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LITERATURE REVIEW SERIES

THE IMPACT OF THE INTERNET ON
CONSUMERS HEALTH BEHAVIOUR

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TURNING EVIDENCE INTO ACTION



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Foreword

The Internet has become a vital source of information for many people, and the trend towards greater use of information technology in health care decision-making is increasing. The Internet provides many features that appeal to different individuals; convenience, anonymity, networking, global perspective etc.

The Internet offers potential for greater patient empowerment, an important element in improving health care quality and outcomes. The National Institute of Clinical Studies (NICS) has an on-going commitment to ensuring that its website best serves the needs of consumers as well as clinicians. To this an evidence-based assessment of effective web-based strategies for changing consumer behaviour was commissioned by NICS.

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Key Messages

- There have been few high quality studies that have assessed the effectiveness of health care intervention delivered over the Internet, and it can be difficult to distinguish between the effectiveness of the intervention and the influence of the medium.
- Several interventions that have been shown to be effective through other media, such as cognitive behavioural therapy and decision aids, have been effectively provided via the Internet. Even in lower intensity interventions, there is some evidence of effectiveness to improve health outcomes.
- There is little information as yet whether use of the Internet by consumers affects the interaction between consumers and health professionals and whether use of the Internet could enhance or interfere with the relationship.
- Knowledge of disease and self management of disease may be positively influenced by Internet interventions, but this effect can be limited by the high rates of drop-outs from studies.
- Qualitative studies indicate that participants feel that there is an increase in social support and enablement as a result of the use of the Internet, but this has not been evaluated fully in quantitative studies.
- The quality of an Internet intervention is dependent on both the quality of the content and the quality of the use of the medium as a means of communication.
- Potential harms of the Internet include access to inaccurate information and distressing social interactions. Neither of these harms is unique to the Internet, however, and reflect harms that have always occurred through other more traditional forms of communication.
- Although there is the potential for the Internet to increase access to information and some forms of health care interventions, at present there remain many barriers to access. While young educated males are the most likely to have access to the Internet and previous experience in its use, stage of disease, how recently diagnosis has occurred and the need for information appear to be stronger predictors of Internet usage for health information.

INTRODUCTION

Conceptual framework

In this review, we have sought to answer five questions:

- I. What web-site interventions are effective in changing disease prevention behaviour or measurable health outcomes?
- II. Does the Internet change the interaction between consumers and health professionals?
- III. Does usage of the Internet by consumers change their understanding of disease?
- IV. Does usage of the Internet by consumers change their self management of disease?
- V. Does usage of the Internet increase consumer enablement?

Use of the Internet by consumers encompasses a diverse range of interventions. Collapsing evidence about all these into one bundle, especially at this early stage of evaluation of Internet-based interventions, is likely to be misleading. The range of uses of the Internet in health goes from totally passive forms of media through to intensive forms of therapy. The approach that we have taken in this review is embedded in a conceptual framework that we hope will result in a more accurate and useful reading of the evidence than derives from clumping together an eclectic set of activities.

From a consumer point of view, the reason for using the Internet can be seen to come from a desire to locate or use one or more of the following (on one's own behalf or for another or others):

- Information and/or infotainment;
- Peer support and learning about living with a condition or problem;
- Contact with professional experts or advisors;
- Tools and resources to enable self-care or better use of the professional services (including finding products or services).

From the point of view of provision of Internet services in health, these can be seen to derive from two very different starting points:

- Using the Internet as a form of media for the communication of information; or
- Using the Internet as an alternative vehicle for the delivery of services or therapies traditionally provided in person (or by other communications technology).

These two very different intentions for provision of Internet interventions cover a broad spectrum of activities. The first begins with, for example, a simple use of a website as a form of mass media to display static information that might traditionally be communicated by a pamphlet. At the other end of the spectrum is a fully-fledged telemedicine service to patients, or intensive therapeutic counselling by email or through a website.

The effectiveness of bringing traditional forms of information or therapies to the medium of the Internet depends partially on each of the following:

- The potential efficacy of the intervention's content;
- The efficacy of the Internet as a medium for its translation or delivery;
- The production values of the intervention (including relevance, quality and usability);
- The nature of the condition or problem being addressed; and

- Consumer interest, use, capacity (including access to the technology) and computer and language literacy.

Thus, a collection of information items that has been proven to have no effect in brochure form may be unlikely to gain in efficacy upon being broadcast via the Internet. And an intensive counselling therapy proven to be of benefit for a particular health problem may lose efficacy in the translation from interpersonal delivery to impersonal self-help manual on the Internet. What has an effect on knowledge levels in a condition where consumers' access to other information on this subject is nil may be very different to the potential for influence in a subject area where consumers have access to a high level of information from other sources already.

Similarly, if there are no treatment options for a person, or no choices for them to make which might affect health outcome, provision of information may have little direct impact on health outcomes (although it may affect service use or psychological outcomes). What has been shown to work for one particular chronic health problem may be totally irrelevant even to another chronic health problem, let alone a healthy lifestyle intervention. A clumsy rendition of information on a fairly unusable website that few people visit may be very ineffective, while a more elegant form of communication of the same information on a highly usable and used website may be very effective. Hence, while the evidence base is small, and perhaps even when it is large, blanket statements about the effectiveness of "the Internet" are essentially meaningless. Both the medium and the message being conveyed will interact in determining the influence and effectiveness of the message.

In addition to providing a new medium for the transmission of services traditionally provided in other media or in person, the Internet may provide some opportunities that can be capitalised on in no other way and thereby fulfil information needs that have been unmet previously. For example, there is the potential for providing peer and social communication to isolated home-bound people, for information to be available 24 hours a day, and to be available from anywhere in the world with an Internet connection. In addition, there are the various possibilities that telemedicine offers, from simple use of email between doctor and patient to diagnostic testing transmitted down datalines for geographically isolated people, or the use of video for consultations or to enable distant parents to view and possibly communicate with their hospitalised child.

We have grouped current uses of the Internet into four broad areas:

- I. Websites, possibly incorporating information and resources in various forms, with or without peer support elements or the ability to send email requests for individual response by an expert;
- II. Websites as a medium for use in delivering traditional forms of structured educational or instructional programs;
- III. Website-based provision of cognitive-behavioural training (CBT) style interventions, or interventions based on CBT principles and methods, intended to influence health behaviour or status;
- IV. Telemedicine, beginning with simple forms of communication in health care provision (eg emails between doctors and patients as part of the provision of health care, with no website involved, or purchasing a medication or health product online) through to major provision of health care services via the Internet and other ways of communicating data down phone lines.

Telemedicine is a distinct category that has little to do with the "mass media" style of intervention people think of as "the Internet". Telemedicine has more in common with service provision than it does with solely information or communication-based interventions. It has also been intensively studied as a separate category (AHRQ 2001, Currell *et al* 2003, Hailey *et al* 2002). In amongst so many other potentially major and powerful components of telemedicine interventions, untangling the respective influence of a particular Internet element (such as an information website that is part of a fully-fledged telemedicine service for the home-bound) would be impossible. We have therefore excluded interventions on the effectiveness and consequences of telemedicine from the current review. However, had there been any study comparing an ordinary website with a fully-fledged telemedicine service, that would have been included under category (1).

For the purposes of this review, no distinction, however, is made between intranet interventions (interventions on an in-house network) and Internet interventions (publicly accessible content on the World Wide Web). From a consumer point of view of effectiveness, there is little absolute distinction between these two. They differ in the potential size of the audience, and thus, the magnitude of ultimate benefit. There is no clear bearing, however, on the potential for effectiveness as interventions in themselves when used by individual consumers.

Even websites that are on the World Wide Web are often password-protected, or have elements that are password-protected, and so are unavailable to the general public. Thus, while a distinction between publicly available online and intranet versions may be made (Bessell *et al* 2002), this serves no clear conceptual or practical purpose for a review on the evidence of the effectiveness of an intervention for those considering delivering an Internet based intervention. The distinction may alter the public health impact of the intervention but we do not consider that it will alter the measure of effectiveness of the intervention that is seen from studies and may have been necessary for the design of the study of effectiveness. The criterion of absolute public availability, if properly applied, would exclude from consideration most of the best quality evaluations of the use of Internet interventions.

