in which contact with the client via the Internet played a significant role (eg email between sessions, the use of Websites as resources);
- short and long term clinical encounters with people that occurred primarily via the Internet (eg therapy via email or chat);
- professional consultations that occurred via the Internet, including, for example, giving advice and/or information to people who contact an online professional and supervision via the Internet (eg via email or message boards);
- face to face therapy cases in which the client's activities in cyberspace were a significant issue in the therapy; and
- online groups and communities in which the mental health professional acts as an organiser, facilitator, or consultant.

e-Mental health services and products in Australia

The National Telehealth Plan for Australia and New Zealand (NHIMAC, 2002) noted that the following services and products were being developed in conjunction with clinicians and health care providers, using telecommunications and information technology (p1):

- Patient services including:
 - patient management consultations
 - second opinions
 - face to face appointments or management of patient referrals
 - diagnostic support, eg radiology
 - clinical information transfer
 - remote patient monitoring
- Continuing professional education
- Collaborative support and training
- Community health information access and education

In the mental health sphere, a number of services are provided by consumers for each other, and these form a part of the use of the Internet in mental health care.

In this report, we classify Internet based interventions for consumers into the following four broad areas:

1. Interventions initiated by doctors/other mental health professionals for patients/clients (Web counselling and email)

In these interactions, there is involvement by the health professional with a patient and the Internet is used to facilitate therapy or medical practice. These include: patient consultations via email or video (Web psychology or Web psychiatry, Web nursing); use of the Internet to provide referrals to hospitals; and Internet based exchange between GPs and specialists. Many of these activities are

included under the Patient services category of the National Telehealth Plan for Australia and New Zealand. Because conventional health care delivery is the defining characteristic of this class of services, it also encompasses activities used by the health practitioners to facilitate communication or knowledge and includes access to scientific information systems, and electronic records. Examples within Australia and New Zealand include:

- Infrapsych (<http://www.infrapsych.com.au>)
- DoctorGlobal (NZ) (<http://www.doctorglobal.com/index.asp>)
- Global Doctor (<http://www.eglobaldoctor.com/>)
- Panic on Line (<http://www.ballarat.edu.au/ruralhealth/panic/>)
- SPHERE (<http://www.spheregp.com.au/sphere.htm>)
- University of Queensland: Cognitive Behaviour Therapy interventions for young people [not publicly available].

These interventions can be highly developed and technically sophisticated, and are capable of extending and reshaping the nature of conventional health care delivery.

2. Interventions designed by organisations to help people manage and improve health through self help

These initiatives do not involve direct contact between health professionals and consumers. These technologies are systematically developed programs that provide interactive services to individuals, and may include Internet, email, Web or video downloading. Examples of these programs overseas for general health include One Health Plan (see Gomaa et al, 2001), and the PA Web (see Fotheringham et al, 2000). Most of these programs aim to prevent disorders and intervene broadly. In Australia, the closest to this form of intervention in mental health is a site that has been launched but is still under development. This site, MoodGYM™ (<http://moodgym.anu.edu.au>), delivers cognitive behaviour therapy to young people. Outcome data on the use and popularity of the site are now available (Christensen, Griffiths & Korten, 2002).

3. Information sites designed by governments, universities, non government organisations, and private individuals and bodies to provide information about mental disorders and their treatment

These sites are designed largely for consumers and carers, but, particularly in the case of clearinghouse sites, may be of use to students for training and professionals for continuing education. Information Websites may encourage mental health literacy and prevention. Examples within Australia include:

- Evidence based information sites developed by universities: BluePages (<http://bluepages.anu.edu.au>), Crufad (<http://crufad.com/hompage.html>), Mood Disorders Unit (<http://www.mdu.unsw.edu.au>).
- Sites describing government and non government initiatives: beyondblue (<http://www.beyondblue.org.au>).
- Government Websites that provide vetted information about mental health issues for both consumers and professionals: for example, HealthInsite (<http://www.healthinsite.gov.au>), Auseinet (<http://auseinet.flinders.edu.au>).

A review of Australian depression Websites has recently been published in the Medical Journal of Australia (Griffiths & Christensen, 2002).

This category also includes sites for professionals such as the Cochrane Collaboration, Medical Prescriber, and PubMed sites and access to and use of diagnostic and decision tools.

4. Sites developed to provide support to those in need

These include Websites for offering support through email, counselling and chat groups. The Internet has seen a proliferation of bulletin boards and chat rooms targeted specifically at health consumers and resulting in increased facilitation of informal communication between health consumers. This development of a worldwide patient to patient network may lead to more effective health lobby groups and may educate health professionals more effectively about the public's perceptions of illness. These sites might also provide Internet call centre services. Examples of Australian mental health sites with these facilities include:

- DepressioNet (<http://www.depressionet.com.au>)
- Reachout (<http://www.reachout.asn.au/home.jsp>)
- Lifeline (<http://www.lifeline.org.au>)
- Kids Help Line (<http://www.kidshelp.com.au/>)

The above classification is useful but imprecise since many sites target both medical health professionals and consumers and offer a range of services. Some sites targeted at consumers have an educational as well as a crisis intervention or call centre function. Because of the potential public health impact of Internet developments and the growth of consumerism and the consumer perspective, we predict that information, support and self help technologies will be those areas that will grow disproportionately faster than other e-mental health sectors in the next decade. These sectors are largely unregulated due to the relatively standard free and egalitarian nature of the Internet. While this lack of regulation has many advantages, there is a need to develop guidelines that will facilitate safe and useful developments on the Internet.

Section 2: The lectures



This section contains edited versions of seven lectures delivered at the 26 June 2001 workshop on e-mental health held in Canberra.

The lectures deal with:

- prevention
- community education
- primary care
- specialist care
- the private sector
- international perspectives on Website quality
- a Commonwealth Government initiative

2.1 'Fearful, Worried, Anxious, Depressed? This is the site for you.' Websites, and the education of the people about mental disorders

Gavin Andrews, MD

Director, Clinical Research Unit for Anxiety and Depression (CRUFAD),
University of New South Wales at St Vincent's Hospital, Sydney

In this paper, Gavin Andrews examines the issues involved in *community education using Websites*. In particular, he outlines the development of his own Website at CRUFAD. This paper is an excellent beginning to the series because it provides an introduction to issues of funding, liability and authentication. These are issues that will be returned to in later sections of the report.

Three issues are of particular importance in this paper. The funding model is one that involves consumers purchasing information from the Website. The second issue is the extent of the interaction between the site developers and the site visitors. In this case, the authors of the site only respond in exceptional circumstances to the consumers who put messages on the bulletin boards. A final point concerns the purpose of the site, which is to provide a service to consumers. There is no intention to evaluate the site using randomised controlled trial techniques.

Gavin Andrews is Professor of Psychiatry at the University of NSW. He is an expert in the treatment of anxiety disorders and the common mental disorders and has a major interest in models of service provision in specialist and primary care.

The excitement of the Web is that it is free, or can be. It is free to the user once they are connected. It is essentially free to the provider. Once the set up and server costs are paid, 200,000 people using the site cost no more than 200 using the site. This paper is an account of the development of the Website <www.crufad.org> which has the alternate URLs of <www.dfordepression.com> and <www.aforanxiety.com>.

In June 2000 we decided to revamp our traditional academic Website <www.crufad.unsw.edu.au> to provide information to people about anxiety and depression, our core business. We resolved to provide information about symptoms so that people could find information quickly to answer 'What is happening to me now?'; information about disorders so that people could be informed about the way that clinicians think and categorise these states to aid their interactions with clinicians; and information about self help strategies so that people unable to access clinical services would know what to do to help themselves.

We did begin with some resources. We had 20 years experience running a clinic that specialised in cognitive behaviour therapy for anxiety and depressive disorders. We had edited and published the *Management of Mental Disorders*, a text for primary care staff that is widely used throughout the world; and we had been teaching a masters course in psychological medicine for general practitioners for seven years and had the teaching materials from that course. We had also written a standard text on the *Treatment of Anxiety Disorders* that contained 'patient treatment manuals' that were very close to the type of material required for self help pages.

The plan for the Website

We divided the site into four components: a self help component for consumers, a clinician support segment, an account of our research activities, and a shop. We budgeted \$50,000 for the development and first year of operation of the site and we aimed to get that back by increased sales of our books, videotapes and CD ROMs from the shop. This paper is about the self help component of the site.

Methods to establish trust

The first problem is how do you enable the visitor to trust the site. We decided no advertising, no cookies, no requests for data from the visitors, just some need to be passively helpful. We did ensure that we were appropriately branded: A World Health Organization Collaborating Centre, St Vincent's Hospital, and the University of New South Wales were all good credentials. The Health on the Net Foundation Code of Conduct (HONcode) was a useful addition. All appear on the home page.

Determining content

Content was not the problem, organising it so that people could use what they wanted was the difficulty. We decided to have three levels of information. The index listed four symptoms and a larger number of disorders separated by the offer of a free test, the K10 developed by Kessler. If people touched the symptom or the disorder then a 100 word 'quick fix' flag was displayed overlaying the existing text. It defined the symptom or disorder and offered pithy advice. We could think of no quick fix for trauma and said so. If they clicked on the symptom or disorder then they got a 300 - 1000 word description that again defined the issue and offered more advice. At the bottom of that there was the invitation to read more. If they clicked on that invitation then the relevant pages of the Management of Mental Disorders would be displayed. The amount of material offered for each keyword/disorder ranged considerably, from a low of 5 pages for Trauma to a high of nearly 100 pages for Depression. The site is little more than an indexed electronic book.

On the top bar there is a discussion button which is labelled as being for people to share experiences and specifically noted as not being for medical advice (although we sometimes do offer advice). There is a button for a list of frequently asked questions and a button for the shop. We had hoped that increased sales of our books, videotapes and CD ROM would offset the cost of the Website, but in addition we did offer complete 'patient treatment manuals' as used in the clinic, saying that the Adobe files could be downloaded for free.

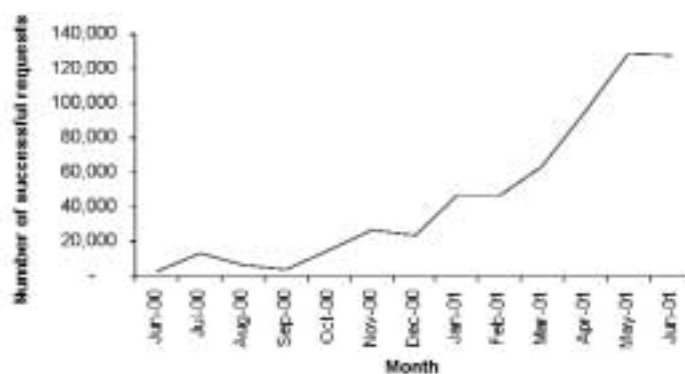
Controlling interactions

The major problem with many Websites is the acute neediness of many people. There is some evidence that meeting manifest needs is not always helpful and we resolved not to emulate 'Lifeline'. On our original CRUFAD Website we had listed the names and email addresses of our staff. Female clinicians especially got a number of emails from desperate people (and some horrifying ones from people simulating desperate people) the needs of whom could not be met over the Web. In this revision of the site we resolved not to provide a crisis helpline but to moderate the discussion board, removing messages we took to be counterproductive, and replying anonymously to messages that seemed to need urgent specific advice. Mostly we let the users care for each other, reasoning that by helping others they learn themselves.

Usage and outcomes from the site

The Website has been used. We spent June to December building the site and throughout that time it had a cover on the front saying that people could enter but they must realise that the site was still being built. In January we removed the cover but did not deliberately let the search engines know we were open for business. In the table below we list the growth in hits over the first six months, a growth rate that averages 30% increase over the previous month. Downloads followed a similar pattern so that at the end of June 120,000 hits were being recorded and 500 MB of downloads were being taken. Comparable figures are difficult to obtain but there is every reason to believe that the site is or will be a success.

Figure 1a: Successful requests per month, CRUFAD Website



Shop sales

We estimate that the increased sales of the books and videotapes probably now net us an extra \$1,500 a month so that we are probably \$20,000 out of pocket to date. We know that income is currently exceeding expenditure by about \$500 per month so that we should eventually pay for the development costs.

Was all this worth it? Probably. The number of referrals to the clinic is falling and whereas we have had a waiting list for many years we now have no waiting list for a first assessment. Perhaps the Website is curing the sick or else they are learning sufficient to avoid having to be treated at a tertiary referral clinic. In the clinician support and research areas we know that enquirers are now better informed so that less time is spent educating the caller. The most amazing thing is that one is impervious to the number of people using the site. Scaling was always said to be one of the advantages of the Web. It certainly is – the work involved in maintaining the site has stayed constant and we have no sense that 20,000 people per month are visiting our site. Next month we will not notice the increase to 200,000 people.

Liability

We are offering advice exactly as one does through a printed book, indeed much of what we offer is direct from our published books. The K10 psychological distress scale is the best available screening instrument and we are explicit in telling people who score in the high range to make every effort to seek professional advice. The sad fact is that more than half of the people who meet criteria for an anxiety or depressive disorder in Australia do not seek professional help and we doubt that exhorting them to see a doctor will change this. Hopefully, they will get information from the site to ameliorate their condition or to let them see that beneficial help is available.

Future Development

Our goal was to develop a self funded sustainable site. This means that we only have a small amount of money to invest in future development of the self help section. Nevertheless there are a number of changes in hand. We are in the process of alerting the search engines that we exist. We are developing interactive advice panels so that instead of reading about Structured Problem Solving we can show an example, and then invite the person to try for themselves, pacing the display of screens to match their reported progress. We will add some audio streaming for people who learn better that way. In this way the site will be an electronic book that has apparently interactive programmed segments.

We have been very cautious about developing links to other sites in part because of the variable quality of people who want to link to us and in part because of an inherent conservatism. We are developing a list of reliable links that offer things that we do not. We will establish a link button so that leaving the site is a deliberate choice and people will be reminded of our URL when they leave. We are not evaluating the efficacy of the advice offered on the site and have no plans to do so. Evaluation means recruiting people into pre-post or randomised controlled trials of efficacy. Many funders demand such evidence as a condition of continued funding. Being self funded we are saved such pressures and think that the anonymity of the user on the site is an important drawcard. We know, because of external evidence in other situations, that the content is appropriate and based on research. <www.dfordepression.com>, <www.aforanxiety.com> and <www.crufad.org> will aim to serve the needs of people in the wider community who are fearful, worried, anxious, depressed. The self help section is a service site, not a research site.

2.2 Web based prevention of depression

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This paper examines the use of the Internet in the prevention of depression. There are three major issues of relevance to the development of e-mental health policy in the area of prevention. The first is the use of the Internet and associated technologies to develop customised programs, the second is the identification of ethical issues in prevention, and the third is the importance of scientific evaluation of the effectiveness of Websites.

This paper outlines recent developments in the design of prevention programs and the relevance of these developments to the delivery of mental health interventions using the Internet. Recent developments in prevention research emphasise the importance of customising the message delivered to individuals in the community. One approach to the challenge of providing customised prevention is an approach which harnesses the capabilities of the Internet (and Internet technologies, including its associated software) to deliver such prevention programs. The Internet has the capacity to extend the nature of prevention programmes in a way that is not facilitated by other technologies nor prohibitively expensive if done through traditional public health programmes.

Recent research has indicated that conventionally delivered prevention programmes can be effective when individuals 'at risk' for depression are targeted. In the area of youth depression there have been successful interventions directed towards 'at risk' school age individuals (Jaycox et al, 1994) and undergraduates at university (Seligman et al, 1999). These interventions have used cognitive behaviour therapy (CBT), a form of therapy that is effective when delivered face to face by a therapist, via self help books (bibliotherapy) and through computer administration.

In areas other than mental health, a wide range of conventionally delivered prevention programs have been conducted in the last decades directed at worksites, communities and schools to change risk factors such as smoking and high fat diet consumption, and thus prevent diseases such as cardiovascular disease and cancer. Sorensen et al (1998) reviewed these findings and noted that the next 'generation of community based interventions' (p 379) should be tailored to the needs of individuals, involve communities in the planning of the intervention and be targeted at multiple levels. They noted that different disciplines brought knowledge that could be used at a range of levels from the micro (biomedical) through to the macro (society and health) level. The focus of these levels suggests different but complementary mechanisms for implementing prevention programs.

