

**2012 UPDATED CHAPTER H:  
DELIVERING DECISION AIDS ON THE INTERNET**

**SECTION 1:  
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**SECTION 2:  
CHAPTER SUMMARY**

What is this dimension?

Delivering decision aids on the Internet is defined here as the process of using the Internet to provide some or all components of a patient decision aid (PtDA) to individuals (e.g., patients, caregivers, clinicians, etc.) involved in the process of choosing between two or more medically-appropriate healthcare options. This definition is intended to differentiate this process from Internet-delivered general health education for patients (e.g., health information websites), and Internet-delivered clinical practice guidelines for clinicians.

What is the theoretical rationale for including this dimension?

Several theories in cognitive psychology, decision psychology, and communication emphasize the value of using the Internet to provide broad and long-term dissemination of information that can be targeted and tailored to patients' needs and preferences. In addition, several theories of active, discovery, and social learning inform the design of interactive PtDAs to effectively provide information and support. Furthermore, theories of dissemination and implementation emphasize the need for the right information (rapidly updated), delivered to the right person (tailored), at the right time (in advance, during, and after a decision needs to be made).

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What is the evidence to support including or excluding this dimension?

In 2011, Internet usage ranges from 74% to 85% in developed countries, with 80% of users searching for health information. Most individuals search for information about a specific disease (66%) or treatment procedure (56%). However, it is unknown how many individuals seek decision support on the Internet, due largely to the breadth of terms used to describe PtDAs and the variety of formats available. Among the 86 studies in the 2011 update of the Cochrane Collaboration's Review of Patient Decision Aids assessed in randomized controlled clinical trials, only 2 studies included PtDAs that were delivered on the Internet.

**SECTION 3:  
DEFINITION (CONCEPTUAL/OPERATIONAL) OF THIS QUALITY DIMENSION**

**a) Updated Definition**

Delivering decision aids on the Internet is defined here as the process of using the Internet to provide some or all components of a patient decision aid (PtDA) to individuals (e.g., patients, caregivers, clinicians, etc.) involved in the process of choosing between two or more medically appropriate healthcare options.

This definition is intended to differentiate this process from Internet-delivered general health education for patients (e.g., health information websites), and Internet-delivered clinical practice guidelines for clinicians.

This broad conceptual definition includes a range of operational definitions—from providing a downloadable copy of a paper-based PtDA, to streaming a video-based PtDA online, to providing interactive decision support websites that tailor information and support to the needs and preferences of each individual decision maker.

**b) Changes from Original Definition**

The updated definition differentiates the process of providing PtDAs on the Internet from general health education websites.

**c) Emerging Issues/Research Areas in Definition**

Given this broad definition, delivery of a PtDA using the Internet could be further categorized according to the development methods, design features, and implementation approaches used.

***Development Methods***

For example, the *development* of PtDAs for delivery on the Internet could be categorized in three ways:

- *Internet-available PtDAs* may include PtDAs that were initially developed and tested in paper, audio, or video formats, and then made available on the Internet. For example, several

PtDA pamphlets were originally created as paper worksheets, and then made available online for individuals to download, print, and complete.

- *Internet-adapted PtDAs* may include paper- or video-based PtDAs that were purposefully adapted to allow individuals to use them directly on the Internet. Examples include adapting paper worksheets into interactive questionnaires, and adapting text and video components of PtDA DVDs into websites. While Internet-adapted PtDAs may have been rigorously tested and evaluated in their original format, it is important to consider whether the adapted version has been tested and evaluated as used on the Internet (see Usability, below).
- *Internet-based PtDAs* may include PtDAs that were specifically designed and tested for use on the Internet. Examples include websites designed to help patients with specific healthcare decisions by interactively tailoring information and support to their needs, or by providing opportunities for family members to participate in the discussion. Internet-based designs may also include e-mail, discussion forums, blogs, or social media sites (e.g., Facebook, patient community websites) facilitated by clinicians, decision coaches, peers, or patient advocacy groups.

It is important to note that delivery of a PtDA on the Internet may be only one component of a larger decision support program. For example, a patient may view a PtDA website coupled with a phone call from a clinician or decision coach. For such programs, evaluation measures should be carefully considered for each component and for the overall decision support program.

### ***Design Features***

PtDAs delivered on the Internet could also be categorized using terms from bioinformatics and graphic design, according to the features available:

- *Linear vs. Open Format* – A PtDA is considered linear if the content is presented in the same order every time and progression through the aid requires completion of each previous section. An open format allows the individual to navigate the website and choose which information to view and in what order.
- *Non-Interactive vs. Interactive* – PtDAs may range from non-interactive if the person viewing the site simply reads textual content, to minimally-interactive if they can select and view videos (see Chapter E, “Using Personal Stories”), to fully-interactive if individuals can navigate the content and/or respond to interactive questions.
- *Static vs. Dynamic* – A PtDA is static if it is programmed to provide all viewers with the same design and content, and dynamic if it provides different information depending on what the individual selects.
- *Text-heavy or Graphics-heavy* – PtDAs delivered on the Internet may present content using a variety of media, including text, figures, graphs, photos, animations, audio, and videos. Worksheets and brochures may rely on text-heavy or text-based presentations, while videos may be more graphic-heavy. Mixed media refers to the use of more than one medium (e.g.,

text and photos), while multimedia refers specifically to the addition of audio (e.g., narration and videos). Rich media specifies the inclusion of interactive components, and hypermedia refers to interactive media that direct the presentation of information (e.g., hyperlinks that allow open navigation between pages).