The Internet is a relatively new form of mass media. It has already been shown that interventions through mass media can be influential on people's health care behaviour (Sowden and Arblaster 2003, Grilli *et al* 2003). Many health websites and Internet health products are also integrated within cross-media outlets, such as the website of a television station, newspaper or magazine, or are linked now into the websites of mass media outlets. Thus, even a small proportion of the audience being affected (apparently low effectiveness) can translate into impact on large absolute numbers of people when an audience is great. Therefore, the principles and skills of effective mass communication have a large role to play in the potential effectiveness of Internet interventions in health.

Some forms of health care interventions that have already been shown to be effective are available through the Internet. For example, many patient decision aids are delivered now on the Internet (O'Connor *et al* 2003). Thus, the potential effectiveness of a website may be enhanced by the inclusion of a patient decision aid which has been proven to be effective when used in CD-ROM form by an individual unaided.

Evidence on other forms of computer-based information is also relevant to a consideration of the potential effectiveness of the web. A systematic review of trials of interactive patient education materials has shown that these can lead to an improved health status in several major areas of care (Krishna *et al*, 1997). Delivery over the Internet would often be feasible for these interventions. There are trials showing value from several of these types of interventions, for example, the CHES interventions (Comprehensive Health Enhancing Support System), which may in the future be capable of delivery on the Internet as technology and people's access to high-speed, high-capacity telecommunications hardware and cable improve (Gustafson *et al* 1999, 2002). Evidence on effective methods of distance learning and specific communication techniques may also be valuable, but were outside the scope of this review.

Resources required to create an Internet intervention

Another key element for the useful assessment of Internet-based interventions is the intensity of effort and resources required to create and implement the intervention. From the point of view of the providers, the Internet may be explored for a variety of purposes, including:

- Wanting to communicate information to an audience of consumers (mass, localised or specialised) via a website;
- Seeking to identify ways to enhance existing educational or support services for consumers by providing a website or other Internet-based intervention;
- Wanting to know how best to use or enhance an existing website (including what other websites to direct people to).

As the resources required for the development and maintenance of Internet interventions can be substantial, we have introduced a categorisation of components and intervention intensity as a key part

of this review. We believe that this categorisation allows a better assessment of the potential effectiveness of the intervention versus the resources that would be required to implement the intervention. Note, that this distinction does not refer to the resources required to create the content of the intervention. Rather it refers to the resources required to implement and maintain a website. For example, a particular form of CBT on the Internet may be very intensive compared with a simple website (thus scoring “high” in this review), but low in intensity compared with long-term personal psychotherapy. A website that is fully automated once online is a “low” intensity intervention to implement, but may require extensive resources to create. The following categorisation of components of Internet interventions (which are eligible for inclusion in this review) was used:

- Low: Material placed on the Internet, which thereafter requires no maintenance or live “attendance” (either because it is static, or all features are automated).
- Medium: Requiring some ongoing activity, active human involvement in the delivery of the intervention (for example, responding to email requests for information).
- High: High level of active involvement and/or therapy required as part of the program (for example, detailed moderation of active communication elements, coaching or motivational support, therapeutic support).

Where possible, we have tried to be more specific in terms of the type of intervention provided, although this has not always been possible from the information provided in the published reports. We have categorised the interventions as:

1. Static website pages (eg information, personal stories).
2. Tools to enable self-help or best use of health care (eg decision aids, referral information).
3. Collation of other materials, directory of other public web sources (eg directories, links).
4. Interactive materials (eg tests, quizzes, online diaries or monitoring forms).
5. Audio-visual communication (sound and/or video).
6. Online peer support, moderated or unmoderated (bulletin boards, chatrooms, posting of users’ stories).
7. Educational programs: systematic instructional programs via modules (either downloadable at any time, or after enrolment/on request).
8. Open public access to an expert reply to emails.
9. Access to therapist or health practitioner as part of a program of behavioural, psychological or motivational therapeutic care (by email, telephone or personal contact).
10. Program or practitioner-initiated contact with participants (other than for research/evaluation purposes).
11. Lodging web diaries or completed forms or modules for monitoring and assessment as part of the program (with or without individualised feedback).
12. Real-time group meetings or classes online.

METHODOLOGY OF THE REVIEW

The search strategy for the review is shown in Appendix A. The citations retrieved by the search strategy were assessed for relevance to the review. Where there was doubt about possible relevance, the citation was assessed by a second reviewer.

All available records, totaling approximately 767, were scanned and the abstracts of those relevant to the subject were read. Articles appearing to contain information pertinent to the review were obtained and examined. Reference lists of those articles, and of relevant review articles were also checked for further sources of applicable information. Figure 1 outlines the systematic review process used in the submission.

Articles were included in the review if they included any form of data that assessed the effectiveness of an Internet intervention in categories (1) to (3) above for a health problem. All levels of evidence were included in the review. We grouped data according to the five questions of our review:

1. What web-site interventions are effective in changing disease prevention behaviour or measurable health outcomes?
2. Does the Internet change the interaction between consumers and health professionals?
3. Does usage of the Internet by consumers change their understanding of disease?
4. Does usage of the Internet by consumers change their self management of disease?
5. Does usage of the Internet increase consumer enablement?

Two systematic reviews were identified that were potentially relevant to this review (Bessell et al, 2002, Krishna et al, 1997). The original papers included in the review were obtained if possible and data extracted from the original paper if it fulfilled our inclusion criteria.

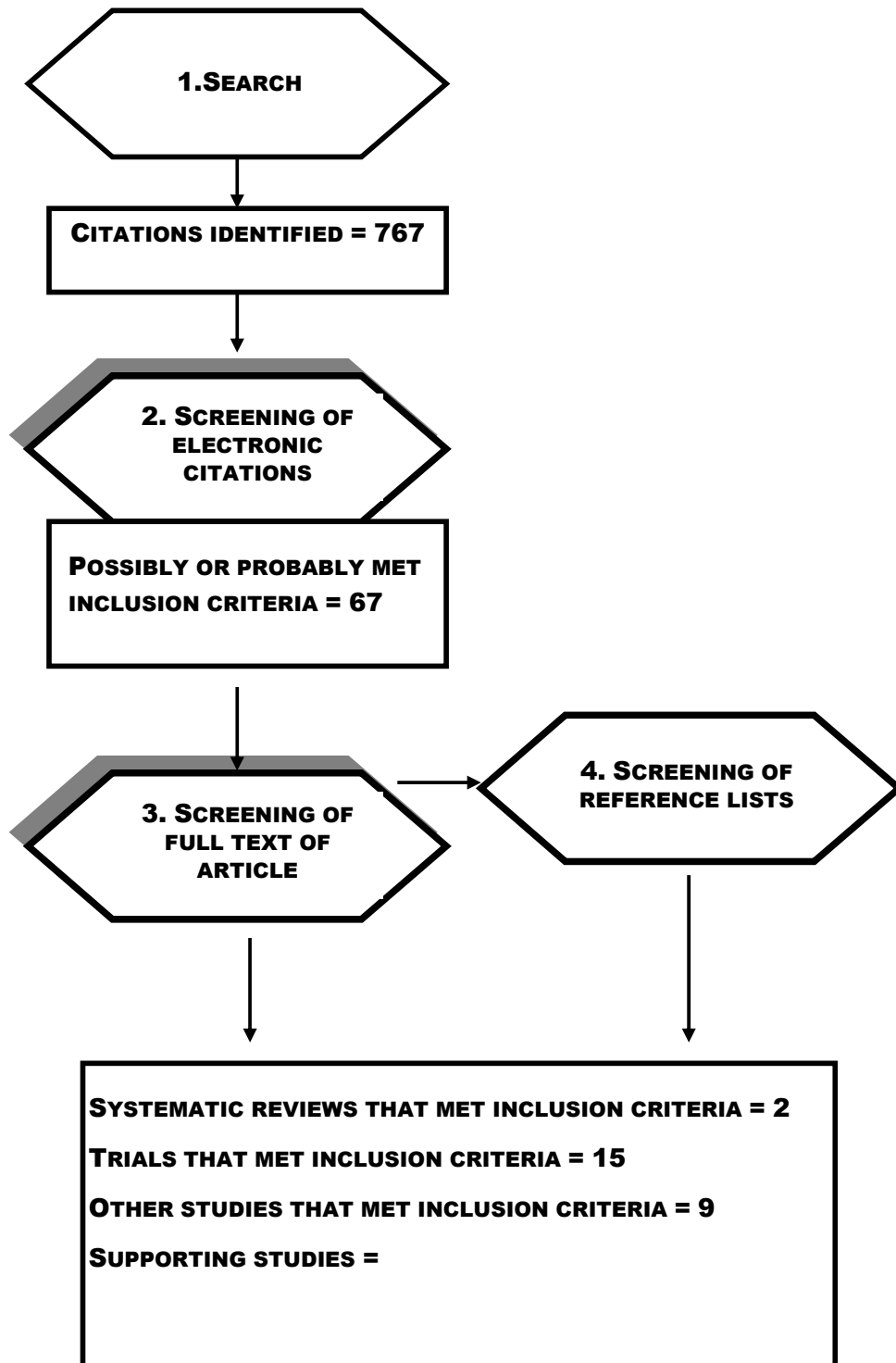
Two categories of studies have been included in this review: studies with a comparison group (group 1) and surveys reporting on health, knowledge and behavioural outcomes, including before and after studies (group 2).