'New generation' prevention programs in mental health (and in the area of depression specifically) will need to take into account these considerations. Incorporating customised tailoring and targeting multiple levels will be challenging. Customised tailoring for depression intervention may require an understanding of an individual's belief system (for example, the person's preferences for medical

compared to alternative or lifestyle interventions, see Jorm et al, 1997) and his or her motivation for change (whether he or she is 'ready' to make lifestyle changes). The person's immediate circumstances and level and type of vulnerability also require assessment. In addiction research, Prochaska et al (1992) demonstrated that successful interventions may require messages customised to a person's motivation to change. Although a number of studies have applied this transtheoretical model to psychotherapy (see Rosen, 2000), a major task will be to examine the relevance of models such as these to the prevention of depression.

One approach to the challenge of providing customised prevention may be to harness the capabilities of the Internet (and Internet technologies, including its associated software) to deliver such prevention programs. The Internet may be a preferred method to deliver prevention programs because it provides 24 hour, self paced access to mental health interventions, has the capability of supporting software that can be tailored for individual needs and is informed by medical informatics (Eysenbach, 2000). The latter discipline is likely to provide specific information about the types of approaches that will lead to faster knowledge uptake and satisfaction by users. For example, there is evidence suggesting that information and self help programs provide the greatest benefit to those with the least previous knowledge. Current work on decision aids will be of use in helping the user clarify their values on the site. The net is already established as a major source of health related information, suggesting that Web based prevention of mental health problems will be well accepted. Marcus et al (2000) report that one half of all US Internet users have used the Internet to obtain health information. Information about the person's experience of the program and their responses to assessment questions can be recorded and used to evaluate the effectiveness of the programs. The recognition that interactive communication strategies will be of use in the development of universal physical activity promotion is growing (see Marcus et al, 2000) and the development of such programs for exercise and diet has commenced (Prochaska et al, 2000).

Although there are now outcomes showing the effectiveness of using the Internet as a means of delivering effective prevention in a number of areas including diet, smoking and exercise (see Tate, Wing & Winette, 2001), there are very few mental health prevention programs. Stanford University's *Student Bodies* program is an example of a successful prevention program using the Internet to change risk for eating disorders. Educational content, a newsgroup, and structured weekly readings, assignments and postings improved body dissatisfaction (Winzelberg et al, 2000).

A number of potential ethical issues arise in connection with the development of prevention sites, including:

- the violation of confidentiality and privacy, which includes taking records of personal details;
- the use of data for purposes other than that intended;
- the failure to identify those needing more help;
- the provision of non evidence based information; and
- the provision of material that may upset some users.

In our view, none of these problems are unique to the Internet and can be resolved using previous guidelines established for epidemiological research.

The Centre for Mental Health at the Australian National University has recently developed an Internet prevention program for depression in young people. The program uses cognitive behaviour therapy (CBT), and aims to increase the accessibility of this proven prevention intervention. Young adults are an age group not easily reached by existing services. They are dispersed across a multiplicity of home, work,

recreational and learning settings. The Internet provides a practical solution to the problem of disseminating preventive CBT programs. To our knowledge, MoodGYM™ is the only CBT depression prevention program on the Web.

MoodGYM™ consists of five modules, an interactive game, anxiety and depression assessments, downloadable relaxation audio, a workbook and feedback assessment. It includes individualised assessments of anxiety and depression, dysfunctional thinking, life event stress, parental relationships and the scheduling of activities, for which we have collected community norms. The graphics of MoodGYM™ have been professionally designed to appeal to this age group. Users register on the site, complete anxiety and depression ‘quizzes’, meet the site characters (Noproblemos, Elle, Cyberman and others), and start Module 1. Module 1 is an introduction to the principles of CBT, and demonstrates through flashed diagrams and online exercises the relationship between emotions and thoughts. There are a number of exercises where users can come to grips with their own emotions and the ‘warpy’ thoughts that might accompany them. Module 2 continues the theme with the recognition of thoughts and their consequences. Module 3 introduces users to techniques other than thought contesting to gain perspective on their emotions and how to handle them. Module 4 deals with stress, pleasant events, scheduling, relaxation and meditation. Because of the significance of interpersonal relationships to people of this age, Module 5 deals with separations and break ups.

The initial development of the package was based on action research involving input and feedback from young people, mental health professionals with expertise in CBT, and a formal advisory board comprising relevant experts and stakeholders. An initial pilot test of the program evaluation was conducted in April to August 2001 using students from the Australian National University and the University of Canberra. In 2002, a randomised controlled trial will be undertaken in the community to determine MoodGYM™’s effectiveness.

Although MoodGYM™ was launched officially by the ACT Minister for Health, Housing and Community Care, Mr Michael Moore in July, the site has been active since late April 2001. Using Webstats and other site databases, we calculate that approximately 7,200 individuals have reached the front page of MoodGYM™ in the last three months, with about half being supported by North American servers. Approximately 30% remain on the site for 15 minutes or more. Of those who register, 25% complete the online assessments of mental health functioning. The demographic and mental health profile of these individuals is currently being investigated.

At present the site is listed on the mental health pages of a number of major portals including Netscape, Yahoo and America OnLine. It is currently ranked fourth in the category of Mood on Google’s Page Rank index, a measure of site authority. The uptake of the site suggests that there is recognition of the importance of prevention sites on the Internet. The major challenge for sites such as MoodGYM™ is sustainability. Because these sites are directed at prevention, and can be accessed free of charge by the community, they are unlikely to be funded by businesses that provide medical support to doctors in primary or specialist care. As a result, sites like MoodGYM™ will require universities and governments to provide funding and maintenance, at least initially.

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Note: Some parts of this presentation and paper were published in the *Auseinet* Newsletter, October, 2001.

2.3 e-Health responses to common mental health problems in primary care

Experiences with 'beyondblue: the national depression initiative' and 'SPHERE: A National Depression Project'

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This paper describes work done with Tracey Davenport, Senior Research Officer, School of Psychiatry, University of New South Wales at St George Hospital; Elizabeth Scott, Conjoint Lecturer, School of Psychiatry, University of New South Wales; and Hugh Morgan, Clinical Psychiatrist, Southview Clinic, St George Private Hospital. The paper summarises developments in Web based interventions and information sites in Australia, provides a structure for how these developments might be viewed, looks at ways in which the needs of Australians who do not reach mental health services might be met using Internet technologies, and examines an initiative designed to provide support to general practitioners.

Background

The National Survey of Mental Health and Wellbeing (McLennan, 1998) described the size of the challenge facing those who wish to provide high quality and accessible mental health services in Australia. Over two million Australians suffer from depression, anxiety or substance abuse every year. Almost two thirds do not present for medical care, and of the medical care that is provided, over two thirds occurs in the primary care sector. There are considerable deficits in the primary care provision of services, with a great lack of adequate assessment, non pharmacological treatment options, specialist support and integration with other aspects of medical care (Hickie, Davenport, Scott et al, 2001; Hickie, Davenport, Naismith, Scott, Hadzi-Pavlovic & Koschera, 2001; Hickie, Davenport, Naismith & Scott, 2001).

Potential e-health roles in primary care

Despite the obvious difficulties delivering mental health interventions in primary care environments, there are substantial reasons to continue to promote the development of more effective service delivery models. These include that:

- over 80% of the adult population visit a general practitioner in any 12 month period;
- most common mental disorders are recurrent or chronic disorders which are associated with a lifetime need for adequate care;
- primary care environments can provide information and treatment services at a relatively low cost per person;

- primary care services are essential for the ongoing management of persons who have received specialist mental health interventions; and
- medical forms of primary care provide the ideal environment for integrated medical and psychological care.

When considering the style of possible service responses to the very large degree of ‘unmet need’ for psychological treatments, it has become important to consider how such services may be provided efficiently to the largest number of persons, how such developments may be integrated into developing primary care systems and how the quality of such services may be enhanced over time. In the context of designing improved primary care systems (Hickie, Davenport, Naismith, & Scott, 2001), we have given consideration to some key structural factors.

These factors have included our capacity to:

- enhance clinical support for general practitioners who provide mental health services;
- provide high quality information to consumers of primary care based mental health services (such information promotes consumer choice at a critical phase of the illness);
- bring the wide range of specialist psychiatrist and clinical psychologist expertise closer to primary care providers;
- provide non pharmacological forms of treatment via improved information technology in primary care environments;
- screen for psychological disorder and/or risk of self harm;
- provide access to services such as clinical guidelines that promote quality practices in primary care;
- monitor responses to treatment in primary care; and
- promote ongoing interaction between professional groups involved in the delivery of mental health services.

beyondblue’s role

‘beyondblue’ was established in 2000 as a national response to the size and impact of depressive disorders in the Australian community. It operates as a not for profit private company with the Commonwealth and Victorian governments as the major shareholders. It seeks to raise additional capital from the corporate sector to enhance its activities. However, the company does not accept support from the pharmaceutical industry. At a program level, beyondblue focuses on increasing community awareness and destigmatisation of persons with depression. Additionally, it targets development of prevention and early intervention programs. Hence, the development of methods for increasing community knowledge of symptoms and signs of depression, pathways to care, treatment choices, consumers and carers experiences of depression, stigma and barriers to participation are central to its mission. Our previous research in primary care (Hickie, Davenport, Scott et al, 2001) has highlighted the ways in which females, those with higher education status, those who are literate in English and those with greater specific psychological knowledge access better mental health care in general practice. If we are to see a further increase in quality, then it is essential that persons attending primary care can access information both prior to and following consultations with general practitioners (and specialist providers).

In April 2001, an information based Website (<http://www.beyondblue.org.au>) was launched and then revised in October 2001 to include a variety of more interactive features. The development recognises

both the lack of number of such sites, the lack of quality of mental health sites generally (Christensen, Griffiths & Medway, 2000) and that many of the international sites are supported directly by the pharmaceutical industry. A more active attempt to market the Website was undertaken in October 2001, and this was associated with considerable increase in traffic to the site. The site also seeks to promote the program activities of 'beyondblue' and a wide range of other mental health Websites and organisations.

Such information based Websites can form an important part of the medical information system, particularly for persons who suffer from disorders that are poorly understood, highly stigmatised and/or are largely dealt with by practitioners who do not have access to highly specialised information. They also assist to overcome the limitations imposed by geographical isolation. Primary care practitioners need to be able to refer patients to such expert and independent sites. Additionally, such sites can increase the consumer's sense of involvement with others who have experienced similar illnesses. Mental health specialists have an important role to play in supporting the development, content and utilisation of such sites. To date, there is little evidence that primary care practitioners or mental health specialists actively promote such information resources to consumers or carers.

Information based Websites, however, have a limited capacity to promote the style of specific skills training that an individual may require to decrease their long term vulnerability to depression or anxiety. Such Websites are under development elsewhere (<http://www.moodgym.anu.edu.au>) and the support and expansion of such activities may be seen to be part of beyondblue's wider population health role.

Web based support systems for general practitioners

General practitioners who take on increasing mental health roles identify a wide variety of needs. Some of these may be enhanced by Web based systems and include:

- provision of rapid responses from experts on individual clinical issues;
- access to mental health specialists who have particular interests in working with general practitioners and/or patients with comorbid medical and mental health problems;
- integration of decision support systems with other ongoing educational activities;
- provision of direct and ongoing feedback to individual practitioners, thereby, meeting their specific educational and support requirements.

During the course of development of 'SPHERE: A National Depression Project', it was clear that there was an urgent need for a clinical support system that had the capacity to respond to some of these issues. The SPHERE Project has provided basic training in issues related to depression and anxiety to over 1,200 general practitioners nationally (Naismith et al, 2001) and has provided additional skills training, focusing largely on cognitive and behavioural strategies to over 200 doctors (Morgan et al, 1999). Such cognitive and behavioural skills are, however, unlikely to be maintained and developed unless they are underpinned by ongoing contact with mental health specialists. Web based systems have the capacity to encourage supervision of individual case work and to promote the sharing of key difficulties while introducing such procedures into regular medical practice.

Consequently, a prototype of the 'Doctor-Support Network' of the SPHERE Project was developed and introduced into limited circulation in 2001 (<http://www.doctorsupport.com.au>). It utilises mental health specialists who have specific interests in working with general practitioners to develop better integrated mental health systems. Additionally, the network is designed to supplement the SPHERE training programs. Such systems are costly to develop and sustain. Mental health specialists are paid for their

time. To date, there are no other payment systems available for specialists in private practice to provide such ongoing clinical support to their general practitioner colleagues. Initial development of the service required considerable investment from the pharmaceutical industry and other private providers. The current system is sustained by ongoing support from Pfizer Inc.

The evaluation of this process is in its early phase but appears to meet several general practitioner needs. It is timely, provides access to specialists with genuine expertise and does not cost the primary care provider. Additionally, the service does not cost the consumer and is not tied to the provision of any specific pharmaceutical agent.

Conclusion

Future development of mental health systems will need to focus more on ways of:

- meeting the challenge highlighted by the epidemiology of and burden due to common mental disorders such as depression, anxiety and substance abuse;
- placing a greater emphasis on provision of information to consumers of such services;
- providing information in a manner that promotes choice, ease of access and confidentiality;
- improving service delivery through direct use of new technologies; and
- promoting improved quality of primary care based practice through greater real time support of practitioners working in these settings.

While developments in Australia are already headed in this direction, they are largely outside the government services sector. At some point government funded services will need to respond to such developments in a constructive and supportive manner.

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2.4 The Internet and specialist practice

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Professor Kirkby was asked to speak on the role of the Internet and specialist practice. In this insightful paper, Kirkby describes vividly the means by which the Internet has altered the dyadic relationship between psychiatrist and patient, the impact of the explosion of sources of information that is now available to both psychiatrist and patient and the greater means of interactive communication through chat groups and bulletin boards. The policy implications of this may be threefold: (i) the need to evaluate the quality of material on the Internet and to provide high quality information by professional organisations; (ii) the need to raise community skills in locating and appraising material to create discerning Web users; and (iii) the increased scope provided by the Internet to allow specialists to ‘engage in population health, health promotion and early intervention approaches’.

Specialist psychiatric practice has existed in a recognisably modern form for around two centuries, the Internet for little more than 5 years. Already the interface between the two has been substantial and the Internet is arguably of the same level of importance to mental health and the nature of specialist practice as have been deinstitutionalisation or the development of psychotropic medications.

While there are many ways and settings in which psychiatry is practised, the predominant model is that the patient and psychiatrist meet in private in a consulting room, referred to in this article as ‘dyadic office practice’. This is so everyday and well established a model that the defining features of such practice are little discussed or debated. However, doing so throws into sharp relief how the Internet irrevocably alters the dynamics of the dyadic office practice model.

It is instructive to follow the path of the patient through a typical episode of specialist care. There are many steps before reaching the psychiatrist, for example feeling distressed or unwell, being noted as such by others, developing an awareness of symptoms or formulating specific complaints and acting on this by initiating change or seeking help. This is informed by input from relatives and acquaintances in the context of culture specific notions of illness causation and treatments, derived in part from books or magazines, radio and television. Help seeking is commonly a consultation with a general practitioner, which may lead to recognition or confirmation of a mental condition, institution of further assessment or management, and in a minority of cases the suggestion of referral to a psychiatrist. If referral is accepted there is typically a waiting list for non urgent referrals, then the day of first attendance at the office practice arrives. The psychiatrist’s office typically contains diplomas on the wall, journals on the shelf, and provides an interruption free confidential setting conducive to providing assessment and delivering aspects of treatment. To varying degrees the psychiatrist is in the role of expert or oracle, the patient is a supplicant seeking some reassurance, wise advice or prescription.

For many patients their experience of psychiatric treatment is conducted in isolation from other individuals with similar problems. Few other domains of their life afford the confidentiality and willingness to work through their difficult issues that the psychiatrist can offer. Some patients may discuss the detail of consultations and treatment with relatives or other confidants; often they will not or cannot comfortably discuss the issues at hand in this way.