- *Passive vs. Active Deliberative Support* – A PtDA may provide passive decision support by merely providing content about the process of making a well-informed healthcare decision, or active decision support by actually leading the individual through the process of preparing to make their decision.
- *Anonymous, De-identified, and Identifiable* – PtDAs may be designed for anonymous use, where it is impossible to identify individual users connection with a PtDA. De-identified means that, if any data that might directly or indirectly identify a user are collected, those data are obscured so that there is only a very small chance the user could be linked to the information entered by a user. Identifiable means that the PtDA collects data that are directly linked to identify the user. Examples include PtDAs that collect users' email addresses. If identifiable information is collected, it is important to determine who will have access to that information. For example, password-protected accounts may be used to allow patients to revisit their information over time and/or clinicians to collect information directly into electronic health records. However, care (i.e., data safety) must be used to ensure secure hosting to avoid access by third party companies and/or Internet service providers.
- *Tailored vs. Non-tailored* – PtDAs delivered on the Internet may modify (i.e. “tailor”) the content provided according to the patients' characteristics, needs, and preferences in three ways. First, they can tailor clinical content to reflect the risk / benefit levels implied by a patient's unique clinical characteristics. Second, they can tailor decision support to patients' decision-making needs and preferences (i.e., preferred “deliberative style”), such as including more/less detailed information, passive/active deliberative support, or an emphasis on information-provision versus values-clarification, etc. Third, they can tailor how content is displayed to meet the needs of all audiences (see “Accessibility of the Design”, below).
- *Accessibility of the Design* – This refers to the degree to which the PtDA is accessible to all people, particularly those with disabilities. PtDAs provided on the Internet may be designed to optimally work with assistive technologies, such as screen reading, screen magnifying, Braille, or speech recognition programs. Visual accessibility may be increased by providing larger font sizes, optimizing graphics for color-blindness, limiting flashing lights in videos, and by providing meaningful descriptions for images and links that can be read aloud by screen reading programs. Providing captions/subtitles for videos may increase audio accessibility. To increase motor accessibility, larger buttons, touch screens, or voice commands may be used. Providing options for high and low literacy levels may increase cognitive accessibility.

### ***Evaluation Measures***

In addition to evaluation measures used to assess the quality of the decision support (e.g., preparation for decision making, information comprehension, decision quality, etc.), the fields of

bioinformatics and implementation science provide several measures of equitable dissemination of the technology.

- *Accessibility of the technology* refers to the degree to which all people can access the Internet, regardless of available service (e.g. cable, mobile, wireless, or satellite broadband, dial-up vs. high-speed, etc.). Dissemination strategies to maximize technology accessibility include providing both text-heavy and graphics-heavy versions of a PtDA, as well as versions for multiple screen sizes and smart phones (known as *responsive design*).
- *Universality* refers to the degree to which the PtDA is appropriate for men and women of all ages, races, ethnicities, religions, and cultures.
- *Usability* "...refers to how well users can learn and use a product to achieve their goals and how satisfied they are with that process" (U.S. ISO/AWI TR 9241-11, 1998). This definition includes a combination of factors, primarily focusing on five areas:
  1. *Ease of Learning* - how easy it is to do basic tasks the first time you see the website,
  2. *Efficiency of Use* - how quickly you can use the website once you know how,
  3. *Memorability* - how well you can remember how to use it the next time you visit,
  4. *Error Frequency* - how many errors are typically made in looking for information, and
  5. *Satisfaction* - how much you like using the website.

Because the provision of PtDAs on the Internet allows for multiple levels of interaction among these sub-types, it will be important to distinguish meaningful conceptual and operational definitions from these multiple perspectives. Furthermore, effective delivery of a PtDA using the Internet may be defined differently for patients and/or caregivers making an acute or chronic decision, than for clinicians helping individual patients, researchers studying groups of patients, public health programs serving communities of patients, or policy makers serving populations of patients. In addition, these definitions will need to be placed in the context of the timing of the PtDA provision (before, during, or after consultation with a clinician) and the device used (e.g., computer, tablet, or smart phone). Finally, additional evaluation and dissemination approaches will be needed for mixed-modal decision support, where delivery on the Internet is coupled with in-person or phone consultations by clinicians or decision coaches.