Quality assessment of included studies

Studies included in the review were assessed for quality against standardised criteria. The quality criteria were:

- If the study was randomised; and
- If the allocation of patients to the arms of the trial was concealed at the point of allocation.

Figure 1. Outline of the review process



QUESTION 1: WHAT WEB-BASED STRATEGIES ARE EFFECTIVE IN INCREASING DISEASE PREVENTION BEHAVIOUR OR CHANGING HEALTH OUTCOMES?

Websites (information and/or peer support and/or available experts for emails)

McKay measured the effectiveness of a 'personal trainer' or cognitive behavioural therapy type intervention versus access to a general information website for people with type 2 diabetes to increase their activity levels. This trial showed an increase in physical activity in both groups but effectiveness was increased in a direct relationship with the intensity of the intervention.

In one low intensity intervention on post-operative pain management (Goldsmith), trial participants experienced a significant reduction in post-operative pain. People on a waiting list for cardiac surgery who received information via the Internet experienced a significant reduction in anxiety compared to those who received the same information in a manual (Scherrer-Bannerman). A trial for women in rural areas with diabetes (Smith) improved quality of life measures were reported.

There were three non-comparative studies. Helwig found that some people expressed the intention of changing lifestyle behaviours after exposure to material on the Internet at their doctor's surgery, and Takahashi showed that a smoking cessation website intervention increased self-reported levels of smoking cessation measured at twelve months. An intervention for adolescents with diabetes (Iafusco) showed an improvement in glucose control.

Websites (educational programs or classroom use)

A cohort study of an educational program for adolescent school students (Winett) resulted in improvements in some lifestyle and disease prevention activities, particularly an increase in aerobic activity and a decrease in consumption of carbonated soft drinks and regular meals. However, the intervention made no impact on other dietary measures, such as high fat, fast food and snack consumption.

Website cognitive behavioural training (CBT) type interventions

Eleven trials of CBT-based interventions delivered through websites or of websites whose contents were based on CBT techniques addressed the question of disease prevention or changes in measurable health outcomes.

The trial by McKay showed that an intervention that included a personal coaching component to encourage both walking and moderate to vigorous activity increased physical activity in people with type 2 diabetes more than website education alone.

A trial of a CBT style website intervention for people with recurrent headaches reported a significant decrease both in headache frequency and severity (Strom). A trial of a high intensity intervention for people with tinnitus (Andersson) reported reductions in annoyance and depression.

Three trials were aimed at encouraging or maintaining weight loss and involved a high intensity of support via the Internet. Tate showed that a high intensity intervention resulted in more weight loss than an information-style website alone. Two trials of similar intensity programs for weight loss, one of 22 weeks' duration (Harvey-Berino B) and one of a year's duration (Harvey-Berino A), were follow-up programs to an in-person weight loss program. Groups had participated in an in-person weight loss program, and subsequently were randomised either to a CBT-website maintenance program or a continuing in-person group. This separation from the in-person group may have adversely affected effectiveness of the intervention, and the participants randomised to the Internet

intervention expressed disappointment and a preference for being in the personal group. In the shorter term intervention, there was no significant difference in weight loss between website and in-person groups (Harvey-Berino B). However, in the longer-term trial, the website group were less successful at maintaining weight loss than those attending classes in person. Further, unlike the personal support group, they gained weight as soon as the program ended. The longer term intervention resulted in increased physical activity.

Two trials (Celio, Winzelberg) and one non-comparison study (Zabinski) aimed to improve body image and reduce eating disorders. All were high intensity interventions. All three interventions resulted in improved body image. One trial also resulted in a reduction in bulimia, less disordered eating patterns and improved personal restraint (Celio). The non-comparison study also reported improved eating behaviour.

In other areas of mental health results of CBT based interventions have been more mixed. A matched cohort study of an intervention for people with depression who were receiving other care had no impact on depression or use of medication (Clarke). Two trials that involved interventions to reduce panic disorder showed generally improved symptoms reported by patients. The trial by Carlbring *et al* reduced panic attacks, daily anxiety, depression and physical symptoms of anxiety. In the trial by Klein *et al*, the intervention reduced fear of panic and general anxiety, but had no impact on depression or sensitivity to anxiety. It should also be noted that both of these trials excluded people with severe anxiety or depression, and so the generalisability of the results may be limited to mild and moderate levels of panic disorder.

One of the non-comparative studies was a medium intensity intervention attempting to reduce depression and anxiety (Christensen). Depression was reduced as people completed modules in the program. A high intensity intervention for people with post-traumatic stress disorder (Lange), also led to improvements in mental health outcomes and the outcomes were reported to be similar to those achieved in trials of face-to-face CBT for post-traumatic stress disorder. A follow-up before-after study to the trial by Klein *et al* showed a decline in scores of panic disorder but not anxiety sensitivity (Richards).



Trials of websites to change measurable health outcomes

<i>Reference</i>	<i>Setting; Location</i>	<i>N</i> <i>Intensity</i> <i>Quality</i>	<i>Intervention(s)</i>	<i>Outcomes measured</i>	<i>Result</i>
Goldsmith, 1999	Ambulatory surgery patients scheduled for surgery, Boston	195 Low RCT B	Usual care plus access to password-protected pain management information section of the website. Control group: usual care: preoperative interview with an experienced ambulatory surgery nurse	Information Post-operative pain	In the Intervention group post operative pain intensity scores, pain scores on arrival to home, for the night of the surgery, and for the day following the surgery were significantly lower. 85% of patients used the computer to access the resources available on the website.
Scherrer-Bannerman, 2000	Patients on the waiting list for cardiac surgery, Canada, British Columbia;	72 Medium preference trial C	Internet-linked computer with access to information in Internet format, online links, graphics and interactive features and an online “ask a nurse” option Control group: access to the same material in printed form	Social support, Anxiety Attitude to surgery	The Internet-based intervention provided increased social support and decreased anxiety more than printed materials. Both formats resulted in an improved attitude towards surgery
Smith, 2000	Type 1 or type 2 female diabetes patients from rural Montana. USA	30 High RCT B	Installing an instruction for computer, plus a notebook of health information, additional health information on the computer, home visit by a nurse diabetes educator, computer training, 4 components in Internet intervention: conversation (email discussion exchange, publicly visible), mailbox (enabled private emailing among women or to the nurse monitor), HealthChat (diabetes education, electronic classroom, with questions visible to all and discussions on articles from the notebook, with nurse educator an active participant) and Resource Rack (bulletin board with postings of items of interest to people with diabetes), toll-free number to contact the team about questions or concerns about the project. 24 hour access to the system. Control group: Hard copies of the information.	Quality of life Adjustment to illness Average log-in Most used area	Intervention was popular and well-used and decreased social isolation. No statistically significant difference was seen in terms of measures of quality of life or adjustment to illness scores.