The psychiatrist on the other hand has access to many professional resources. They will typically attend conferences or meetings where visiting experts from around the country and around the globe share their knowledge, clinical experience and enthusiasm. They have access to professional journals, textbooks, peer review activities and opportunities to talk shop with colleagues. Their professional activities are fostered and supported by professional colleges, from training right through their professional lifetime.

Typically there is little overlap between the professional networks and learning resources of the psychiatrist and those of the patient. Rather the specialist is the conduit, gatekeeper and interpreter who mediates between the professional domain and the individual patient. This has some inherent strengths. For example, the specialist through their training, breadth of experience, participation in maintenance of professional standards activities, and often their enthusiasm for their vocation, is well placed to guide and advise the patient. The patient has the reassurance that the specialist has undergone extensive training and ongoing professional development. The accoutrements of professional titles, diplomas on the wall and a full bookshelf reinforce this.

However, most individuals with mental problems never see a specialist. Services are effectively rationed at around one psychiatrist per 10,000 people across Australia, more in specific areas within large cities, generally fewer and often distant in regional areas. Further, most mental problems are extant for some months, not infrequently years, before the specialist is seen.

The Internet has irrevocably altered these dynamics. All the information available to professionals is steadily migrating to the Internet, where most of it is available to anyone with sufficient searching skills, literacy and perseverance. For example, Medline searches are available to all; clinical practice guidelines are available for common conditions, including guidelines written for consumers with little jargon. A proliferation of health related sites discuss every manner of illness and treatment. Lectures are available online, treatment modules, such as for cognitive behaviour therapy, are available and are being evaluated in research. Increasingly sites are being appraised in terms of accuracy and conformity with evidence-based practice. Healthcare provider sites offer links to sites they approve of. At every step of the pathway to specialist care the patient has ready access through the Internet to more information than the specialist could possibly keep abreast of. Further, the information providers have a worldwide audience, rather than one person at a time. The specialist is no longer the principal portal to information; this role has been assumed by Internet health portals and sites. Furthermore, this information can be accessed with greater anonymity than is afforded by attending the psychiatrist's office, and is available both prior to specialist consultation and in the absence of specialist consultation. Further, this information is available both to the patient and to members of their social network and can be accessed, for example, together with a relative, as well as alone.

The specialist has not been usurped; rather the one to one information conduit of dyadic office practice has been supplemented by access to vast amounts of information from around the world. The specialist is no longer the gatekeeper but has a continuing and arguably increased role as interpreter and guide, working with an increasingly sophisticated patient population. As such, the specialist is a stakeholder in the information economy, interested in the provision of high quality Internet delivered information and learning packages by health agencies, industry, professional colleges and consumer organisations. The rationing inherent in the individual consultation model does not apply to this supplementation through

Internet delivered material. The access costs of the Internet are born by the recipient or their community infrastructure. Recurrent costs to the provider of running a file server and developing materials are not insignificant but are traded off against economies of scale on sites with high hit rates, and by the international pooling of material. The specialist as an individual can participate in the Internet mental health information sector but public, private, professional and voluntary organisations have an important role to play. These organisations also have the financial, voluntary or marketing resources to develop, deliver and evaluate Internet content and outcomes. Similar forces are working in primary care, where the majority of mental health assessment, diagnosis and treatment occurs.

The ready access of the patient to information prior to reaching the specialist's office has a number of other implications. It frames how the individual discerns and conceptualises their health concerns. Through Internet material, the individual acquires schemas to understand their difficulties, ranging from lifestyle and life cycle explanations to specific psychological and biological theories. Symptoms may become reified; increasingly the individual will arrive at their own diagnosis and prognosis of their problems, based on information acquired from the Internet. They may present asking for specific forms of medication or other treatment. Much information on the Internet does not conform to evidence based criteria. This should come as no surprise given that the market in Australia for alternative medicines such as herbs and vitamins, is a similar dollar volume to all PBS listed drugs.

The other key change wrought by the Internet thus far is as a means of interactive communication. Through bulletin boards, chat rooms, email and other contact details, individual patients can now communicate freely with other interested individuals throughout the world. The discourse using these means, unlike most specialist shoptalk is predominantly neither technical nor symptom focused. Rather, common themes include problems in relationships or at work, acceptance and understanding from the community, what can help, where to access it and what is new or happening at a research level. A range of levels of engagement from complete anonymity, to joining an organisation, to inviting personal correspondence is available. Membership based consumer organisations, special interest and advocacy groups are greatly enabled by this technology. It also substantially increases the contribution of the voluntary sector in mental health, by marshalling the input and enthusiasm of many people. These patient to patient networks in many ways replicate what specialists have valued for many years in their own professional development and support networks, except that they are far more extensive. In the numbers game, the level of Internet and email driven interconnectivity amongst patients already dwarfs the one in ten thousand of the population engaged in psychiatrist networks.

With Internet material developing apace the agenda for specialists, whether individually, collectively or in broader partnerships, is to promote and provide high quality material through the Internet and critically appraise the appropriateness and utility of what is on offer. Further the specialist can assist in raising community skills in locating, appraising and applying Internet material as an integral part of the overall health system. The Internet provides increased scope for specialists to engage in population health, health promotion and early intervention approaches. Various tele treatment options are also available using Internet and mobile communications technology. These have substantial implications for delivery of specialist services outside of the physical location of the consulting room, whether in other countries, at home, or out and about.

Overall the changes identified are complementary to the eclectic nature of specialist practice. Although dyadic office practice remains a dominant model, considerable energy in mental health care is devoted to areas such as family and group therapies, rehabilitation, delivering care into the community, promoting greater autonomy and self help, and helping build social networks. The Internet is a vehicle that can enhance this spectrum of interventions and broaden their reach.

2.5 e-Psych issues in the private sector or from the private sector: Is there an Internet private sector? Is it a universal sector with private and public revenue streams?

Dennis Tannenbaum

Private Practice, Perth, Western Australia

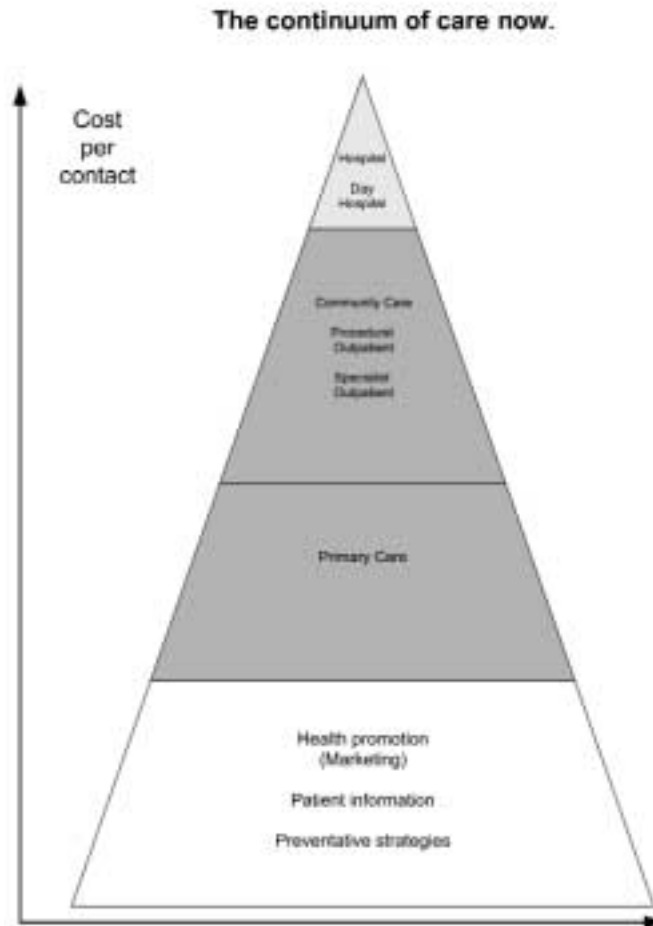
In this paper, Dennis Tannenbaum explores the implications of the Internet for medical and health delivery. He raises questions about the role of the Internet in accommodating ‘unmet’ need, as a means of extending traditional services, and as a means to augment the consumer’s knowledge of services as well as facilitating more efficient data management practices. Tannenbaum believes the Internet may reduce high costs of health service delivery, and that it should be used to advantage in both public and private health systems.

The Internet and related technologies will have a major impact on medical service delivery: The new technology offers a greater potential for meaningful integration of health services than any other technology. The Internet will play a major role in the entire continuum of care: from the less expensive health promotion, right through to the most expensive health hospital care (see Figure 2). We are only just beginning to understand the future potential of the new technologies in our lives and in the delivery of health services, and in particular, its potential in the delivery of psychiatric services.

We are moving towards a society that will be dominated by the Internet and mobile devices. It is predicted that by the end of 2001 10 million Australians will have mobile devices. The tremendous take up of Internet devices will create huge market place opportunities for incumbent service providers and content providers, as well as completely new breeds of companies.

It is important that the Internet be understood not as a disembodied entity, but rather as a powerful medium providing a set of tools which will enable a business or group of businesses to do their business more efficiently. Internet systems will be developed to assist in micro and macro management, and their introduction will both speed up transactions and reduce the cost of transactions. This capacity to facilitate the management of massive amounts of data will have substantial, and surprising implications for the medical system.

Figure 2: The role of the Internet in the continuum of care



The current problem – continuum of care

There are substantial pressures on the health system, particularly with respect to the imperative to reduce the costs in health delivery while improving the quality of care for the whole community. Health costs are increasing inexorably, due to population age increase, the costs of new technologies and medications and changes in illness prevalence while the health systems are under increasing pressure to manage the ever increasing cost drivers. The health system faces the ambivalence of promoting knowledge about a particular illness, and then having to meet the corresponding/resulting demand on their resources.

The goal of decreasing costs while raising the quality of the health system and thus the health of the community is extremely ambitious, and it is made more complicated by the differing agendas or incentives between the private and public sectors. In the current health system there are considerable differences in the pressures on, and roles played by the private and public sectors (see Figure 3). In the public system the greatest incentive is to reduce expensive intervention, in particular hospital treatment, and to focus the taxpayers' dollars more on health promotion and preventative strategies. By contrast, the desire for profit leads the private sector into focusing on expensive treatment interventions, and to market hospitals and hospital systems rather than health promotion.

Figure 3: Differences between the public and private sectors in the current health system

What are the current health system sectoral differences - a simplified view?

Private	Public
Infrastructure paid for out of profits. Profits necessary to provide investor incentives to invest.	Infrastructure paid for out of the taxpayers dollar.
When margins are tight profits fall leading to service cost pressure and inability to replace infrastructure.	When pressure for services is high infrastructure often suffers. Pressure to reduce service present. More pressure on some areas where benefit not clearly visible.
Incentives are highest to do procedures and not to drive patients from the hospital end of the continuum of care.	Incentives are highest to move patients to the base of the continuum of care ie away from hospitals.
There are unclear incentives for health promotion but clear incentives to market hospitals and hospital systems. Prospective payments ie casemix funding promotes selected efficiency. Few drivers for moving down the continuum of care.	Conflicted major incentives to reduce disability and to contain costs. Pressures for efficiency but with limited outcome and health measurements. If those with disorder move into system, the system cannot cope.
Insurers note cost increases and can only respond by preventing services, refusing services, and increasing fees.	Response to cost pressure is by rationing (wait lists) and developing methods of managing costs better. Managed care without managed care.
High activity is positive if payment type is fee for service	High activity is negative for health but may be positive for disability
<p>The Internet offers more integration of service possibilities than any other technology. Emphasis on private and public sector customer more than on the sector where the capital originated. Sustainability is the issue. "Then is it of value?" is the question. Value will be clearer in time.</p>	

With current health care delivery systems stretched to their limits, no country can cope with serving even a small fraction of the unmet need should it manifest itself as a demand for current service delivery systems. The question then to arise is whether the Internet can provide practical, innovative service delivery including information, health screening, evaluation of disorder severity, service direction capacities and treatment management tools which augment current health service delivery capabilities, in a cost effective way. In particular:

- Can the Internet facilitate effective health promotion and then augment the processing of the demand for effective education, screening, diagnosis and treatment from the unmet need market?
- Will it significantly extend the productive capacity of current health delivery systems that are required to deal with increased demand for services?
- Will it increase the quality, uptake and improve outcomes of treatment for those in existing systems?

Psychiatric illness: the use of the Internet to augment existing services

The size of the current problem of psychiatric illness in Australia is massive. It is second only to heart disease as the most disabling and costly health problem, affecting one in five people. This estimate equates to 3.6 million people. Left untreated, psychiatric illness can lead to a deterioration in quality of life, loss of productivity, hospitalisation and even suicide. In productivity alone, sick leave absenteeism driven by psychiatric illness costs Australian organisations A \$7 billion per year: over 50 times more than the cost of lost time due to industrial action.

Clearly an Internet opportunity arises from both the large hidden pool of undiagnosed illness and the significant numbers who receive suboptimal treatment for psychiatric illness and existing cost pressures (see Figure 4).

The Web service concept

The Web service concept is made up of a number of key elements. These elements support the core relationship between the doctor, other treatment providers, hospitals and the patient and their families or carers to enhance diagnosis and treatment (see Figure 5).

Some concerns to be addressed in the use of the Internet in the delivery of health services

Information, security, privacy and credibility: There are potentially serious concerns resulting from consumer concerns about data security and privacy: consumers may provide inaccurate data or withhold relevant information. It is crucial that data is protected from unauthorised access or alteration and that a credible audit trail of access to personal information is instituted. Consumers must be able to trust the security and accuracy of the information accessed online. It is crucial to the credibility of e-health that the privacy concerns of consumers be addressed.

Capacity for e-health businesses to fail: The history of e-commerce business has seen many small companies grow rapidly and then fail. This pattern, if it is repeated in the e-health arena would have serious implications for the continuity of care. When the revenue streams are known and the value of the business is clarified, the market will stratify and consolidate rapidly. It is crucial that e-health business develops into sustainable, viable business.

Who pays?: The question of who pays for the development of e-health is critical: is there an Internet private sector; or is it a universal sector with public and private revenue streams? The Internet offers more integration of service possibilities than any other technology. One way to conceptualise the situation is to consider users or customers as private or public sector users rather than in terms of private and public capital streams.

Figure 4: The use of the Internet to augment existing services

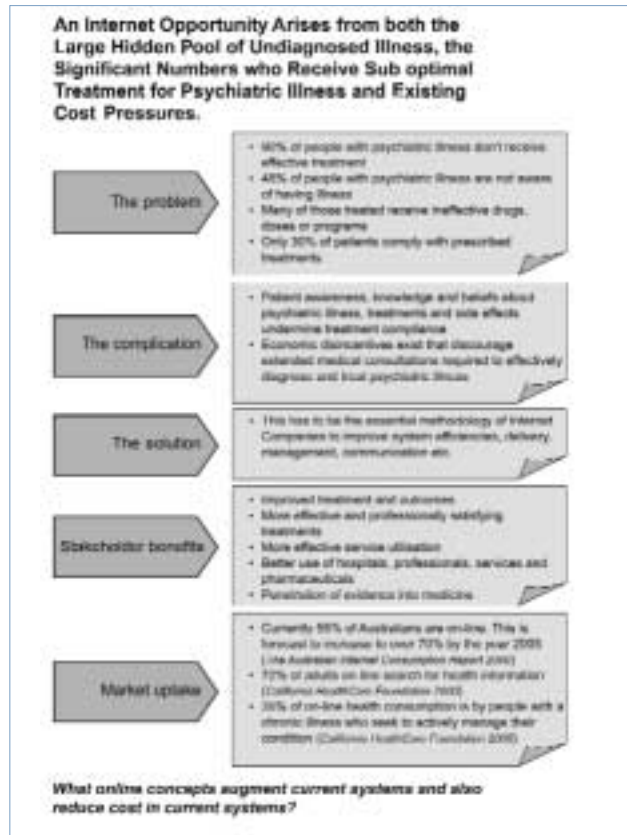
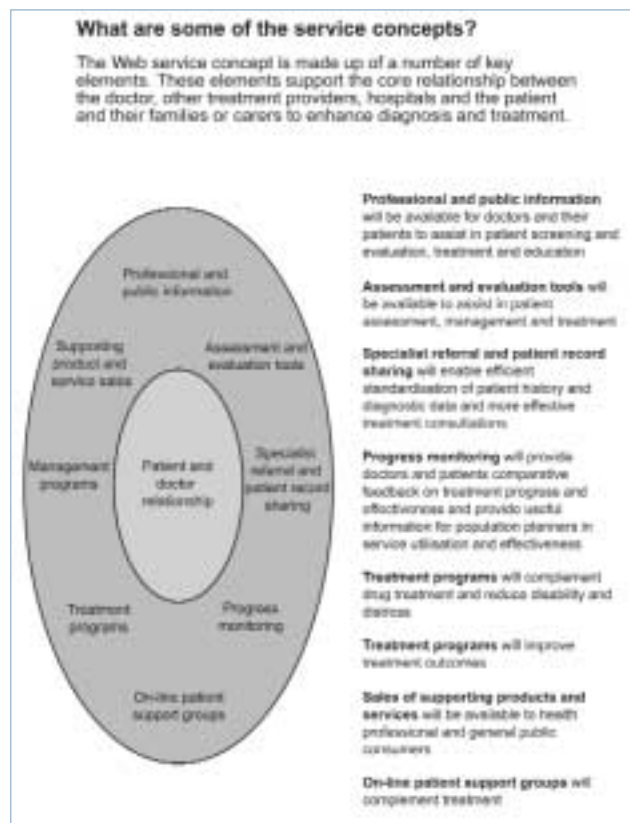


Figure 5: The key Web service concepts



BOX 3: AN EXAMPLE

Intermountain Health care implemented a Web based quality care tracking system to reduce costs and improve quality of care

Intermountain Health Care (IHC) is a nonprofit integrated delivery system (IDS) of 23 hospitals, more than 70 clinics and nearly 22,000 employees with an annual operating budget of approximately two billion dollars. Its health plan covers approximately one million people and the organisation provides approximately 55% of the health care services for its regional market.

In an effort to reduce costs while concurrently improving the quality of care, IHC recently e-business-enabled a client server application it calls its Quality Care Tracking System (QCTS). The new Web enabled QCTS works by seamlessly linking quality improvement teams with IHC's data warehouse through its intranet. The new QCTS tracks goals, treatment outcomes, and improvements across the enterprise, enabling quality improvement teams to efficiently leverage knowledge and innovation throughout the organisation.

The business value created by the e-business initiative has been substantial. The new Web based QCTS allows IHC's users to share project information, reduce rework and waste, improve quality, benchmark best practice models, and archive projects and activities. Several efficiency gains have already been made while using the new system. For instance, via the new QCTS IHC has reduced costs at six surgical sites by \$1.8 million per year. Additionally, several other IHC facilities have reduced STAT testing by more than 40%. Most importantly to the end consumer/patient though, the new QCTS has enable the development of better clinical care practices that save and/or extend the lives of patients. Finally, having moved QCTS to its intranet, IHC will save almost \$800 on software licensing and training costs per new user, allowing it to QCTS-enable 30% of its employees without incurring a significant cost.

Conclusion

It is becoming clearer to us all that the Internet will play a major role in the future of health service delivery. The technology is suitable to both augment the consumer's knowledge and access to services, as well as to facilitate more efficient data management practices. There is the potential to assist in meeting the enormous area of unmet need in the community, as well as reducing the ever increasing costs inherent in health service delivery. The Internet must be seen as an unique tool with an unrivalled capacity to enable effective integration across sectors. It is critical that the Internet be understood as an universal enabler, for both the public and private sectors.

2.6 e-Mental health quality: Global perspectives

Kathleen M Griffiths

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In this paper, Kathy Griffiths discusses some international initiatives aimed at assisting consumers to identify high quality Websites. In particular, she describes in some detail, a collaborative project designed to provide a global infrastructure that will permit content experts and agencies to label sites in such a way that consumers and search engines can access their ratings. Since only the infrastructure and not the assignment of ratings are centrally controlled, this proposal provides a means by which quality of Internet content can be regulated using a distributed, bottom up approach.

The Internet and the World Wide Web (WWW) provide an unprecedented opportunity to increase mental health literacy in the community, to prevent mental health problems and to provide mental health services.

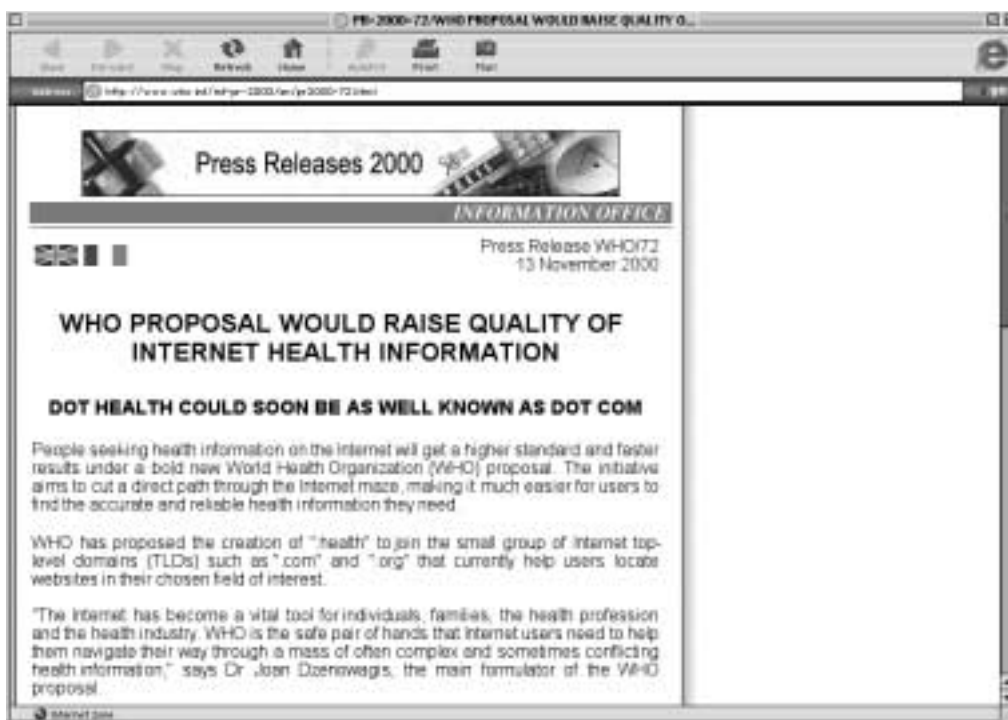
Unfortunately, there is evidence that the quality of the content of mental health information on the Web is poor (Griffiths & Christensen, 2000; Berland et al, 2001; Lissman & Boehnlein, 2001). Of course, as anyone who has visited the CRUFAD site (<http://www.crufad.org>) might tell you, there are high quality mental health information sites around! But how are consumers to tell which sites are of high quality and which sites are best avoided?

Some rating agencies claim to provide a guide to good quality health sites and there are over 40 different scales for measuring the quality of health sites (Jadad & Gagliardi, 1998). However, it is not clear what these agencies or scales really measure. Sites may be 'cool', 'cooler' or 'coolest' or even 'hot', but to my knowledge there are not any e-health rating systems out there that have been appropriately validated against quality, and in particular, the accuracy of site content.

A second problem is that health Websites may use an agency rating to which they are not entitled. For example, it was recently reported that one site that claimed to cure almost everything carried the Health on the Net Foundation (HON) rating (<http://www.hon.ch>), a code that is intended to signify that the site developer adheres to high standards in producing the site (Eysenbach, 2000). Special health portals which claim to link only to sites of high quality could potentially assist the user to locate quality information (eg HealthInsite). However, to my knowledge, the validity of the inclusion criteria that quality health portals use has not yet been established. In addition, most people searching for health information on the Web use public search engines. Obviously, portals do not assist this type of user.

Not surprisingly, the issue of quality assurance has been the subject of considerable international interest. In November 2001, the WHO proposed that a restricted 'dot.health' top level domain should be established that would signify a quality health care site (WHO, 2000) (see Figure 6). Such a proposal raises questions as to who should vet health sites for their suitability for registration and how this might

Figure 6: World Health Organization proposal to ICANN for a dot health top level domain



be done. However, such questions may be of little more than theoretical interest since The Internet Corporation for Assigned Names and Numbers (ICANN), the agency that assigns to level domain names, rejected WHO's application for the top level domain.

Today I would like to talk about another interesting proposal for filtering quality health information on the net: MedCERTAIN (or MedPICS Certification and Rating of Trustworthy health information on the net). The MedCERTAIN initiative is part funded by the European Union under the auspices of their Action Plan for safe use of the Internet. Although funded by the European Union, MedCERTAIN is intended to be an international initiative. It is based in Heidelberg and is also referred to as the Heidelberg collaboration.

The overall aim of MedCERTAIN is to assist consumers to assess the quality of health information and identify trustworthy information on the Internet. Eysenbach and his collaborators (2000), the originators of the project, liken MedCERTAIN to the Cochrane collaboration where the aim is to provide high quality information for consumers rather than for health professionals (see Figure 7).

The MedCERTAIN project identifies four specific strategies for improving health information quality. These are: (1) to educate the public; (2) to encourage high ethical standards among Website providers; (3) to evaluate sites; and (4) to enforce the MedCERTAIN standards. Today, I would like to briefly describe the first three of these aims.

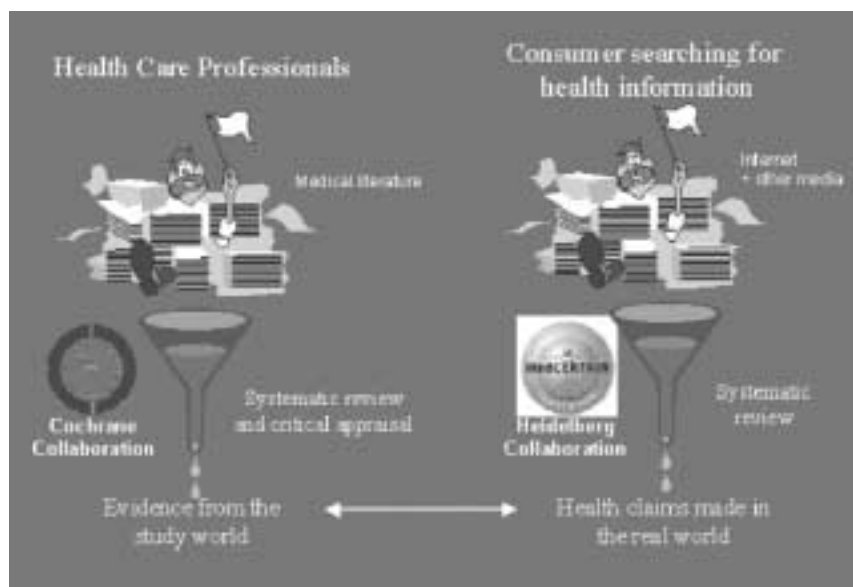
The first aim is to educate the public about quality health information and how it can be recognised or found. For example, MedCERTAIN promotes the consumer use of the instrument DISCERN which has been developed by the Oxford Evidence Based Medicine Unit (Charnock et al, 1999). This tool is intended to assist consumers assess the quality of written consumer health information and it has been

suggested that it might be suitable for assessing information on the Web. DISCERN covers such aspects as whether the material in a health publication is balanced, whether it is supported by evidence, and whether different treatment alternatives are considered, and their benefits and risks described. There are a total of 16 different questions on the DISCERN scale and these are accompanied by a training manual of somewhat daunting size. The suitability of such a rating system for the typical Internet health information seeker must at least be questioned. It is not clear that consumers would take the time to familiarise themselves with the rating system or even to routinely sit down and rate each health site they visit according to the DISCERN criteria. The other problem is that the validity of DISCERN as a measure of content quality has not been established¹.

The second aim of the MedCERTAIN project is to encourage site owners to adhere to the highest possible ethical standards, as reflected in the International e-health code (2000). The e-health code was developed as a result of an e-health Ethics Summit held in Washington early in 2000, and hosted by the WHO/Pan-American Health Organisation. Fifty experts from around the world attended the summit. They drafted standards, which after public consultation, were modified to produce the final code of ethics. The code comprises eight main guiding principles including candour, honesty, quality, informed consent, privacy, professionalism in online health care, responsible partnering, and accountability.

The final and arguably most important and innovative aim of the MedCERTAIN project is to provide an infrastructure for the standardised evaluation and dissemination of information about the quality of individual Websites (Box 4). Evaluations would be made by content experts such as doctors and medical organisations. Although evaluative information would be stored in a central MedCERTAIN database,

Figure 7: DISCERN aims to assist consumers to identify high quality information on Websites just as the Cochrane Collaboration assists health professionals to filter the published medical literature



(Source: G Eysenbach. Journal of Medical Internet Research 2000, 2(suppl 2):e1. Reprinted by permission)

1 Since June, 2001 when this talk was delivered, Griffiths and Christensen (2002) have reported some preliminary data that suggests that DISCERN may be a valid indicator of content quality.

BOX 4: MEDCERTAIN

A basic idea of MedCERTAIN is to foster cooperation and interoperability... If all health information rating services on the Internet would use a common, standardized 'language' (evaluative metadata) to describe and rate health information on the net and if this data can be exchanged and communicated to the consumer in a standardized way, then the user will have a huge resource of metainformation at his fingertips, helping him to assess the credibility of any health information he finds.

(Eysenbach et al, 2000, p 7)

the system would not involve a centralised rating agency. Rather, the system would involve a decentralised global collaboration in which ratings would be assigned by third parties around the world. For example, a site might be rated by a number of agencies, and then consumers, portals, search engines and others would be able to access the ratings, as well as the identity of the rating organisations and filter this information according to their needs. This would be achieved by means of a standardised meta-tag language.

As most people are aware, meta-tags contain metainformation and metainformation is information about information. Eysenbach et al (2000) has pointed out that metainformation can be either 'descriptive' or 'evaluative'. In this context, descriptive information might include such items as the author's name, the date, the subject of the site, the name of the sponsor and whether there are any conflicts of interest. Evaluative data on the other hand, would for example, describe the accuracy of the site content, the completeness of the site information, and the degree to which the site is biased.

Currently, a site owner can place some descriptive information in meta-tags but other descriptive information, such as sponsorship and conflicts of interest cannot be accommodated within existing meta-tag frameworks. More importantly, there is no standard means of incorporating evaluative data. Eysenbach and his collaborators have therefore proposed that a standardised vocabulary be developed to allow evaluative data to be included in a meta-tag system.