Quality criteria: A = concealment of allocation, B = allocation unclear, C = allocation unconcealed



Non-comparative studies of websites to increase disease prevention behaviour or change measurable health outcomes

<i>Reference</i>	<i>Setting; Location</i>	<i>N</i> <i>Intensity</i> <i>Quality</i>	<i>Intervention(s)</i>	<i>Outcomes measured</i>	<i>Result</i>
Helwig, 1999	Community based family practice clinic, available during the visit, and assistance with using Internet	50 High Survey	Hypertext Web page directory to patient education sites	Intention to change health behaviour	77% stated they would change their health behaviour.
Iafusco,2000	Adolescent patients with type 1 diabetes, Pediatric Diabetological Unit	43 Medium Before-after	Diabetologist moderated chatline	Changes in medication compliance, concentration of HbA1c	The mean concentration of HbA1c decreased from 8.95 to 7.8%, p<0.0001
Takahashi, 1999	Enrolled through both the Internet and newspapers and journals.	224 Medium Survey	Internet site with facts on smoking and health and how to take part in a quit smoking marathon. Involves daily emails to participants throughout 60 day programme.	Smoking cessation	At twelve months, 52% of 102 smokers <30/day and 43% of 122 smokers >30/day had ceased smoking. Email communication spontaneously decreased in volume after the first three weeks.



Carlbring, 2001	People with panic disorder recruited by Internet and media, Sweden	41 High RCT B	CTB via website, self-manual in modules with exercises including role plays, written exercise to complete which were assessed by therapist within individual feedback within 24 h, passwords for next module sent as each exercise completed, therapist initiated follow-ups emails when modules not submitted, panic diaries online and submitted. OR wait-list control	Daily panic diary: frequency of panic attacks, duration and intensity, also daily anxiety, depression and physical symptoms of anxiety.	Reduction in self reports of panic attacks and daily anxiety, reduction in depression and physical symptoms of anxiety. Overall life satisfaction increased. The mobility score for agoraphobia did not increase but the length of treatment may have been too short (12 weeks). Appears to be feasible over the Internet, without the excessive cost. Compared to normal CBT for panic disorders, there was a minimal therapist involvement.
Celio, 2000	Female university undergraduates with high body image dissatisfaction, USA, North California	76 High RCT B	Classroom group instruction (3 face to face sessions), academic readings and essay writing, plus CBT style online readings on body image etc including CBT exercises, online body image journal, discussion group messages (obligatory), pass or fail program OR Classroom education program (not CBT content or style) (8 x 2-hr class meetings), pass or fail program, including academic reading and essay writing each week OR wait-list control	Body image score Bulimia Drive for thinness Weight/shape concerns Eating concerns Restraint	At 4 months there were mean differences between the 3 groups for body image score, bulimia, drive for thinness, weight/shape concerns, eating concerns, restraint and social support. This Internet-based program was effective in reducing body image dissatisfaction and disordered eating attitudes and behaviours in college-age women and showed a greater effect size than the classroom based intervention. Dropout rate higher in classroom group than Internet group (5/25 cf 1/27)
Clarke, 2002	Depressed adults receiving traditional medical services Nondepressed adults age/gender matched Kaiser Permanente members (US HMO)	199 Low Matched cohort C	Experimental Web site- Internet Depression Skills Intervention Program was a self-paced, skills training program focusing on the acquisition and use of cognitive restructuring techniques. Incentive to complete elements – Amazon vouchers Control group: no-access to Internet program, but access to usual KP information website	Assessments on self-reported depression The use of health care service or psychoactive medications	The study failed to find an effect for the Internet program across the entire sample. This may be due to infrequent use of the site or the recruitment procedures attracted a more seriously depressed sample than intended, resulting in participants who may have been too depressed to have benefited from such a low intensity self-help program
Harvey-Berino,	Healthy overweight adults, just finished	122	12 months duration. Biweekly email contact with therapist, with online review of self-reporting	Weight changes	An intensive weight maintenance Internet program was not as effective at facilitating long-term



2002a	attending an identical 24-week behavioural weight control program	High RCT B	<p>information on activity, diet and weight, therapist-led Internet video and chat sessions, moderated email discussion group on a bulletin board (and opportunity to book chatroom for other chats), incentive program (points for participation converting to lottery tickets).</p> <p>Control group 1: Minimal in-person support program (classes, monthly, first 6 months of 12-month weight maintenance program), incentive program.</p> <p>Control group 2: Frequent in-person support program (Biweekly therapist led contacts (weigh-ins, group meetings, review of self-monitoring diaries), therapist led problem solving discussions, peer-led sessions and peer-initiated phone contact, phone and mail contact during weeks when therapist-led group did not meet (12 months), incentive program.</p>	Increase in physical activity	<p>weight loss as either the minimal or frequent face-to-face contact programs. The Internet condition participants gained more weight almost immediately after treatment ended.</p> <p>At the end of treatment, twice as many participants in the frequent in-person support and the minimal in-person support groups sustained a clinically significant weight loss of at least 5% of baseline body weight, with no statistically significant difference found between these two groups.</p>
Harvey-Berino, 1998	Volunteers recruited to weight loss program (a 15 week behavioural course in person) by newspaper ads, USA	44 High RCT B	<p>Group 1: <u>in person</u>, therapist led sessions (biweekly group meetings for 22 weeks, self-monitoring diaries, social peer support program, weigh-ins, incentive system, phone and mail contact with therapist</p> <p>OR Group 2: <u>Internet</u>, therapist led : biweekly meetings in an Internet chat room real time and therapist led email list, biweekly emails with therapist, bulletin board, submission of self-monitoring data online, incentive system</p> <p>OR control</p>	Weight loss	<p>There was no significant difference of weight loss between the groups. the average weight loss over the 22 weeks of the trial was 1.6kg.</p> <p>The Internet is a possible method of delivering a weight maintenance program but is less acceptable than the in person method of communication.</p> <p>The Internet users were less likely to come into maintenance group sessions than the in-person participants.</p> <p>In this study, the Internet may have been most effective as a way to facilitate peer-initiated support and to maintain communication for long-term behaviour change.</p>
Klein, 2001	People with mild – moderate panic disorder from Melbourne and regional Victoria	23 Medium RCT B	<p>One week of self-monitoring, following by one week CBT intervention via the Internet, followed by one week of post-intervention assessment. Internet-based CBT program in two parts, part 1 focusing on the nature, effects and causes of panic, and the second on useful and non-useful ways of managing panic. Techniques to overcome cognitive errors were</p>	<p>Panic frequency</p> <p>Anticipatory fear of panic</p> <p>General anxiety</p> <p>General</p>	<p>This was an effective intervention for people with panic disorder, in the short-term (assessment only one week after treatment, and the treatment duration was only one week). There was an improvement in all variables except anxiety sensitivity and depressive affect.</p>



			explained. Access via password. Use of colour, animated illustrations, hyperlinks, and self assessment quizzes with immediate feedback. The program needed to be completed within one week	depression Self-efficacy Body vigilance	
			Control group: Self-monitoring only : filling in the questionnaire and assessment forms, without access to the Internet CBT intervention	Anxiety sensitivity	
McKay, 2001	Type 2 diabetic patients, Recruited by email postings to websites and web groups, USA and Canada	78 High RCT C	8 week personalised active lives intervention (personal trainer/coaching and CBT). Control group: access to general information website	Daily activity level	There was an overall moderate improvement in physical activity levels within both intervention and control groups (approximately 10min of moderate to vigorous exercise and seven minutes of walking per day), but there was no significant difference between the two groups. There was considerable variation between usage of the site and in the intervention group (but not the control group) increased usage was related to increased physical activity.
Strom, 2000	Adult headache sufferers recruited by newspaper articles	45 High RCT B	Internet self-help relaxation and problem-solving training with minimal therapist involvement, especially created website about headache, with some publicly available, interactive elements were password protected (including headache diary, medication diary, online relaxation training and problem-solving techniques, emailed weekly modules for 6 weeks) Control group: waiting list	Improvement in Headache Index (daily headache activity) Headache frequency (days per week) Peak intensity	In the intervention group, 50% of patients showed a reduction of headache activity of 50% or more (clinically significant improvement) compared to 4% in the control group. However, this does not appear to be an intention to treat analysis and 56% of the trial population dropped out before follow up. All the participants who were followed up reported the Internet communication as easy and handy to use Treatment via the Internet can be twice as cost-efficient as minimal therapist contact treatment and 12 times as cost efficient as traditional clinical treatment.
Tate, 2001	Healthy, overweight adult hospital employees, USA	91 Medium RCT B	CBT Internet group Control group: Website education only	Weight loss Achieved the 5% goal by 6 months Changes in	Participants that were given a structured behavioural treatment program with regular contact and personal feedback had a better weight loss outcome than those who were given links to educational Web sites (mean loss = 4.1 (4.5) kg in the behaviour therapy group vs 1.6 (3.3) kg in the