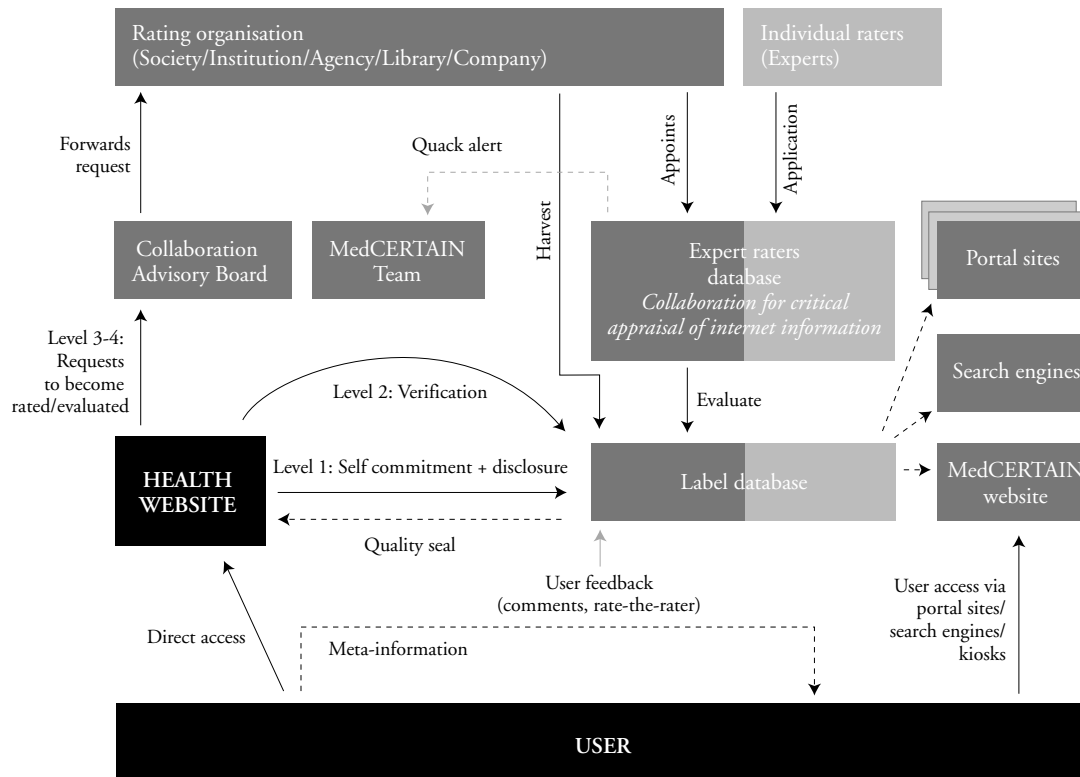
The MedCERTAIN concept requires that reviewers independent of the author attach meta-tags. Eysenbach and his collaborators propose that the metadata vocabulary be based on a standard called medPICS (Platform for Internet Content Selection),² which would allow evaluators to attach their ratings.

The aim is to enable Web users to search by descriptive and evaluative data to find the information that they want. But how would this actually work? According to the Eysenbach team, this metadata could be made available through special software or plug ins. By means of this software, a user who accessed a site, would simultaneously access the MedCERTAIN database to obtain certification information (Figure 8). I understand from my IT contacts that this aspect of the project is highly ambitious and presents major technical, practical and logistical challenges.

Nevertheless, the idea of a common metadata language is very exciting. It would mean that a specially tailored search engine on a health portal, such as the bluepages search engine (<http://bluepages.anu.edu.au/search.html>) could filter information according to MedCERTAIN criteria.

2 Now referred to as HIDDEL (Health Information Disclosure, Description and Evaluation Language)

Figure 8: The MedCERTAIN infrastructure for Website evaluation



(Source: Eysenbach et al, 2000. Reprinted by permission)

For example, the search engine could be programmed to retrieve only those health sites achieving a certain level of MedCERTAIN rating or only those sites conforming to a particular user requirement such as sites written for a consumer, or by a university centre without pharmaceutical company sponsorship.

Whether or not the Heidelberg collaboration is a suitable model for moving forward in the area of quality assurance, it is clear that move forward we must and that working towards some sort of standardised system of coding evaluative information has much to recommend it. Is this suggestion tantamount to calling in the ‘thought police’? On the contrary. Since only the infrastructure and not the assignment of ratings are centrally controlled, this proposal provides a means by which quality of Internet content might be ‘regulated’ using a distributed, bottom up approach (Eysenbach et al, 2000). Consumers can still choose to ignore evaluative information and to visit the sites of their choice. However, like health professionals they are entitled to receive the best possible guidance about the quality of available health information.

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2.7 Outline of HIRaD (Health Information Research and Development) project

John Payne

Department of Health and Aged Care

This paper describes one of the Commonwealth Government's initiatives to advance the role of Internet and related technologies in health care. The HIRaD project is one of several research and development projects under the IT Integration initiative announced in the 1999 Federal budget under the Enhanced Primary Care Package. HIRaD is based on the premise that the efficient and effective coordination of care for individuals across different services and locations relies on the timely and relevant communication of confidential information about those individuals between different health and community care service settings. The Commonwealth encourages the involvement of consumers in their health care, and the development of partnerships. The Commonwealth also emphasises the importance of privacy and security in Internet usage for patient related communications between providers, and emphasises the importance of evaluating such innovative projects.

The focus of the Commonwealth is in improving health outcomes for individuals and in the delivery of health services to the community as a whole. The Internet and related technologies bring with them the potential for meaningful advancements in primary and coordinated care. It is crucial that the new technologies and the possibilities they bring be integrated into future health policies. The Commonwealth is currently involved with the HIRaD project. This project has been established to seek tenders for information technology assisted service delivery projects. The Commonwealth is keen to understand, demonstrate and evaluate the contribution that the use of secure Internet technologies can make to the Australian health delivery services.

Goals

The key goal that the Commonwealth has articulated is to ensure that each proposal, or proposed solution that it will contribute to, will assist in improving the health outcomes for individuals and for the whole community. The Commonwealth anticipates that technological advancements in primary care to individuals will be combined with efficient and effective solutions in delivering health services to the broader community. The Commonwealth is interested in exploiting the capacity of the new technologies to draw together all the stakeholders in the health, information management and in the technology arenas to form an integrated and more efficient health community.

The HIRaD project has distinct goals in three critical areas: health records, coordinated care, and in future policy development. The Commonwealth is committed to the development of secure Internet technologies to record personal health information. We believe that such records can significantly contribute to the effective coordination of an individual's care between different health and community care service providers. It is anticipated that the integration and coordination of patient care can be enhanced by encouraging the development of innovative approaches in the use of secure Internet technology. The third, and equally important, goal is to use the knowledge we gain, through an

appropriate evaluation of the projects, to inform future policy development on the use of Internet technology in health service delivery. It is critical to integrate future mental health policies with the exciting possibilities opened up by the new technologies.

Principles

The Commonwealth has developed a number of guiding principles for information technology assisted service delivery projects. They are as follows:

- **Integrated health community:** It is essential that the technological solution proposed be based on supporting service delivery objectives for a health community (in this setting, a community may be defined by physical location, clinical service or by service commitments). This means that collaborative partnerships with stakeholders in service delivery are identified and formed. The solution design must be accessible to all the stakeholders, it must minimise the burden on consumers as well as individual health service providers and administrative staff.
- **Consumer centric:** The design of information technology assisted health delivery services must be consumer centric and incorporate the consumer perspective wherever appropriate. It is critical for the success of any proposals put forward to the Commonwealth that the design encompass adequate and secure protection of both patient and health provider information. The design of the health delivery service must be readily accessible by consumers, and must allow consumers to easily access information about themselves. It is essential too that the issue of gaining consumer consent to the confidential exchange of information (about them) be addressed.
- **Privacy protection:** The protection and accuracy of patient related information records are critical. It is envisioned that patient related information will either be captured and maintained at its source, or held under appropriate data management and security rules. Nationally agreed security, data definitions and communications standards, as maintained by the Australian Institute of Health and Welfare and Standards Australia, are to be used wherever available and applicable. Technological solutions are to include Security Management Plans and Security Policy Documents in accordance with AS4444 – Information. In addition to the protection of data it is essential where Internet sessions are to be conducted in ‘real time’ that proponents identify and justify their approach to the authentication of external users, and the allocation of privileges to ensure the protection of both the link and the data holdings.
- **The technology:** The service delivery project proposals must encompass the notion of flexibility. They must not be proprietary or bound by platform dependencies. They must have potential for scalability, or use in other health service delivery locations or communities.

Evaluation

It is crucial that all projects the Commonwealth is involved in be appropriately evaluated. The Commonwealth believes that the Telehealth Evaluation Methodology is sufficiently generic to contribute to the development of evaluation plans for information technology assisted service delivery projects. The methodology is available from <www.telehealth.org.au>.

There are a number of factors to consider in an evaluation of any proposal. It is clear that the perspective of consumers and clinicians are relevant, as is the effectiveness of the data management. The success of service delivery can be measured, in part, by the confidence expressed by the consumer in the technology: patients and clinicians must feel secure that their privacy is adequately protected. The impact on privacy, data security and the related issue of duty of care will need to be evaluated. Another area critical to the success of any proposed health delivery service is the perception by the

stakeholders of observable clinical benefits. In particular, it would be important to ask if the new delivery service will lead to the better use of clinical information. This would assist with the provision of care, compliance with care management plans, and an improved understanding of the consumer's condition by the consumer, or their carer.

In addition to the user's perspective, the information data management and information infrastructure must also be addressed in any future evaluation. It would be important to examine the information and data management through an evaluation of availability, access, agreed definitions, quality and accuracy, consumer participation, and wider compliance with national initiatives such as the Health Online and HealthConnect plans. The information infrastructure too must be evaluated, through an examination of information management practice, training and skill levels, change management, agreed and maintained service levels and again, consumer confidence.

How will the Commonwealth know if they are successful in attracting the right proposals?

The Commonwealth has a number of key points that are believed to be critically important in an electronic service delivery system. As we have emphasised throughout this paper, it is essential to the success of any health delivery system proposal that the consumer perspective be incorporated into the proposals. The important issues such as consumer consent to information exchanges; the protection of patient/provider information and consumer access to information held about themselves must be addressed in any proposal. The extent to which the proposal demonstrates a commitment to the confidentiality, integrity and availability of consumer and clinician information is extremely important to the Commonwealth.

In addition, the Commonwealth is keen to build a health community by fully exploiting the reach capacity of electronic health service delivery. We would like to see a high level of collaboration and commitment from all the stakeholder organisations in the development and implementation of the proposed solution. The technology must address the service delivery needs of different components of the health sectors, in particular rural, remote and urban communities as well as the community sector. It is crucial that any proposed solution demonstrates a high level of understanding of the roles and responsibilities of the various service providers and the relationships between service providers and the organisations providing health care to individual consumers.

In conclusion, any proposal must be capable of contributing to the wider health sector. We are keen for any proposed solution to contribute to the understanding, development, and clarification/classification of national HealthConnect and Health Online. The design of the health delivery system must be capable of being scaled and applied to other organisations delivering health services.

Added note: Two projects have since been funded under HIRaD and commenced in June 2002. The Tasmanian General Practice Divisions (in conjunction with the Tasmanian Department of Health and Human Services) will use Internet technologies to create an electronic interface between general practitioners and the departments of emergency medicine in the three major public hospitals within Tasmania. It will enable the generation of secure email between these health care provider groups to enhance primary health care.

The NSW Rural Doctors Network Pty Ltd will use Internet technologies to provide timely access to, and enable updating of, patient related information in the form of a comprehensive electronic health care record. This will assist clinicians manage multi disciplinary treatment, or care plans, in a remote region of NSW. (Advice received from John Payne on 30 July 2002)

Section 3: The workshop



This section summarises the views of workshop participants on three issues:

- the perceived advantages of the Internet (Section 3.1)
- the barriers of the Internet for mental health (Section 3.2)
- the methods for overcoming these barriers (Section 3.3)

3.1 Advantages of the Internet in the delivery of health prevention, promotion, education, and treatment

Workshop participants identified a large number of advantages of the Internet in the delivery of mental health 'services' (Appendix C). These advantages can be broadly categorised as (a) cost reduction; (b) facilitation of conventional service delivery; (c) introduction of innovative services; (d) democratisation of health care and facilitation of consumer empowerment; and (e) improved access. Each of these advantages is discussed below together with relevant evidence from the literature.

a) Internet delivery could lower medical health costs

There is recognition worldwide that mental illness is a major cause of disability and burden and a major contributor to the costs of health services in Australia. Mental health services are currently stretched to their limits.

Many individuals with mental health problems do not receive help. It is likely that already burdened health services would not be able to cope if these individuals did seek help. This finding also suggests that current services may not appeal to many individuals with mental health problems.

Attendees at the workshop agreed that lowering the cost of providing mental health services was an advantage of Internet technologies. In particular:

- the cost of current services may be reduced if technology could be used to decrease the burden of routine procedures and processes; and
- the ability of the new technology to reach a large audience relatively cheaply and to deliver an alternative, complementary, targeted program could help manage service delivery and health costs. Web based preventative programs, aimed at educating consumers, alerting them to possible symptoms and offering a degree of treatment to prevent the development of mental health symptoms, may decrease the need for more expensive medical treatment.

Evidence from the health literature supports these suggestions. For example, it has been found that technology based disease management that is designed to improve self management of health may be very cost effective. Gomma et al (2001) reported that using personalized feedback and an education campaign results in improved clinical outcomes and cost saving. The ONE HEALTH PLAN, a subsidiary of a large US insurance company, provided evidence for both improved clinical outcomes and savings of between \$US300 to \$US1000 per member using the intervention, depending on the type of disease.

The evidence also suggests that telemedicine may be cost effective (Wootton, 2001). However, although call centres, which provide emergency as well as routine help, have been found to be safe (for example, NHS Direct in the United Kingdom) there is no direct evidence that they reduce demand on other aspects of the National Health Service (Wootton, 2001).

b) Internet technology could facilitate conventional service delivery

While the workshop recognised the enormous potential for e-mental health, it was a theme throughout the day that e-mental health must complement and expand existing services, and not seek to replace them¹. It was envisaged that the provision of services, particularly those relating to prevention strategies, should be linked to, and integrated within, the established health and community sectors. Explicitly

fostering linkages with a range of relevant community groups would make e-mental health services far more accessible and attractive to (targeted) populations. In addition, the Internet was considered to bring with it an increased opportunity for the development of partnerships between the traditional health sector and the community sector in the development of e-mental health resources.

There is certainly evidence to support the proposition that Internet technology is acceptable to patients. Most patients find the use of email and Internet technologies in their relationship with doctors highly acceptable. For example, patients from a range of settings including those from outpatient radiology settings (Horton et al, 2000), genetics clinics (Taylor et al, 2001), genitourinary clinics (Ross et al, 2000) and gastroenterology clinics (O'Connor and Johanson, 2000) have been found to search for medical information on the Web. In the latter study, over 25% of patients reported searching for information from the Web in the previous 12 months. In a small controlled trial, Demiris et al (2001) demonstrated that patients provided with TeleHomeCare (videoconferencing using the Internet) perceived the system in a positive light and believed that their medical problems could be understood by nursing staff using the system. This finding was interpreted as indicating that TeleHomeCare is likely to enjoy wide patient acceptance.

The acceptability of the Internet to doctors and other providers also seems to be high. Doctors reply spontaneously to email from patients (Eysenbach & Diegpen, 1998) and general practitioners use online groups for continuing education (Marshall et al, 2001).

c) Internet technology could offer capacities that may be difficult or impossible to achieve in normal service delivery or education

- The Internet is able to offer *individually tailored (customised)* help that may not be achievable in the timeframe provided in normal service delivery. Customisation refers to the development of individually targeted help that is provided to people on the basis of need. Technology can elicit people's individual needs and provide specific help in response to that need. This alternative health delivery medium is unique in its ability to deliver tailored information and advice at low cost. The technology facilitating customisation is developing rapidly and is changing traditional approaches to the delivery of mental health services. The technology could be especially useful in the delivery of mental health prevention programs, particularly to young people, who are adept at using Internet technology. The Internet also provides the opportunity to deliver up to date and relevant mental health information (eg locally relevant resource information).
- Internet technology creates *new networks and partnerships* that would not be possible without a suitable communication infrastructure. These networks and partnerships may be between individuals, among organisations, and across and within sectors and levels (consumer to consumer, peer to peer, client to doctor, general practitioner to specialist, service provider to service funder).
- Information can be delivered consistently and this may be of benefit in ensuring that information provided is both accurate and comprehensive. Although it is difficult to control how the user interprets or acts upon the information, there is potential for information to be delivered accurately and for treatments to be delivered with fidelity.
- Internet technologies make the task of storing and locating information easier, for example, through the use of distributed networks and *powerful search capacity*.
- e-Mental health can provide a unique opportunity for confidential access to a broad range of services and treatment options. This may be an issue of particular relevance in mental health: it is likely that

many people avoid accessing information and treatment from traditional sources due to the stigma associated with mental illness. The development of Web based prevention programs and information sites may reduce the barriers (shame and embarrassment) that prevent some people from accessing information by traditional means².

- The Internet has the advantage of being inherently self paced and available twenty four hours a day, seven days a week.

d) Internet technology may contribute to the democratisation of health care and to consumer empowerment

The growth of Internet technology represents a fundamental paradigm shift in health delivery, and has the capacity to dramatically alter the relationship between the health expert and the consumer. It is generally accepted that an increased access by the community to knowledge, once the preserve of experts, empowers that community. The Internet makes possible the widespread dissemination of accurate mental health information. It leads to a more informed and educated community. This is especially desirable in the arena of mental health because an increased generalised mental health literacy may improve the health outcomes for the entire society.

The technology may empower the consumer in another way as well: it extends the possibilities as to who can be involved in the delivery of mental health preventive strategies. Not only does the technology facilitate the integration of health services into the community sector, it also facilitates the development of partnerships between members of the community and health professional sectors. This means that the Internet technologies may increase the capacity of the broader community to be involved in the development of mental health services.

There is evidence that '*more Americans try to change their health behaviors through self help than through all other forms of professionally designed programs*' (p. 205, Davison et al, 2000). These same authors report that the 12 month prevalence of self help is approximately 3-4% of the American population. In a review of online activity the researchers examined for two weeks all postings on two online domains (America OnLine and the Internet) for 20 disease conditions. Thirty seven virtual support groups were identified from AOL, and 40,000 newsgroups from the Internet. The third highest rate of postings on AOL was found for depression (after multiple sclerosis and diabetes). The highest for the broader Internet, were chronic fatigue, diabetes, and breast cancer followed by depression in fourth place. Although this research was not specifically focused on Australia, it is likely that self help on the Internet is also prevalent in Australia.

e) Internet technology allows greater access to mental health services

One clear advantage of the new technologies is the potential for universal access to information and services to assist in meeting the huge (unmet) need for mental health services in our community. The workshop participants were confident that the expansion of technology and the ever increasing computer literacy in Australia could assist in addressing some critical issues of relevance to certain disadvantaged groups, particularly those living in rural and remote areas. The new technologies can facilitate greater access to mental health services and other forms of social support for all Australians³.

It was agreed by some participants that progressive developments in the telecommunications area will provide all Australians with the opportunity to access and utilise the new technologies⁴. It was felt that people generally, particularly young people, are becoming more computer literate and that as time goes by more people would have access to e-mental health applications⁵.

3.2 Barriers to the implementation of the Internet in the delivery of health prevention, promotion, education, and treatment

Despite its many advantages, workshop participants agreed that the Internet is not without its challenges (Appendix C). Barriers to the implementation of e-mental health initiatives include: (a) the lack of established funding models in conjunction with high development and continuing maintenance costs; (b) increased short term costs associated with increased uptake of conventional and other services; (c) issues relating to ethical responsibility and liability; (d) privacy issues; (e) poor quality of information; (f) lack of evidence of efficacy or effectiveness; (g) lack of uniformity of access; and (h) limitations to the availability of optimal technologies. Each of these barriers is discussed below together with relevant evidence from the literature.

a) Internet technologies and systems are expensive to develop, require maintenance and have no demonstrated funding models

One common theme raised at the workshop was a concern over the high cost of the new technologies. Participants raised the issues of the enormous start up costs, and the need for ongoing funding to ensure the sustainability of e-mental health programs. It was unclear how the funding for these developments was to be achieved but participants acknowledged that the costs would need to be shared by government, the telecommunications industry, the private (health) sector and individuals such as consumers and professionals.

At present, the most highly developed funding models were those involving primary care and specialist care, where Internet services such as telepsychiatry and 'Web counselling' were likely to be paid directly by the medical provider, or by the person's insurer and underwritten by the Health Insurance Commission. Other areas are likely to develop less quickly or less carefully because the funding models are not present. These might include community education, Web counselling by non professionals, or counselling by Commonwealth and Foundation supported sites such as Reachout. Funding models for consumer to consumer support were much less developed, as attested by the owners of sites such as depressionNet.

However, it is clear that current mental health resources are stretched, and it is difficult in the short term, to see how additional Internet based services can be provided without reducing funds elsewhere.

b) The uptake of the Internet may lead to short and long term increased costs because previous non users begin to use conventional and other services

An additional concern was that the widespread expansion of e-mental health and the increased promotion of a disorder may lead to an increased demand on the health system. This would further burden an already exhausted system. To our knowledge, there are no systematic studies of the impact of increased mental health literacy on the health system, but it is interesting that Gavin Andrews (see Lecture 2.1) reports a reduction in waiting times since the development of the CRUFAD site.

c) The transfer of information or help over the Internet creates issues of ethical responsibility and liability

The issue of the nature of legal liability for treatment or information disseminated over the Internet is a critical issue in the development of policy on e-mental health. Some of the participants considered that the resistance to the use of the Internet for providing treatment and disseminating information can be

explained in part by the professions' fear of liability. In particular, there was concern that information offered over the Internet may be misconstrued or used in an inappropriate way.

While the fears of professionals must be addressed it is also critical to remember the rights of consumers when addressing issues of liability. Arguably, the high standards of accountability demanded of health professionals have developed (in large part) as a response to the increasing willingness of courts to find that liability exists in a professional/client relationship. It is critical that these standards of accountability be maintained in the Internet environment, and the consumer be afforded adequate protection. Clearly, the issue of legal liability is closely related to quality assurance.

While liability is an issue that can be addressed with professional groups, liability issues also concern non professional practice and information that is posted on the Internet – for example, for prevention sites and information sites. Are professionals and Web developers ethically or legally obliged to respond to cries for help on their Websites?

International evidence suggests that professional and non professional e-mental health practice is inconsistent and unstructured. There is evidence that doctors and other mental health professionals have inconsistent practices with respect to, for example, unsolicited emails from 'patients'. Eysenbach and Diegpen (1998) described the responses of doctors to a fictitious email sent by a 'patient' with a dermatological problem to 58 physicians and Web masters. Over 50% responded to the unsolicited mail, but the response varied and Eysenbach suggested that appropriate standards were required for such communications. A survey by Neinstein (2000) of 99 health care centres confirmed that although e-communication was common, the centres typically did not have a policy to guide electronic communication between patients and their staff.

Moreover, evidence from the literature suggests that doctors are not aware of the ethical implications of establishing email contact with patients. At the same time, email consultations do not necessarily compromise patient care. For example, Eysenbach and Diegpen (1999) found that many emails sent by dermatologic patients seeking teleadvice from physicians could have been answered by a librarian or by a physician without consultation.

d) Information about Internet users may be stored and the privacy of individuals may be compromised

The perception that privacy is protected is crucial to the uptake and utilisation of e-mental health services. Concerns about privacy frequently focused on the issue of personal health records. There is an underlying assumption that it is desirable for people to have access to their own records. There is a basic tension between the need for access to health records and the need for security of those records. The new technologies raise important questions in relation to access to patient records: who should have access to what records, how should that access be regulated and can patient privacy be protected. In addition, the new technology raises important questions of authentication. While in the traditional doctor/patient relationship it is easy for each party to verify the identity of the other, this is not the case with Internet based consultations or records access.

While the majority of discussion focused on the protection of personal health records another issue raised was protection of the data gathered on information, prevention, and consumer sites. It is critical to the success of e-mental health preventive strategies that consumers feel assured that any identifying data gathered on them will not be used, or conveyed to third parties, inappropriately.

An interesting issue was raised by one participant who argued that privacy in modern life was redundant: there is no privacy. Many public institutions have access to so much of our lives – credit ratings are readily accessible, video cameras in public places are ubiquitous, and what was once regarded as personal information is freely available. Thus, the participant argued that excessive concern with privacy is out dated⁶.

e) The quality of the information on the Internet is not uniform and in many cases may be poor or false

The quality of information on the Web is of major concern to consumers, governments and professional bodies internationally and in Australia. The workshop focused on the problems associated with poor quality information on Websites for the public. There were concerns that information may be inaccurate and even dangerous; that the information is often not referenced; that it is sometimes not possible to tell if a Website is endorsed or sponsored by a particular group or company, nor to know what effect a developer's potential conflicts of interest may have on the quality of the information. It was noted that there is no external regulation of Internet sites, and that there are no intelligent search engines that can retrieve only information that is accurate and consistent with evidence based standards. Consumers are not necessarily in a position to judge the validity of Internet material. In these circumstances, it was felt that health consumers could not feel confident about the accuracy of currently available Web based mental health information. Quality assurance is also important when technology is used as an alternative to or adjunct to traditional face to face treatment, for example email communication between a psychiatrist or counsellor and a patient.

Consistent with the views of workshop participants, there is evidence that the quality of information on the Web is variable and that many mental health Websites produce low quality information for mental health consumers (Griffiths & Christensen, 2000). Some may even produce misleading or potentially dangerous information. There have been a number of attempts to address this issue (see Risk & Dzenowagis, 2001). Although some of these offer promise (see Griffiths, Lecture 1.5; Griffiths & Christensen, 2002), there are as yet no currently available appropriately validated methods by which consumers can assess the quality of Web based information.

f) There is little evidence to suggest that treatment, counselling or information on the Internet improves mental health symptoms or mental health literacy

While participants clearly believed that the Internet could and should play an important role in the delivery of mental health services, there was a concern about the lack of evidence about the effectiveness of Internet delivered services. In addition to the need to evaluate the efficacy of e-mental health services it is imperative to develop an evidence base for their effectiveness and to understand how consumers use and interact with e-mental health services.

A review of the literature on e-health and e-mental health sites supports these concerns. Although 20,000 Internet health sites and many health technologies are available to users, there is as yet little evaluation of the information and interventions that are offered on the Internet. It is crucial that mental health and other technologies are evaluated if they are to be fully recommended and supported (Wootton, 2001).

For this report, we examined the international literature to see if health technologies, telemedicine interventions, support groups, email lists, and other Internet technologies produce good outcomes in both the health and mental health areas. We found few research reports on the outcomes of Internet interventions. Those that were located tended to report positive outcomes.

We concluded from our review that:

- It is too early to comment on the effectiveness of telemedicine interventions (Currell et al, 2001; Wootton, 2001).
- Health care education, which involves the patient in self management but is supervised by mental health care professionals, has been reported to be associated with good outcomes (Lewis & Behana, 2001).
- There is evidence from randomised controlled trials that Internet delivered treatment and prevention for eating disorders is effective (Winzelberg et al, 2000).
- Professionally mediated support groups are popular, may be effective, and are used more by individuals with stigmatising illnesses, such as depression than by individuals with other less stigmatising disorders (Zrebiec & Jacobson, 2001; Davison et al, 2000; Witt, 2000; Muncer et al, 2000).
- There is evidence that epidemiological surveys can be conducted on the Web. The Internet has been used to collect epidemiological data on menopause (Comboy et al, 2001), risk taking (Pealer et al, 2001) and depression (Houston et al, 2001). Results from these surveys tend to correspond with data collected by standard survey or telephone methods pointing to the validity of these techniques in collecting epidemiological data. However, there is some evidence that Web based questionnaires result in fewer 'socially desirable' responses suggesting that respondents may be more honest in the context of Web delivered surveys.
- There is some evidence to suggest that young adults are as likely to use a Web based survey as a postal mail survey and that they are more likely to answer 'socially threatening' items when the electronic medium is used (see Pealer et al, 2001). However, older individuals and those from minority backgrounds may be less likely to complete questionnaires on a community Website (Houston et al, 2001).

g) While the Internet can improve access, access may not be uniform for all groups

The issue of access was identified by many participants as a major barrier that must be addressed in future policy development on e-mental health. There is clearly a disparity of access to the technology necessary for e-mental health in Australia – a technology divide based on education, income, language, region, age and computer ability. It appears that those who most need access to health care are those least likely to be able to effectively bridge the digital divide. In our community there is a self perpetuating cycle of low education, low health literacy, low income, and poor health (Eysenbach, 2001). To adequately exploit the new technology, consumers not only need access to the physical technology, they must also have the research skills and general and computer literacy to use that technology.

Another access issue identified was in the design of the services. Currently many sites are designed by computer experts without sufficient input from the people for whom the site is intended. This lack of involvement from the targeted group in the design of the services makes the Website less accessible to the target group⁷.

Certainly in Australia, research suggests that although access to the Internet is increasing more rapidly than the uptake of any other technology, there are inequities in the use of Internet technologies (Parent et al, 2001; Bernhardt, 2000). In Australia, higher income families, families with children and people living in cities rather than rural areas are more likely to have computer and Internet access (ABS, 2000). Apart from work and home, other access points are libraries and places of education. Internet usage is much less frequent in those aged over 55 years. Similarly, New Zealand and US studies indicate the digital divide differentially affects the less well educated, and older and minority groups.

It would appear that the very 'groups that are arguably disadvantaged in traditional medical healthcare' may also be those who would benefit most from Internet delivered health services (Brebner et al, 2001). However, lack of access among these groups may serve to further widen disparities in health outcomes and the full potential of the Internet as a medium for health delivery, illness prevention and health promotion (see Bernhardt, 2000) may not be realised.

h) The technology to use the Internet maximally is not universally available and limits the extent to which Internet technologies can be used

The workshop discussion focused on the issue of bandwidth and government policy, and more specifically the desirability for a high bandwidth rollout. It appears that despite the government policy of universal service obligation few Australians have access to high bandwidth since it is considered too costly for Telstra to provide high bandwidth services. This can result in a frustratingly slow service, and places serious limits on the use of state of the art technology by the majority of Australians. The basic technological standard needed to practice psychiatry over the Internet in people's homes cannot be met. In addition, the current pricing structure used by the telecommunication companies depends on distance, and this too limits technological take up.

A further technology barrier identified is the insufficient number of people trained to use the technology for creating applications (hypertext, streaming, multimedia etc). Sites and software must be designed that go beyond the linear text sites currently favoured, and which target and engage a wider range of users.

3.3 Moving forward: Overcoming barriers and capitalising on advantages

From the workshop discussion, five major areas where barriers might be overcome were identified. These are summarised in Box 5.

BOX 5: MAJOR AREAS REQUIRING ACTION

Access

The means by which access to the opportunities of the Internet could be made available to those on the other side of the 'digital divide'.

Ethical issues

The means by which ethical issues which impact on Internet mental health provision could be understood and overcome. A number of issues were identified:

- How the ethical responsibilities and legal liabilities associated with online relationships might be understood; and
- How confidentiality and privacy might be protected.

Quality and effectiveness

The means by which quality of information and positive health outcomes might be ensured. This involves two important issues:

- How the quality (eg accuracy) of information on the net could be optimised; and
- How the effectiveness of Internet services could be maximised.

Technology

The means by which technology could be developed quickly and equitably.

Funding

The means by which costly mental health Internet applications might be funded, and who might provide the funding.

In the following sections we summarise (with reference to the literature) the views of the workshop participants and the results from the online survey (Appendix C) about how these issues might be advanced.

a) How access to the opportunities of the Internet could be made available to those on the other side of the ‘digital divide’

In Australia, the information divide parallels socioeconomic and demographic divides. The workshop recognised the important role of government in seeking to establish strategies to bridge this information divide. Leaving to market forces the task of ensuring equal access to information is unlikely to improve equity of access.

Several participants suggested schemes to facilitate access to Internet terminals. These included:

- to use resources of commercial and public organisations ‘out of hours’;
- to more effectively subsidise access by disadvantaged Australians; and
- to seek deals with Internet Service Providers to gain discounted rates for viewing health sites.

In addition to physical access to the technology, access will be improved if all members of the community are sufficiently ‘information literate’ to use the new technologies. Regardless of the attractiveness, and apparent simplicity of a site, users need a basic level of computer literacy and research skills. While a growing percentage of people, especially the young, are comfortable with the new technologies, there is still a group of marginalised Australians without physical and educational access to Internet technology. If e-mental health initiatives are to be successful, this cycle of inadequate information and health literacy, and low income and poor health must be broken.

It was also suggested that access could be improved if the end users (both professionals and consumers) were involved in the design of the sites. Consumer users, including young people, older people, Australians from rural and remote regions, indigenous peoples and people from culturally and linguistically diverse backgrounds, need to be involved in the design of the services, and to identify what will work for them⁸. Related to this is a need to understand how consumers understand and use the information they are accessing. An understanding of the consumer’s needs, values and preferences will lead to a greater understanding of what information is most desired and useful to consumers (Eysenbach, 2001).