Winzelberg, 1998	Female university undergraduates with body image problems, West Coast USA	60 High RCT B	8-week structured CBT through the Internet, interactive software including text, audio & video, online self-monitoring journals and behaviour change exercises with weekly writing assignments, bulletin board (weekly postings expected as well as an answer or comment to respond to another), followup by email when people missed assignments, anonymous long-on names, moderated by psychologist who added postings from time to time Control groups: no intervention	waist circumference Changes in body image Drive for thinness Compliance with program requirements	education group, $p = 0.005$. A statistically significant difference was also seen in the proportion of participants who achieved the 5% weight loss and mean change in waist circumference at 6 months ($p = 0.005$). There was a significant improvement in body image and decreased desire for thinness. On average, people completed less than two thirds of the program, and weekly compliance dropped over time.
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Non-comparative studies of CBT interventions to increase disease prevention behaviour or change measurable health outcomes

<i>Reference</i>	<i>Setting; Location</i>	<i>N</i> <i>Intensity</i> <i>Quality</i>	<i>Intervention(s)</i>	<i>Outcomes measured</i>	<i>Result</i>
Christiansen, 2002	Internet site developed at ANU	465 (anxiety) and 223 (depression) Medium Assessment via the Internet	Cognitive behaviour based therapy for anxiety and depression delivered as modules via the Internet	Self reports of anxiety and depression after the completion of modules.	There was a decline in anxiety and depression scores as participants progressed through the modules. There was also a high level of dropout between the modules.
Lange, 2000	University students in Amsterdam with symptoms of post-	20 High	Intervention for post-traumatic stress disorder and pathological grief delivered via the Internet. Participants received credit course points for	Symptoms of post-traumatic stress and pathological grief	Symptom scores improved strongly with participation in the program. Improvements were maintained at 6 weeks



	traumatic stress disorder	Before-after study	participation. There were 10 sessions of about 45 minutes each over a period of 5 weeks.	Psychological functioning	follow-up.
Richards, 2002	People with mild – moderate panic disorder from Melbourne and regional Victoria	9 Medium Before-after	Development from Klein et al above. More comprehensive treatment program with 5 modules over 5-8 weeks.	Panic disorder severity Anxiety sensitivity Body vigilance	There was a significant reduction in average panic disorder severity pre- to post intervention. Anxiety sensitivity scores and body vigilance showed no significant change

QUESTION 2: DOES THE INTERNET CHANGE THE INTERACTION BETWEEN CONSUMERS AND HEALTH PROFESSIONALS?

To date, there have been few studies of how the use of the Internet may influence the interaction between consumers and health professional. In a survey of 490 men with prostate cancer, 19% had used the Internet to obtain information regarding their diagnosis and treatment and approximately one third of these said that the information from the Internet had influenced their treatment decision (Pautler *et al*, 2001). A survey of consumers who had used the Internet for health information showed that of the 37% of those who discussed the results of their searches with a health professional, only a tiny minority said their health care professional disagreed with the information they found online (Ferguson, 2002). There is also some evidence that consumers may have a reluctance to discuss information from other sources with health professionals. 47% of people who had searched the Internet in relation to radiation oncology found that the information they saw varied from their own management plans, but they did not tell their doctors (Duffy *et al*, 2000).

Websites (information and/or peer support and/or available experts for emails)

Few trials or studies reported on relevant outcomes regarding the interaction between consumers and health professional as a result of using the Internet.

The study by Helwig *et al* of patients experiencing an Internet session at a family medical centre showed that it increased patients' satisfaction with their clinic visit. The use of electronic support group for adolescent males with cystic fibrosis did not change the perceived support from clinic staff (Johnson).

A survey of consumers who had used the Internet for health information showed that of the 37% of those who discussed the results of their searches with a health professional, only a tiny minority said their health care professional disagreed with the information they found online (Ferguson, 2002).

Website cognitive behavioural training (CBT) interventions

None of the trials and studies on CBT-style interventions and websites addressed the interaction between consumers and other health care providers. The only study reporting on health service experience was a trial of CBT for depression (Clarke). There were no changes in the use of health care services as a result of this intervention.



Non-comparative studies of websites that measured interaction between consumers and health professionals

<i>Reference</i>	<i>Setting; Location</i>	<i>N</i>	<i>Intervention(s)</i>	<i>Outcomes measured</i>	<i>Result</i>
		<i>Intensity</i>			
		<i>Quality</i>			
Helwig, 1999	Community based family practice clinic, available during the visit, and assistance with using Internet	50 High Survey	Hypertext Web page directory to patient education sites	Satisfaction with clinic visit	90% stated that they were more satisfied with their visit than usual.
Johnson, , 2001	Adolescents with cystic fibrosis	18 Medium Survey	Highly interactive electronic support group	Clinical and social support	Patients felt they had more friends that they could relate to. There was no significant change in perceptions about the perceived availability and comfort with the clinic staff and faculty, or support available through peers.

Trials of CBT interventions that measured interaction between consumers and health professionals

<i>Reference</i>	<i>Setting; Location</i>	<i>N</i>	<i>Intervention(s)</i>	<i>Outcomes measured</i>	<i>Result</i>
		<i>Intensity</i>			
		<i>Quality</i>			
Clarke, 2002	Depressed adults receiving traditional medical services Nondepressed adults age/gender matched Kaiser Permanente members (US HMO)	199 Medium RCT C	Experimental Web site- Internet Depression Skills Intervention Program was a self-paced, skills training program focusing on the acquisition and use of cognitive restructuring techniques. Incentive to complete elements – Amazon vouchers Control group: no-access to Internet program, but access to usual KP information website	Assessments on self-reported depression The use of health care service or psychoactive medications	There were no difference in self reported depression outcomes, and no differences in the use of health care services or psychoactive medications.

Quality criteria: A = concealment of allocation, B = allocation unclear, C = allocation unconcealed

QUESTION 3: DOES THE INTERNET CHANGE CONSUMERS' UNDERSTANDING OF A DISEASE OR HEALTH PROBLEM?

Websites (information and/or peer support and/or available experts for emails)

In a trial of information for patients awaiting cardiac surgery, those randomised to receive the information by the Internet rather than a printed manual experienced increased assurance that they would survive surgery (Scherrer-Bannerman).

In two non-comparative studies, patients reported feeling more informed but this was either not measured or not confirmed on testing in both studies. Patients who experienced an Internet session at a family medical centre reported that they felt that they were now more informed (Helwig). Adolescents with cystic fibrosis in a medium intensity intervention perceived that they were more informed but did not improve their knowledge of their disease (Johnson).

Websites (educational programs or classroom use)

School students using a website within a health education class reported an increase in knowledge, although knowledge was not tested (Borowitz).

Website cognitive behavioural training (CBT) interventions

Knowledge and disease understanding was not specifically reported in any of these studies, although changing people's understanding of their disease, and attitudes towards it are the basis of the intervention. As the interventions achieved their health outcome goals in most instances, a change in attitude or understanding is implied by these results.

Trials of websites that measured consumers’ understanding of a disease or a health problem

<i>Reference</i>	<i>Setting; Location</i>	<i>N</i>	<i>Intervention(s)</i>	<i>Outcomes measured</i>	<i>Result</i>
		<i>Intensity</i>			
		<i>Quality</i>			
Scherrer-Bannerman, 2000	Patients on the waiting list for cardiac surgery, Canada, British Columbia;	72 Medium preference trial C	Internet-linked computer with access to information in Internet format, online links, graphics and interactive features and an online “ask a nurse” option <i>control group: access to the same material in printed form</i>	Social support, Anxiety, Lifestyle changes, Attitude to surgery	Internet-based intervention provided increased social support, decreased social anxiety and improved attitudes towards surgery ‘Website was feasible and viable means of providing patient education for users little computer experience’ Both methods (printed manual and website) of education were effective. ‘Use of an on-line support group may further increase support and reduce patient anxiety.

Quality criteria: A = concealment of allocation, B = allocation unclear, C = allocation unconcealed

Non-comparative studies of websites that measured consumers’ understanding of a disease or a health problem

<i>Reference</i>	<i>Setting; Location</i>	<i>N</i>	<i>Intervention(s)</i>	<i>Outcomes measured</i>	<i>Result</i>
		<i>Intensity</i>			
		<i>Quality</i>			
Helwig, 1999	Community based family practice clinic, available during the visit, and assistance with using Internet	50 High Survey	Hypertext Web page directory to patient education sites	Information found on Internet helpful	94% of patient found information that was helpful, with many patients stating that they had found new information
Johnson, 2001	Adolescents with cystic fibrosis	18 Medium Survey	Highly interactive electronic support group	Knowledge of cystic fibrosis	There was no significant difference on patient scores at the beginning and the end of the study.



Non-comparative studies of educational programs that measured consumers' understanding of a disease or a health problem

<i>Reference</i>	<i>Setting; Location</i>	<i>N</i>	<i>Intervention(s)</i>	<i>Outcomes measured</i>	<i>Result</i>
		<i>Intensity</i>			
		<i>Quality</i>			
Borowitz, 2001	Information website on childhood constipation Children Medical Centre. University of Virginia, USA	1142 feedback forms Low Survey	Multimedia tutorial on childhood constipation	Understanding of information Ability to take care of child	98% of respondents felt that the tutorial helped them understand why children develop encoporesis and 91% felt better able to take care of their child.

QUESTION 4: DOES THE INTERNET CHANGE CONSUMERS' SELF-MANAGEMENT OF A DISEASE OR CONDITION?

Websites (information and/or peer support and/or available experts for emails)

Few reports included measures relevant to this question. The trial of an intervention for post-operative pain management (Goldsmith) resulted in improved pain scores, which presumably included an element of improved self-management.

In a non-comparative study in adolescents with type 1 diabetes, the number of times that patients had decided to change their treatment in the previous 3 months was used as a marker of the capacity for self-management. The percent of positive answers increased from 32% to 84% (Iafusco).



QUESTION 5: DOES THE INTERNET CHANGE CONSUMERS' ENABLEMENT OR SOCIAL SUPPORT?

Websites (information and/or peer support and/or available experts for emails)

Two trials of Internet interventions showed mixed results (Scherrer-Bannerman, Smith) and one non-comparative study (Johnson) showed that participants felt that they had more social support at the end of the study but did not have any measure increase in social support. A trial by Klein et al of an Internet based treatment for panic disorder showed an increase in self-efficacy. A qualitative study of individuals infected with HIV showed that individuals infected with HIV believed that the Internet allowed them greater empowerment and augmented their social support.

Website cognitive behavioural training (CBT) interventions

Measures to increase social support were a component of many of these interventions, but not all. One trial reported perceived social support as an outcome, but there was no difference between the Internet intervention and the classroom delivered intervention for this measure (Celio).



Trials of websites that measured social support and consumer enablement

<i>Reference</i>	<i>Setting; Location</i>	<i>N</i> <i>Intensity</i> <i>Quality</i>	<i>Intervention(s)</i>	<i>Outcomes measured</i>	<i>Result</i>
Klein, 2001	People with mild – moderate panic disorder from Melbourne and regional Victoria	23 Medium RCT B	One week of self-monitoring, following by one week CBT intervention via the Internet, followed by one week of post-intervention assessment. Internet-based CBT program in two parts, part 1 focusing on the nature, effects and causes of panic, and the second on useful and non-useful ways of managing panic. Techniques to overcome cognitive errors were explained. Access via password. Use of colour, animated illustrations, hyperlinks, and self assessment quizzes with immediate feedback. The program needed to be completed within one week Control group: Self-monitoring only : filling in the questionnaire and assessment forms, without access to the Internet CBT intervention	Self-efficacy	Significant improvement, (p < 0.01)
Scherrer-Bannerman, 2000	Patients on the waiting list for cardiac surgery, Canada,	72 Medium preference trial C	Internet-linked computer with access to information in Internet format, online links, graphics and interactive features and an online “ask a nurse” option <i>control group: access to the same material in printed form</i>	Social support,	Internet-based intervention provided increased social support compared to the control group
Smith, 2000	Type 1 or type 2 female diabetes patients from rural Montana. USA	30 High RCT B	Installing and support for Internet. Four components in Internet intervention: conversation (email discussion exchange, publicly visible), mailbox (private email among women or to the nurse monitor), HealthChat (diabetes education, electronic classroom, with questions visible to all and discussions on articles from the notebook, with nurse educator an active participant) and Resource Rack (bulletin board with of items of interest), toll-free number to contact the team about questions or concerns about the project. 24 hour access to the system. Control group: Hard copies of the information.	Psychosocial support	No difference observed in the measure of social support between the two groups.

Quality criteria: A = concealment of allocation, B = allocation unclear, C = allocation unconcealed



Non-comparative studies of websites that measured social support and consumer enablement

<i>Reference</i>	<i>Setting; Location</i>	<i>N</i>	<i>Intervention(s)</i>	<i>Outcomes measured</i>	<i>Result</i>
		<i>Intensity</i>			
		<i>Quality</i>			
Johnson, 2001	Adolescents with cystic fibrosis	18 Medium Survey	Highly interactive electronic support group	Clinical and social support	Patients felt they had more friends that they could relate to. There was no significant change in perceptions about the perceived availability and comfort with the clinic staff and faculty, or support available through peers.
Reeves, 2000	HIV infected individuals, Atlanta Georgia	10 any Internet usage Survey	Interviews of HIV infected individuals regarding their Internet usage	Qualitative data on: Empowerment Social support	HIV infected individuals felt that the use of the Internet promoted empowerment and augmented social support.

Trials of CBT interventions that measured social support and consumer enablement

<i>Reference</i>	<i>Setting; Location</i>	<i>N</i>	<i>Intervention(s)</i>	<i>Outcomes measured</i>	<i>Result</i>
		<i>Intensity</i>			
		<i>Quality</i>			
Celio, 2000	Female university undergraduates with high body image dissatisfaction, USA, North California	78 High RCT B	Classroom group instruction (3 face to face sessions), academic readings and essay writing, plus CBT style online readings on body image etc including CBT exercises, online body image journal, discussion group messages (obligatory), pass or fail program. OR: Classroom education program (not CBT content or style) (8 x 2-hr class meetings), pass or fail program, including academic reading and essay writing each week. OR: wait-list control.	Social support	No difference was seen between the two intervention groups for perceived social support at the end of the study.

Quality criteria: A = concealment of allocation, B = allocation unclear, C = allocation unconcealed

OTHER FACTORS THAT MAY AFFECT THE USE OF THE INTERNET BY CONSUMERS

Quality of Internet products: content and usability

The studies found in this review rarely included a clear method to evaluate the quality of the content of the Internet information or its presentation. Few included any reliable measures of consumer usability for their products, although some included consumers in the development of their products. Often the interventions were developed by clinicians, and did not involve experts in communication or publishing. The range of expertise and skill involved in the design of the websites, a key factor to usability, was not reported and is likely to have been of variable quality.

There was also little information on the evidence base of much of the content material developed. Often, assurances were given that the content had been developed and/or assessed by clinicians. However, this is not a guarantee of quality and accuracy of content. Most health websites have clinical authorship or input, yet most fail on measures of quality of the content. Indeed, estimates of the quality and reliability of health websites generally indicate that a substantial proportion of websites are less than adequate. One review found that 70% of 79 studies that had assessed quality of Internet health websites found there to be a problem with the content (Eysenbach *et al* 2002). A study that specifically addressed the evidence basis of content in 121 apparently credible health websites found that less than half addressed a major portion of the recommendations in accepted guidelines for best practice in that subject area (Kunst *et al* 2002). However, there is also some suggestion that in some areas at least, the quality of health information on the Internet might be increasing (Pandolfini and Bonati 2002).