Respondents to the online survey also pointed out that there is a need to invest in service supply and remote system technology, and that there seems to be considerable variability in the technology available within Australia.

b) How ethical issues which impact on Internet mental health provision could be understood and overcome

Currently, there are international efforts underway to examine the ethical responsibilities and liabilities involved in mental health and other professional contact on the Internet (Dyer, 2001). However, given the pace at which e-mental health counselling is developing, there is an urgent need to develop a position on the role of professionals and others in mental health service delivery in Australia. Dyer (2001) notes that basic questions such as 'What is an online relationship – does the person need to be spoken to in order for a relationship to involve an ethical obligation?' and 'Is e-therapy different from traditional forms of therapy?' have not been comprehensively addressed. However, some organisations, including the International Society for Mental Health Online (<http://www.ismho.org>) and the American Medical Informatics Association Internet Working Group (Karen & Sands, 1998) have made a start in examining these complex issues.

There is a clear need to develop procedures for conducting professional to consumer relationships using the Internet. These procedures should be developed by professional organisations in consultation with the government and with consumers. The aim of guidelines should be to ensure that individuals and organisations who use the Internet to deliver health services take responsibility for their content and ethical provision according to agreed conditions and procedures.

Confidentiality and privacy

Patient (and professional) privacy is clearly a critical issue in e-mental health. It is imperative that there is nationally consistent privacy protection that spans both the private and public sectors. There is a need to establish a secure e-mental health network which would facilitate appropriate access by consumers to their health records and the sharing of relevant health information among authorised clinicians⁹. Confidentiality and privacy guidelines need to be developed with the involvement of all relevant stakeholders: providers of e-mental health services including consumer providers; mental health consumer and carer representatives; research bodies, including NHMRC; and relevant statutory authorities. The aim of the guidelines would be to clearly indicate where responsibility rests for ensuring the privacy, confidentiality and security of all e-mental health related information.

The relevance of the *Privacy Amendment (Private Sector) Act 2000* was discussed at the workshop. This Act, which came into force in December 2001, amended the Privacy Act 1988, and its provisions apply to all health service providers in the private sector. The effect of this Act is (in part) to ensure that all the health information that these organisations hold is treated responsibly and complies with the National Privacy Principles (NPPs). The NPPs located at Schedule 3 of the Act apply to conventional, electronic and digital environments. The explicit inclusion of the new technologies recognises the importance of e-health in the Australian health sector. Some respondents to the online survey emphasised that it was possible to rely on these provisions to protect patient information. Other workshop participants advocated initially retaining some functions, especially those relating to individual health records, within the traditional health delivery system. They favoured the gradual introduction of e-mental health services, and the associated generation of online data on consumers, to allow time to understand and develop solutions to confidentiality and privacy issues.

In relation to personal health records there must be the capacity with any medical record database to mask and unmask components of the record depending on who logs on. This means, for example, that a patient could specify that particular information on their record could be available to their psychiatrist but not to their general practitioner. In addition, while it was important that patients were able to access

their health records it was equally important, particularly in emergencies, that health providers could do so. It is crucial that policies and administrative and technological infrastructures are established that ensure a powerful audit trail, with all logins being recorded. In addition, appropriate penalties need to be imposed for any security breaches.

While there are certain structural barriers still in relation to authentication, important questions must still be asked: how should someone seeking to access a record be identified; and what level of access should be granted according to the identifier? It is important that appropriate qualifiers are recognised by the new technologies. These could be numbers, fingerprints, smart cards, or biometrics. Some information might be made available only when the patient and the doctor act jointly.

A further area of concern was the possibility that identifying data might be collected and aggregated when consumers visited e-mental health prevention sites. One participant suggested that the level of privacy that is appropriate depends in part on the level of the intervention. According to this argument, health records should be afforded a higher level of protection than those found when merely accessing a Website designed as a preventive strategy. However, others recognised that the perception of privacy by consumers would affect peoples' willingness to use a particular service, especially in the area of mental health. Clearly, this raises a number of ethical and technical issues for site designers and researchers. It may be appropriate to delete the information provider number of the computer visiting an e-mental health site from the database. Privacy and confidentiality issues are also highly relevant to the area of mental health research on the Internet where the need to conduct research for the public good must be balanced against the right of individual consumers to privacy and confidentiality in their online interactions.

c) How the quality of e-mental health services might be improved

Workshop participants considered that the duty of care and the standards of care afforded across the Internet should not differ from more traditional service provider models. Sites providing consumer information needed to meet standards, to make explicit their basis for advice and endorsements, and to identify site authors and note the dates of revisions. However, it was recognised that the regulation of non government or non university sites is more complicated, and one strategy may be to educate the consumer to become more discerning. However, there is a need to identify valid indicators of site or service quality that do not require content expertise.

There is clearly an important role for government in the ongoing development of the notion of quality assurance, since this is arguably one of the core areas of the government's role. While an initial attraction of the Internet was its very lack of restrictions, there are now Commonwealth initiatives for government departments to implement common standards. All sites that have a relation with government will need to meet these standards.

In the future, initiatives such as the MedCERTAIN project (Griffiths, Lecture 2.5) may prove helpful in providing consumers with evaluative information about the quality of Websites. It may be appropriate for Australia to become involved in, or at least explore the potential relevance of the MedCERTAIN collaboration to the Australian context. The development of intelligent search engines which automatically return high quality mental health sites also offer a potential means for facilitating consumer access to high quality information.

Effectiveness of Internet services

Both the workshop participants and the online survey responders pointed to the lack of evidence in the area of e-mental health services and the importance of evaluation. They considered it imperative that these services be evaluated, and that the nature of consumers' interactions with e-mental health services be examined empirically.

d) The means by which technology could be developed quickly and equitably

The issue of bandwidth attracted a great deal of attention at the workshop. It was generally assumed that speeding up the high bandwidth rollout was desirable because it would allow individuals to access the Internet more efficiently. However, the simple assumption that greater bandwidth would facilitate the development of e-mental health was challenged to some extent. One participant pointed out that the broadband technology was currently not sufficiently advanced that it mattered¹⁰, and another queried the simple assumption that greater bandwidth would necessarily lead to improved health outcomes¹¹. Wootton (2001) supports this view suggesting that the main problem in telemedicine is not a lack of technology but rather the organisational problem of knowing how to take advantage of the technology. He asks, for example, 'how health services change their delivery practices to take advantage of what the technology can do?'

The issue of the telecommunication pricing structure must be addressed. It is crucial if all Australians are to have access to health services over the Internet that prices are capped at a reasonable level. While this is a task for the Australian Competition and Consumer Commission (ACCC), it would appear that current pricing reflects pricing policy rather than real costs incurred by the communication carriers.

In addition to a greater expansion of digital technology, it is crucial that more people be trained to use the technology, and to learn hypertext markup language, streaming, multimedia and other skills. Sites and software must be designed that go beyond the linear text sites currently favoured, and target a wider range of users. There is a need to nurture technological skills and for these to be integrated with mental health knowledge. People should be brought together, working in competition but also in collaboration, to design appropriate technology. The role of government might be to facilitate partnerships and an open process and to fund demonstration projects.

e) Resources and costs

Both participants and online responders pointed to the need to develop models of funding for Internet health care technologies within the Medicare Benefits Scheme and through the health funds. In particular, it was suggested that there should be a determination of the resources that were sustainable by private resources and those that were not. Health promotion and prevention were not considered to be sustainable through private or Medicare sources and it was considered that they might need to be funded by the government. Possible funding arrangements were mentioned, including grants and industry support. User pay arrangements were also mentioned. An e-mental health Cooperative Research Centre may be viable and partnership grants through industry and the Commonwealth may be a suitable model for funding. There was a need to develop e-expertise infrastructure both technologically and in mental health areas.

f) Conclusions

All the workshop participants who responded to the followup survey were adamant that e-mental health should be integrated into future mental health policy planning. The general consensus was that Commonwealth involvement was essential because there is a rapidly increasing use of the Internet in the delivery of mental health services, and the new technologies will increasingly be used for the provision of information, assessment, diagnosis, and counselling and treatment¹². Indeed it was felt by Kirkby that because of the strength of the impact of the Internet on mental health treatment that e-mental health should be a special initiative or an identified priority area (Kirkby, Lecture 2.4).

In this report, a distinction has been made between the use of Internet resources in facilitating normal services and the development of the Internet in bringing new methods to solving mental health programs. Many of the barriers to e-mental health are not unique to the Internet but extend across the whole service delivery sector in mental health.

It would therefore seem reasonable to explore ways of extending the usual standards for face to face services to those involving professional contact between Internet users and general practice and specialist individuals and organisations. The extension of e-mental health services to the professional sector may be difficult to negotiate because of ethical responsibilities and concerns about the quality of interventions. Nevertheless, there are many international precedents that can provide a starting point for developing ethical guidelines and quality assurance guidelines. Professional organisations, mental health professionals, consumers and government agencies should be involved in this process. It is in areas that provide new models of how mental health services can be delivered that there may be more difficulty and where the challenges will be greatest. These include areas of community education, chat groups, mediated chat groups and peer to peer support groups.

ENDNOTES

- 1 Nicholas J, Response to survey stemming from the e-mental Health Workshop, 26 June, Centre for Mental Health Research, Australian National University
- 2 Pethick L, Response to survey stemming from the e-mental Health Workshop, 26 June, Centre for Mental Health Research, Australian National University
- 3 Graham D, Response to survey stemming from the e-mental Health Workshop, 26 June, Centre for Mental Health Research, Australian National University
- 4 *ibid*
- 5 *ibid* and Nicholas J, Response to survey stemming from the e-mental Health Workshop, 26 June, Centre for Mental Health Research, Australian National University
- 6 Martin G, Response to survey stemming from the e-mental Health Workshop, 26 June, Centre for Mental Health Research, Australian National University
- 7 Blignault I, Response to survey stemming from the e-mental Health Workshop, 26 June, Centre for Mental Health Research, Australian National University
- 8 Blignault I, Response to survey stemming from the e-mental Health Workshop, 26 June, Centre for Mental Health Research, Australian National University
- 9 Kirkby K, Response to survey stemming from the e-mental Health Workshop, 26 June, Centre for Mental Health Research, Australian National University
- 10 Pethick L, Response to survey stemming from the e-mental Health Workshop, 26 June, Centre for Mental Health Research, Australian National University
- 11 Kenardy J, Response to survey stemming from the e-mental Health Workshop, 26 June, Centre for Mental Health Research, Australian National University
- 12 Richards J, Response to survey stemming from the e-mental Health Workshop, 26 June, Centre for Mental Health Research, Australian National University

Section 4: Towards an e-mental health policy



4.1 Policy suggestions

It is increasingly clear that e-mental health needs to be integrated into future mental health policy planning. There is a strong case for e-mental health to be established as an identified priority area given its importance in the delivery of mental health services. The Internet will play a major role in the future delivery of programs aimed at increasing community awareness and in providing prevention, assessment, diagnosis, counselling and treatment programs. The Commonwealth Government is positioned to take a leading role in developing policy in e-mental health. The following suggestions and strategies are intended to provide a basis for developing a coherent e-mental health plan for Australia.

General

A more systematic and informed approach is required to realise the potential of the Internet to contribute to better mental health services, prevention and improved community awareness. At present, there are no national e-mental health policies and little is known about the use of the Internet by mental health professionals and by members of the community in Australia.

Suggestion 1: e-Mental health should be a priority area in mental health policy planning.

Strategies:

- Establish a national Reference Group comprising representatives from key stakeholder groups to:
 - advise on e-mental health policy issues;
 - convene, establish the terms of reference for, and oversee relevant working parties;
 - provide input into the consultation process for developing the Third National Mental Health Plan; and
 - present the case that e-mental health should be a priority area within the Plan.

Suggestion 2: e-Mental health initiatives should be integrated effectively into current mental health programs.

Strategies:

- Undertake a comprehensive review of what e-mental health services are currently available. To avoid duplication, this review should take into account other initiatives currently in progress and coordinated by the National Health Information Management Advisory Council and other key groups. The review document should examine:
 - current Internet mental health information sites as a function of type of intervention strategy and funding source, including a description of services, who provides them, the modes of delivery, the target groups and the users of such services;

- telemedicine mental health services including Web counselling, Web psychiatry and Internet and other e-technology assisted therapy, in particular, Web based ‘call centres’ which offer online advice and counselling;
 - available and emerging e-mental health technologies;
 - Internet crisis services, support groups and chat groups in Australia;
 - initiatives that aim to provide physical access to the Internet and to other e-mental health services for those with mental health symptoms;
 - the attitudes and expectations of consumers and doctors about the role of e-mental health; and
 - the full range of different types of interactions that occur online. This may also include a review of interactions that occur via electronic technology.
- Undertake an analysis of potential methods for integrating Internet services into current mental health programs. Without proactive analysis, Internet services may be disproportionately driven by market forces rather than by consumer or national needs. Delivery systems other than the Internet should also be considered. This analysis of potential methods should draw on:
 - strategies adopted overseas and in Australia;
 - the views of experts in e-mental health and mental health;
 - work in progress occurring at the national level in relation to improving the practice and outcomes in other health areas. Strategies include the use of e-technologies for improving and speeding up communications, coordinating and integrating communication between people within and between disciplines and sectors, and providing more effective diagnostic and prescribing tools;
 - results from prototypical interventions and test cases; and
 - the funding and development of demonstration models for how the new technology might work. The latter will depend to some extent on which models are funded under Networking the Nation program and the National Communications Fund, two initiatives set up by the Commonwealth Department of Communications, Information Technology and the Arts.
 - Develop training and continuing education programs targeting medical schools and existing health care provider services to encourage and educate future and existing practitioners to integrate e-mental health initiatives into their practices.

Access

Access to Internet technologies should be improved for those communities which are not currently served. Initiatives currently underway to improve Internet access for all Australians should continue. However, there is a need to develop specific access strategies for those with mental health symptoms since mental health may differ qualitatively from other areas of health. In particular, there is greater stigma and less openness about mental health problems and the evidence suggests that mental health consumers are taking to the Internet very quickly.

Suggestion 3: Investigate strategies for improving access to information on the Internet for those not currently served by the technology.

Strategies:

Taking into account relevant national strategies developed under the auspices of the National Health Information Management Advisory Council:

- Identify the factors such as lack of physical access, lack of interest and lack of information literacy that contribute to the 'digital divide' among mental health stakeholders and serve as barriers to Internet use within Australia. Include in this strategy current literature on the nature of the 'digital divide' in Australia. A relevant publication may be that of Hellwig and Lloyd (2000).
- Together with relevant government, non government and practitioner organisations, plan and devise strategies for education and training of mental health consumers, carers and providers in mental health technologies.
- At a national level, identify methods for removing barriers and increasing equity of access to the Internet. Improve Internet content for communities not yet served through the development of local content, catering for lower levels of literacy, and through the involvement of local communities, consumers and carers. Individuals with mental health problems who are older, from a culturally or linguistically diverse background or of Aboriginal and Torres Strait Islander background should be provided with the opportunity to contribute to the content of mental health sites. Moreover, these individuals should be supported in these endeavours through the development of appropriate guidelines.
- Ensure that health professionals and consumers are given the opportunity to provide input to all government mental health information sites.

The quality of information

The Commonwealth Government is positioned to play a lead role in developing quality assurance standards for the use of the Internet in mental health. The Commonwealth could also play a key role in educating providers and consumers of the importance of the quality of Web information. Support groups are proliferating and there is a need to develop guidelines for both providers and users on standards for the operation of these sites. Although the Internet is essentially unregulated, guidelines will help to encourage good practice.

Suggestion 4: Develop guidelines that encourage and promote high quality mental health information on the Internet in Australia.

Strategies:

- Under the direction of the proposed e-mental health Reference Group, establish a national working party with representation from major stakeholders with responsibility for:
 - developing a protocol for evaluating mental health Websites;
 - reviewing and ratifying mental health Websites with representation from major stakeholders;
 - reviewing the strategy used by HealthInsite to develop high quality information;
 - developing strategies to educate consumers about evaluating the quality of information on mental health Websites; and
 - developing strategies for educating mental health Web producers about the importance of high quality information.