Some attempts at evaluating the quality of websites and Internet resources which were incorporated into websites (either in full, or as links) were described in some reports, but there was little use of systematic measures of quality assessment. There is, as yet, no method of measuring quality of websites that is either empirically supported or widely agreed (Eysenbach *et al* 2002, Gagliardi and Jadad 2002). The European Union has a consensus-based set of criteria (Commission of the European Communities 2002), but this has not been validated in any empirical way. Three of the four major English-speaking government consumer health websites (HealthInsite in Australia, the Canadian Health Network, and NHS Direct Online in the UK) have chosen rather to rely on credentialing information providers as a means to ensure quality (Eaton 2002), but there is no evidence that this assures quality of content.

The quality and potential of the website material to attract and engage attention is an unquantifiable variable in these studies, but it is likely to have had an impact on results (Eysenbach and Jadad 2001). Trying to unpack the two dimensions of content (the message and the quality of communication) has been characterised as trying to separate the “signal” and the “noise” (Van Der Weyden 1997). Internal quality and validity of website content and usability and popularity with consumers do not necessarily correlate: what is medically meritorious is not necessarily “good” from a user point of view (Meric *et al* 2002). In order to achieve significant benefits in people’s health outcomes, a website would generally need to achieve well on both content quality and attractiveness to users.

Several of the website interventions in this review encountered significant difficulties in attracting and retaining an audience. This was the case even in areas where the consumers had high levels of interest in the subject. Research on usability of health websites has indicated several domains of quality essential to an Internet audience. One of these is the professionalism of the design and editorial production values (Eysenbach and Koehler 2002). This is critical for any form of mass media intervention. There is a good deal of wastage in mass media interventions, in the sense that most of the audience for a particular piece only glance at items. Content is, effectively, wasted on most of the people who may read or watch a piece of media, as there is a lot of competition for people’s time and

attention, and there are many media outlets employing considerable resources and skills in sophisticated ways to capture attention. Good communication and production values are needed to lessen the wastage.

Potential harm from use of the Internet

A variety of experiences of Internet health interventions could have negative effects:

- Misinforming people (exaggerating fears or raising unrealistic expectations of cure);
- Distressing encounters in chatrooms or on bulletin boards;
- Conflict between health care providers and their patients as a result of challenging information from the Internet;
- Encouraging over-use, under-use or incorrect self-diagnosis;
- Internet addiction, with superficial Internet ties substituting for higher quality personal relationships. (Finn 1999)

However, while medical fears about the impact of the Internet are often quite high, there is also a quite high degree of wariness among Internet users about what they read on the Internet. Fears about the impact of poor quality information on the Internet may be exaggerated in relation to the real risk. However, there is not enough evidence in this area. Few of the studies in this review discussed potential harms, or reported information about this. Internet use of information is in many ways simply an extension and amplification of the informal information-seeking and information-sharing behaviour long present in the community. That is, it is a change of medium and capacity, not a new phenomenon.

In one study, a very small number (three out of 569 participants) reported being so upset by reading about complications of diabetes that they would not return to the website (Zrebiec and Jacobson 2001). However, many more found it helpful and “normalising” (making the experience and the issue seem more real and normal, seeing other people facing it and dealing with it). The issue of the experience of reading about other people’s experiences being “normalising” is a key theme in the qualitative literature about people’s experiences of the Internet in health.

In one of the studies in this review (Murero *et al* 2001), 18 cardiac surgery patients had already used the Internet in their search for information. Six of these complained about the information being “overwhelming” (although whether this was in quantity or also referring to content was not explained).

Despite many fears that computer-mediated interventions may actually limit people’s social interaction, there does not seem to be enough evidence to justify this concern for most people (Finn 1999).

Accessibility of Internet interventions

Although a website can be available 24 hours a day, it does not necessarily follow that the Internet is an accessible medium. Accessibility of Internet interventions involves a variety of issues, including:

- Availability of the computer, modem, telephone line and Internet service provider, ability to print out information, and the quality and cost of each of these technological elements;
- Accessibility to the technology even when it is “available” (eg other competing uses for the phone line or the computer in the home, waiting times at public access points);
- Computer and language literacy;
- Accessibility/readability of the material on websites.

As well as considering the access a particular group has personally to the Internet, it is important to remember that people may have access through others who search out and download/print information on their behalf. Among a group of people having cardiac surgery in one of the studies in this review, for example, 12 of 18 surveyed who had used Internet information had involved at least one relative in their search for information when they were facing surgery (Murero *et al* 2001). Internet use in Australia is growing rapidly, from 41% of Australians using the Internet generally in 1999 to 47% in 2000 (ABS 2002). Households with children and those with higher incomes are more likely to have household access to the Internet, with 50% of adult males and 43% of adult females

having access at home. A variety of initiatives are underway to increase access of Indigenous peoples in Australia, and Indigenous health workers, to the Internet (http://www.healthinfonet.ecu.edu.au/html/html_home/home_home_home.htm).



A survey in South Australia in 2000 showed that over 20% of people aged 15 years and over had used the Internet to get health information, with over 10% using the information to change their health care management and another 16% discussing the information with their doctor or pharmacist (Bessell *et al* 2002). Estimates from other studies show that for people with some chronic diseases, Internet usage for health information in the high-use Internet countries may be as high as 40 or 50% (Meric *et al* 2002).

Accessibility of the technology

Claims are made in both directions about this technology: that it will create barriers to access, and that it will enable access (Fell *et al* 2000). To some extent, both of these are likely to be true. The reality of people's experiences is likely to be more complicated than is widely appreciated. While stereotypes are developing, many of these may be misleading. Stage of disease and need may be more predictive of likely participation in Internet programs than age or gender, for example. Women may be less likely to be Internet adept, yet may be more likely to use the Internet for health information. Younger people may be more likely to use the Internet, but less likely to do so for health information (and adolescents' access to the Internet may be restricted by their parents).

While access to the Internet can be prohibitively expensive, the barriers to access to health services can also be high, including transport difficulties. The health care providers involved in an ongoing trial of attempting to deliver Internet-based support for rehabilitation after cardiac surgery see Internet service as a potential "technological solution to a clinical challenge" (Flatley Brennan *et al* 2001). While support in the period after surgery is beneficial, many patients do not have access to programs, or do not participate in available programs. The Internet service is an outreach attempt, to widen the group who may possibly benefit from post-operative support.

In only three of the trials in this review were computers and relevant technologies provided to the participants (Johnson *et al* 2001, Smith and Weinert 2000, Winett *et al* 1999). All the other studies were conducted among people who were already connected to the Internet (at home or school/place of work). The lack of computer or Internet skills was not a great barrier to effective use of the Internet.

A study looking at acceptance of Internet self-management among novice users of the Internet found that non-participation was not related to issues about comfort or skill with the technology (Fell *et al* 2000). In a small study among women with breast cancer and no Internet experience, people acquired the skills to enable them to participate in an online support group together very quickly (Weinberg *et al* 1996). Physical accessibility (comfort sitting and use of arms) was more of an issue, especially when women had recently had surgery (Weinberg *et al* 1996).

In some ways, online services may be more accessible to some groups of people than other types of service, where interpersonal contact itself may be a barrier. Some people are more likely to report information about sensitive subjects in computerised situations than they are face-to-face (Kobak *et al* 1996, Krishna *et al* 1997). The anonymity of online participation can also be valuable to people who ordinarily face stigma and prejudice in face-to-face situations (Finn 1999). People who might prefer to listen to others, rather than participate actively in a group. They may not feel comfortable in face-to-face support groups, and thus be excluded from traditional support interventions, even though they may benefit from participating in their own preferred way. "Lurking" and listening may be easier on the Internet than it is in person (Finn 1999).

Availability does not equate with accessibility. In several of the studies included in this review, difficulties with a person gaining access to the services, even when the computer was in their homes, was an issue. This related most often to the phone line or computer being in use by others in the home, phone lines to the Internet service provider being engaged, and other reliability issues with their Internet service providers. For some young people, parents restricted their access to the Internet, particularly in terms of time.