Guidelines with respect to evaluating the effectiveness of Internet sites

Although many mental health sites are available on the Web, very few are evaluated. Without such evaluation it is difficult to know whether they are useful, satisfying for consumers and mental health professionals, or even harmful. Internet interventions and information sites in mental health should be evaluated for their effectiveness. There is a special need to evaluate the effectiveness of support groups in mental health since these are growing, popular and often cater for specific needs.

Suggestion 5: Promote the development of useful and effective mental health Websites.

Strategies:

- Assess all submissions and tenders for Commonwealth/State/Territory/local government funded Websites against an agreed assessment protocol and agreed standards.
- Assess all submissions and tenders for government funded Websites for inclusion of an appropriate evaluation protocol.
- Ensure that government funding of Internet applications is contingent on these sites developing suitable process and outcome evaluations.

Guidelines with respect to ethical principles and liabilities

There is a need to develop guidelines for professional and non professional practice on the Internet. Societies and professional organisations need to educate their members about the ethical and legal implications of interacting with patients on the Internet. Community centres, mental health services and other organisations within the mental health community need to identify procedures for handling Internet inquiries and requests. Without clear practices and protocols, mental health professionals may be at risk and patients may develop unrealistic expectations. Guidelines to determine professional practice on the Internet are urgently needed.

Suggestion 6: Under the auspices of the National Health and Medical Research Council (NHMRC), develop and implement guidelines for mental health research activity on the Internet in Australia.

Strategies:

- Establish a mechanism by which the research community in cooperation with the NHMRC can develop guidelines for conducting ethical research on the Internet.
- Develop strategies for implementing the guidelines, ensuring particularly that other ethical guidelines both within and outside the NHMRC are upgraded to incorporate guidelines for Web based research.

Suggestion 7: Develop guidelines for the professional practice of online therapy and other e-mental health therapy.

Strategies:

- Encourage professional organisations to develop guidelines and future training and accreditation requirements for the practice of professional online therapy and other e-mental health therapy.
- Use available service guidelines and standards to assist in this process and in the development of future guidelines and standards.
- Extend current initiatives to develop training and support activities for general practitioners, as outlined in Health Outline (NHIMAC, 2001), to psychiatrists, clinical psychologists and psychiatric nurses.

Suggestion 8: Promote the highest standard ethical code of conduct in all e-mental health interactions.

Strategies:

- Under the direction of the proposed e-mental health Reference Group, establish a national working party to:
 - facilitate the development, implementation and monitoring of ethical guidelines and standards for e-mental health intervention;
 - identify and examine relevant legal issues, and in particular, professional liability issues associated with online delivery;
 - use developments in broader areas of health (eg from Health Online, NHIMAC, 2001) to inform this process; and
 - as part of the guideline implementation process, encourage relevant health professional bodies to integrate guidelines with the existing codes of professional behaviour that govern the conduct of their members.

Confidentiality and privacy

Suggestion 9: Protect confidentiality and privacy of e-mental health interactions while improving accessibility and continuity of care through the use of e-records.

Strategies:

- Continue current initiatives with respect to medical records (*HealthConnect*), and include and be informed by current developments in the broader health sector.
- Identify any legal issues associated with confidentiality and privacy that are specific to the area of mental health.

Guidelines with respect to funding models

There is little evidence available in Australia to determine how the development of applications is funded, and further information is required to assist in policy developments.

Suggestion 10: Identify means by which the development and provision of innovative e-mental health applications and infrastructure can be funded.

Strategies:

- Review the roles of industry, community and government stakeholders in funding innovative e-technologies. In particular, review:
 - current initiatives in broader areas, such as developments in establishing a research and development agenda by the Office of Rural Health of the Commonwealth Department of Health and Ageing, and findings of a working party set up by the New South Wales Department of Health to investigate telehealth financing;
 - the suitability of different levels of intervention (prevention, early intervention, raising mental health literacy, treatment) to funding from each sector. For example, the former interventions are likely to be highly suitable to the new technologies and cost effective. However, they may not prosper without government funding due to the absence of alternative funding mechanisms. Treatment such as psychotherapeutic interventions may be more amenable to a fee for service approach and may therefore be more suitable to private sector funding;

- the costs and benefits of funding innovative e-health technologies for each level of intervention and conduct an economic analysis of the costs of the Web interventions and counselling relative to face to face service delivery;
- the means by which existing public funding arrangements for mental health could be changed to integrate the new technologies;
- mechanisms for joint State and Territory funding of nationally accessible e-mental health developments; and
- strategies to develop e-mental health infrastructure and in particular to encourage the development of e-mental health technologies and e-mental health expertise. It is clear that high quality sites and useful health information require input from mental health professionals and consumers with expertise in e-mental health.

4.2 Timing of the implementation of the strategies

Clearly a number of these strategies could be implemented immediately. Indeed it may be crucial that work towards including e-mental health as a priority topic in a Third National Mental Health Plan commences without delay. Other strategies can be implemented once e-mental health is established as a priority area in the Third National Mental Health Plan.

Immediate strategies

- Convene a reference group to provide input into the consultation process for developing the Third National Mental Health Plan, to advise on e-mental health policy issues and to oversee key review activities (Suggestion 1).
- Review e-mental health services (Suggestion 2).
- Review potential strategies for integrating Internet services into current mental health programs (Suggestion 2).
- Review strategies which promote high standards and ethical conduct in e-mental health (Suggestion 8).

Short term strategies

- Identify the means by which the development of innovative e-mental health applications and infrastructure can be funded (Suggestion 10).
- Investigate strategies to improve access to information on the Internet (Suggestion 3).
- Plan and devise strategies to improve access to local content (Suggestion 3).
- Develop protocols for evaluating mental health sites (Suggestion 3).
- Develop strategies for educating consumers and Web producers about the quality of information (Suggestion 3).

Strategies once e-mental health becomes a priority area under the Third Mental Health Plan

- Re-form the Reference group into a Steering Committee to oversee the planning, implementation and evaluation of key developments in e-mental health (Suggestion 1).
- Establish a consumer representative working party to provide input into the Steering group (Suggestions 1 and 4).
- Implement strategies to overcome the digital divide, including the development of local content for communities not yet served (Suggestion 3).
- Test protocols and evaluate education campaigns to improve quality of Websites (Suggestion 4).
- Put into place evaluation protocols for all government funded Websites (Suggestion 5).
- Facilitate and implement guidelines for mental health research using the Internet (Suggestion 6).
- Develop guidelines for professional practice of online therapy (Suggestion 7).
- Put into place strategies that encourage adherence to relevant standards (Suggestions 7, 8 and 9).

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Appendices



Appendix A: List of workshop participants

Name	Organisation
Tony Jorm (facilitator)	Centre for Mental Health Research (CMHR), The Australian National University
Helen Christensen	Centre for Mental Health Research (CMHR), The Australian National University
Kathy Griffiths	Centre for Mental Health Research (CMHR), The Australian National University
Jonathon Nicholas	ReachOUT!
Leanne Pethick	DepressioNet
Tony Hill	Internet Society of Australia
Gavin Andrews	Clinical Research Unit for Anxiety and Depression
Ken Kirkby	University of Tasmania
Justin Kenardy	University of Queensland
Philip Chynoweth	Microsoft, Canberra
Craig Rochfort	110 Design_Logic
Dennis Tannenbaum	Psychiatrist
Ian Hickie	beyondblue
David Hawking	CSIRO Mathematical & Information Sciences
Mick Sam	ACT Department of Health, Housing & Community Care
Richard Bromhead	ACT Department of Health, Housing & Community Care
John Payne	Commonwealth Department of Health & Aged Care*
Mick O'Hara	Commonwealth Department of Health & Aged Care
Suzy Saw	Commonwealth Department of Health & Aged Care
Dermot Casey	Commonwealth Department of Health & Aged Care
Stephen Castle	Commonwealth Department of Health & Aged Care
Sheila Holcombe	Commonwealth Department of Health & Aged Care
Irene Krauss	Commonwealth Department of Health & Aged Care
Allen Morris-Yates	Strategic Planning Group for Private Psychiatric Services (SPGPPS)
Ilse Blignault	Queensland Division of General Practice
Phillip Taylor	Australian Medical Association (AMA)
Des Graham	Mental Health Council of Australia
Abby Patterson	Australian Early Intervention Network (AusEINet)
Jeff Crumpton	Royal North Shore Hospital
Claire Kelly	Centre for Mental Health Research (CMHR), The Australian National University

Name	Organisation
<i>Apologies:</i>	
Jeff Richards	University of Ballarat
Peter Conroy	110 Design Logic
Graham Martin	Flinders University, AusEINet
Nick Kowalenko	Royal North Shore Hospital
Peter Yellowlees	University of Queensland
Judy Proudfoot	Beating the Blues
Elizabeth Scott	Southview Clinic
Michael Kidd	University of Sydney
Julie Marr	Commonwealth Department of Health & Aged Care
Kim Walker	Commonwealth Department of Health & Aged Care
Peter MacIsaac	Commonwealth Department of Health & Aged Care
Judith Davis-Lee	Commonwealth Department of Health & Aged Care
Penny Farnsworth	ACT Department of Health, Housing & Community Care
Chess Krawczyk	Approved Systems
Bill Buckingham	Buckingham & Associates
Stephen Rosenman	Psychiatrist

* Now the Commonwealth Department of Health and Ageing

Appendix B: Respondents to the online survey

Name	Organisation
Helen Christensen	Centre for Mental Health Research (CMHR), The Australian National University
Jonathon Nicholas	ReachOUT!
Leanne Pethick	DepressioNet
Ken Kirkby	University of Tasmania
Justin Kenardy	University of Queensland
Dennis Tannenbaum	Psychiatrist
David Hawking	CSIRO Mathematical & Information Sciences
John Payne	Commonwealth Department of Health & Aged Care
Peter MacIsaac	Commonwealth Department of Health & Aged Care
Ilse Blignault	Queensland Division of General Practice
Des Graham	Mental Health Council of Australia

Appendix C: Perceived advantages and disadvantages of the Internet

Each participant at the workshop was asked to write down on separate sheets of paper, three advantages and three disadvantages of the Internet in the area of mental health. The responses were then clustered into themes on workshop whiteboards. These themes and individual responses are reproduced in Box C.1 (Advantages) and Box C.2 (Disadvantages).

BOX C.1: ADVANTAGES OF THE INTERNET AS DESCRIBED BY WORKSHOP ATTENDEES

Power of the technology:

- Dissolves traditional boundaries
- Can do technology
- Powerful search
- Opportunity for interactive communication
- Information exchange/increased equity
- Ability to communicate a common message (consistency)

Increased potential for combined services:

- Linking
- Universal
- Potential for combined service provision
- Increased opportunities for integration of health care (within health sector, across sectors – community etc)
- Partnerships
- Potential for sectors to work together
- Potential for partnerships ie – culturally specific groups, young people
- Peer/network contact
- Partnership with widely accepted young people's site providing professional support. <ReachOut>
- Partnership with young people in developing resources

Consumer empowerment:

- Selection of information based on want
- Empower – all users
- Increase currency + relevance of mental health information (localise, personalise)
- Lends itself to 'consumer' control
- Increased mental health literacy
- Potential for universal service adapted to user requirements
- More informed/educated culture
- Informal decision making by empowering consumers (more information, timely

information, accurate/referenced information)

- Greater access to 'experts' and informed individuals in specific areas
- Certificate vs network of trust

Customisation:

- Improve health outcomes – individual & population
- Self paced access
- Customised delivery
- Ability to collaborate (consumers + professionals)
- Alternative way of providing treatment – increase options
- Allows new ways of doing things
- Customised
- Technology moving fast
- Prime emergent phenomena
- Potential for interactive and tailored information provision and advice
- Promotion of treatments (ALTERNATIVES) that may not have been considered
- Changing traditional approaches to the delivery of mental health to youth
- Attractive to young people
- Way of communicating

Flexibility:

- Flexibility
- Prevention delivery

Improved consumer privacy/reduced stigma:

- Main mode of information gathering for young people → low stigma
- Consumer privacy
- Lack of stigma compared to current services
- Private
- Overcoming stigma – acceptable anonymity
- Anonymity

Economic advantage:

- Low cost
- Efficiency
- Can reach large audience at low cost
- Cost savings for consumers + providers
- Efficient delivery systems cost effective
- Improved mental health outcomes with reduced cost
- Cost/resource efficient
- Low cost delivery

Increased access:

- e-health access for all Australians
- Improved access to information for providers and consumers
- Broad population impact possible
- Potential for universal access to information and services
- Access
- Access to resources
- Meet unmet need

- Export (international access)
- Very wide access
- Wherever I am
- Access – All can access no matter where they live
- Information accessibility
- Good access for rural and remote
- Access for disadvantaged communities
- Access to more info than by ‘traditional’ means ie range of alternatives
- Individual access – no need to disclose if not appropriate
- Increased access
- Accessibility to information + services
- Gets to cover current unmet need
- Integration of mental health into just young people’s lives
- Increase access to mental health services + information to underserved populations
- Potential to reach many quickly
- 24 hours a day ‘someone there’
- Ability to reach new market

BOX C.2: DISADVANTAGES OF THE INTERNET FOR MENTAL HEALTH AS DESCRIBED BY PARTICIPANTS**Cost:**

- Revenue models
- Lack of start up money
- Sustainability: financial
- Other measures of sustainability
- Cost – high – development, infrastructure, maintenance
- Funding (Development & maintenance)
- Branch economy
- How is e-treatment funded?
- Resources, scalability, tension

Lack of quality assurance:

- Authority of information/treatments
- Lack of national coordination of disparate efforts
- GIGO: Garbage In Garbage Out = difficulty of quality assurance
- Identifying and branding quality information
- Governance marketing
- Quality assurance

- Quality assurance – Information not referenced
 - How do you know evidence of information
 - Not local information eg US drugs not approved in Australia
- Endorsement by whom
- Unofficial endorsement – by association or linkage
- Censorship potential
- Lack of quality assurance/standards – what is best practice?
- Information verification
- Establishing common standards
- Impact constrained by (vested interests) external factors
- Inconsistent quality of information
- Government regulation
- Overcontrol
- Achieving agreement regarding standards (is it the role of government to coordinate this)
- Concepts & models – regulatory framework

Will e-mental health models work?

- Lack of evidence on effectiveness
- Lack of evidence base for effectiveness
- Lack of evaluation
- Evaluation

Lack of confidentiality and privacy:

- Confidentiality issues with local system administrators
- Access vs security
- Achieving a trusted environment – privacy, security
- Privacy/confidentiality
- Confidentiality and security of personal information
- Record access:
 - patients } not the same
 - carers } not the same
 - families } not the same
- Confidence in use – consumer, provider, funder

Technology:

- Killer applications and links
- The Disney expectation
- Browser/platform variations
- Bandwidth (speed of data transmission)
- Reliance on levels of technology that only few people have
- Technology moving too fast
- Technology changes too quickly
- Achieving workable consensus
- Technology is vulnerable – virus

Access:

- Access to groups with low education, NESB etc
- Lack of access by marginalised (eg homeless)
- Access issues – ie rural/remote; older adults; lack of computer familiarity

- Access – availability, affordability, appropriateness
- Digital divide
- Reaching everyone – scalability
- Integration with traditional services
- Ensuring accessibility – cost, languages other than English, physical disability, low level browsers
- Demand outstrips supply → scalability
- Scalability of current models of use
- Professionals lack skills of younger people in net use

Infrastructure:

- Lack of local area support
- Lack of facilitation
- Inertia
- Risk aversion (unjustified)
- Risk aversion (justified)
- How to identify who benefits from e-solutions vs face to face
- Moving from early adopter to majority
- Risk of failure or disaster → rejection of – change management
- Lack of overarching framework/models – how it fits/ departs from modes of service and information delivery
- Professional resistance

Outliers:

- Empire strikes back mine
- Limited use of e-health advantages and methods
- What you want isn't always what you need