People with different conditions may have differing experiences with, or responses to, Internet-based interventions. Specific reviews on Internet interventions in particular conditions, or groups of

conditions (such as mental health), may be of more value to people contemplating Internet interventions for particular groups than an all-purpose review such as this one.

Internet-based support interventions may be the only feasible option for reaching groups of people who currently are not able to benefit from in-person services. Professionally led support groups are sometimes over-subscribed, and people with disabilities or particular health problems may be unable to participate in any other form of self-help or peer support group (Finn 1999). For chronic health problems such as diabetes, the long-term in-person support interventions that are needed to achieve higher levels of exercise and improved self-management are very costly, and transport and time are a major barrier to participation (Fell *et al* 2000). Internet-based interventions may be useful in extending at least some of the benefits of support to people who may never participate in more intense personal programs (Fell *et al* 2000). Online

support groups have been described as possibly resistant to some of the pitfalls of traditional support groups (particularly fluctuating attendance and inconvenient meeting times) (Klemm *et al* 1999). It also extends the possibility of communicating with people who have rare conditions (Klemm *et al* 1999).

Readability and educational levels

Of perhaps more or at least equal concern to physical accessibility to the technology is the accessibility in terms of readability and usability of the information generally provided about health on websites. A review of studies of computerised patient education concluded that while it was becoming clear that age did not affect acceptability of computer-based interventions, the results for people of low reading ability have not been sufficiently studied (Krishna *et al* 1997).

The studies in this review did not provide much information about people's educational levels. In one study of people having cardiac surgery, 18 had already used the Internet for information related to their surgery (or the condition which necessitated their surgery) prior to recruitment into the study (Murero *et al* 2001). Only three of these people rated the readability of Internet medical information on cardiac surgery as acceptable. The majority (83%) encountered difficulties understanding the information. In spite of this, 94% found the information helped them cope better with stress and anxiety during the pre-operative and post-operative period. Almost all felt that easier language should be used in medical information on the Internet. In two studies of people with cancer, those who had used the Internet to search for information on their condition were more likely to be of a higher educational level than those patients who had not used the Internet (Duffy *et al* 2000, Pautler *et al* 2001). In a more general assessment, a study of people with HIV/AIDS found that those who used the Internet were generally better resourced and healthier than those had not used it (Kalichmann *et al* 2002). However, a random telephone survey in the USA found that Internet use for health information was more common in those with poorer health (Houston and Allison, 2002). Just over half the people who used the Internet for health information were tertiary graduates, with 70% earning more than US\$30,000 per annum, and 87% were white.

An assessment of the readability of information on neurology on the Internet compared this with the reading levels of 520 patients at neurology clinics (both public and private) in the USA. The mean reading level of patients was at American 7th-8th grade, while 91% of information on the Internet on neurology was at 9th grade or higher (Murphy *et al* 2001). Many were strikingly inappropriate: a guide to seizure recognition and first aid for people with epilepsy, for example, was assessed as being at the 15th grade reading level. Several major websites for consumers in neurological conditions such as epilepsy and multiple sclerosis scored at the American 15th grade level, and one even required 17th grade literacy levels (Murphy *et al* 2001).

The patients' reading levels were determined using the REALM instrument (Rapid Estimate of Adult Literacy in Medicine) (Davis TC *et al* 1994). The website material was assessed for readability of using a software program (Wampler and Williams 1991) that calculates both the Fog (Gunning 1968) and Flesch-Kincaid (Flesch 1974) indexes. The materials were also assessed for suitability using SAM (Suitability Assessment of Materials), the instrument developed by Johns Hopkins for people with low reading levels (Doak *et al* 1996). While there are difficulties applying Flesch-Kincaid type processes to medical information, the overall conclusion of a major mismatch between the reading levels of the materials and people's ability to understand was clear.

Gender

Neilsen ratings of Internet usage has found that while initially, Internet use was dominated by men, women are now the heaviest users of health care information on the Internet (Zrebiec and Jacobson 2001). A national random telephone survey in the USA found that among 521 people who had used the Internet for health information, 64% were female (Houston and Allison 2002). This is supported by the experience of recruiting participants to the studies included in this review, most of which had more women eventually participating.



An analysis of gender differences in online cancer support groups concluded that men were more than twice as likely to be giving information to others, while women were more than twice as likely to be giving encouragement and support ($p < 0.0001$) (Klemm *et al* 1999).

However, assumptions about gender could also be misleading for providers of information on the Internet. An analysis of the content of discussions on a bulletin board for people with implantable cardiac defibrillators found that the gender mix was fairly balanced (15 women, 16 men) (Dickerson *et al* 2000). There was no significant difference in gender of those neurology outpatients in the UK who had used information from the Internet (Larner 2002). A report of Internet usage among patients at a urology clinic in the UK found that 19% of general outpatients and 24% of men with prostate cancer

reported using the Internet to retrieve health information (Hellawell *et al* 2000). In Canada, a similar survey found that over 30% of men with prostate cancer had sought information about their condition on the Internet (Pautler *et al* 2001).

Age

A random telephone survey in the USA found that 29% of people who had used the Internet for health information were below 35 years of age, with 54% aged between 35 and 54 years, and 14% 55 years or older (Houston and Allison 2002).

In two studies of people with cancer, those who had used the Internet to search for information on their condition were more likely to be younger than those patients who had not used the Internet (Duffy *et al* 2000, Pautler *et al* 2001). Throughout the studies in this review, there was a trend to younger people being more likely to have used the Internet before the study.

While in general terms, younger people are more computer and Internet adept than older people, it may be simplistic to assume that this means the audience for Internet health information is younger. In several of the studies in this review, while the younger participants were more Internet literate, they actually dropped out of the interventions more quickly than older people did (perhaps at times related to the severity of their health problems, and thus need for assistance). A study looking at the feasibility of establishing Internet-based support for older people with diabetes, none of whom had used the Internet or had the necessary equipment, found that 60% of them were willing and able to enter the program and make use of the service (Fell *et al* 2000). While those who were interested in the program were more likely to be younger, this did not mean that interest among older people was very low.

In an analysis of the content in Internet discussion groups on diabetes, a broad base of patients and families were found to be involved (Zrebiac and Jacobson 2001). Most were older than 30 (84%). Stage of disease and need were strong indicators of usage of the discussion groups, with 34% of participants having been recently diagnosed.

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APPENDIX A: SEARCH STRATEGY

The following search strategy was used in the review:

Search words	MeSH/Descriptors	TI only	Free text
Internet	✓		
Worldwide web or world-wide web or world wide web		✓	
WWW		✓	
Cybermedicine			✓
E-Health or ehealth			✓
Online, on-line or on line		✓	
Web-based			✓
Email			✓
Chat room			✓
Patient		✓	
Patient-Compliance		✓	
Patient-Participation	✓		
Patient-Education	✓		
Patient-Satisfaction	✓		
Consumer participation	✓		
Consumer health information			✓
Patient decision aids			✓
Patient decision support			✓

Search conducted in WebSpirs Medline 1996-2002

- #1 explode 'Internet-' / all subheadings in MIME,MJME (9999 records)
- #2 cybermedicine (20 records)
- #3 e-Health (112 records)
- #4 ehealth (21 records)
- #5 (online or on-line or on line) in ti (2198 records)
- #6 web-based (827 records)
- #7 WWW in ti (109 records)
- #8 (worldwide web or world-wide web or world wide web) in ti (434 records)
- #9 email (161 records)
- #10 chat room (17 records)
- #11 web portal (1 record)
- #12 consumer health information (71 records)
- #13 patient decision aids (7 records)
- #14 patient decision support (26 records)
- #15 (explode 'Internet-' / all subheadings in MIME,MJME) or ((cybermedicine) or (e-Health) or (ehealth) or ((online or on-line or on line) in ti) or (web-based) or (WWW in ti) or ((worldwide web or world-wide web or world wide web) in ti) or(email) or (chat room) or (web portal) or (consumer health information) or (patient decision aids) or (patient decision support)) (12350 records)



#16 (explode 'Patient-Compliance' / all subheadings in MIME,MJME) or (explode 'Patient-Participation' / all subheadings in MIME,MJME) or (explode / all subheadings in MIME,MJME) (36108 records)

#17 #16 and #17 (767 records)