#### **SECTION 4: THEORETICAL RATIONALE FOR INCLUDING THIS QUALITY DIMENSION**

##### **a) Updated Theoretical Rationale**

Several theories in cognitive psychology, decision psychology, and communication emphasize the value of using the Internet to provide broad and long-term dissemination of information that can be targeted and tailored to patients' needs and preferences. The Health Belief Model emphasizes the importance of providing tailored information to motivate active engagement in healthcare (Becker 1974). Similarly, interactive deliberative tasks foster self-efficacy and lead to increased engagement (Social Cognitive Theory; Bandura 1977). Within communication theories, the Elaboration Likelihood Model proposes that people attend to and actively process

information more if it is perceived as personally-relevant (Petty 1981). The theory of Goal Setting and Performance proposed by Locke and Latham (1990) supports the role of interactivity in producing tailored actionable personal health goals. Finally, the Stages of Change Theory supports the value of having up-to-date information and accessibility over time, so that patients can revisit it as needed in their progression of both disease changes and decision-making changes (Prochaska 1983).

Theories of active, discovery, and social learning also inform the design of Internet-delivered decision support tools that effectively inform and educate individuals (Ally 2004). Behaviorism emphasizes the need for measurable behaviors to confirm learning. For example, optional activities such as information quizzes can reinforce awareness and facilitate realistic expectations of outcomes (Thorndike 1913, Pavlov 1927, Skinner 1974). Cognitive psychologists emphasize the internal processes of memory, motivation, thinking, and reflection on how new information fits within one's existing knowledge and experience ( Craik & Lockart 1972, Ausubel 1974). Therefore, interactive activities such as clarifying one's personal attitudes about the individual risks and benefits of each treatment option can reinforce comprehension and personalization. Constructivism builds on these theories to discuss the roles of observation, processing, and interpretation of information to build onto one's personal reality (Cooper 1993, Wilson 1997). Ally (2004) integrates these three theoretical bases to describe how information provided online can and should be designed to help individuals learn about the "what" (behaviorist), "how" (cognitive psychologist), and "why" (constructivist) of their options (Ertmer and Newby 1993).

Alongside theories that inform the optimal design of Internet-delivered PtDAs for individual patients, dissemination and implementation theories emphasize the importance of effectiveness for larger populations. Theories of innovation, knowledge translation, and organizational change may inform strategies for effective use of web-based PtDAs within and alongside medical centers (Brownson 2012). Health equity frameworks support the development of technology-supported interventions to extend the reach of medical centers into rural or underserved communities. RE-AIM, Precede-Proceed, and other community organizing models can guide consumer-informed design approaches, particularly for chronic disease self-management and for implementation within community programs (Glasgow 2001).

**b) Changes from the Original Theoretical Rationale**

The updated theoretical rationale incorporates theories from multiple disciplines that support both the use of the Internet to deliver PtDAs, and the potential design components of Internet-delivered PtDAs.

**c) Emerging Issues/Research Areas in Theoretical Rationale**

As decision support health technologies begin to include modes of social connectivity, researchers will need to consider how established theories (e.g., Social Development Theory; Vygotsky, 1962) inform their study of how people perceive, value, and use personal experiences shared online in making healthcare decisions. Emerging websites such as PatientsLikeMe.org allow patients and family members to document and share their healthcare treatment experiences in order to help others make informed decisions. While this content carries a high potential for

presenting biased information to consumers, it does represent an emerging social experiment highlighting the importance of shared information, connectivity, and outcomes that are of the greatest importance to patients. Further research is needed to clarify what types of socially shared content are needed, preferred, and beneficial to patients, as well as whether socially-generated information can be collected and presented in neutral, unbiased, culturally-relevant formats.

Similarly, the increasing use of “patient testimonials” on the Internet raises the need for research into the effects, ethical issues, and appropriate use of this experiential information. On the one hand, some communication and education theories support the use of written or video “patient testimonials” because of their saliency, and qualitative studies confirm patient requests for such experiential information; on the other hand, others advocate further study due to concerns about social matching, misrepresentation of risks/benefits, and biases (see Chapter E, “Using Personal Stories”). Additional research is needed to determine which formats (written, audio, video), functions (narration, guidance, content provision), and what content (information about the disease, the treatments, the outcomes of treatments, the process of decision making, and/or the outcomes of decisions) are optimal within the various types of decision support (implicit information, explicit guidance, automated coaching) that may be provided on the Internet.

As decision support interventions begin to be designed and used for long-term health behavior change (e.g., managing chronic pain, quitting smoking, weight loss, dementia), the theories related to stages of change will need to be tested in the context of preference-based decision making. For example, the Trans-Theoretical Model related to Stages of Change has been used in the development of Internet-delivered resources for patients seeking to improve their healthy behaviors (Prochaska 1983). In situations in which decision support is nested within motivational counseling (for example, when choosing which weight loss diet and exercise strategies work for you), this model will need to be tested in the context of providing online decision support tools.

Until Internet access and usage becomes universal, several issues in implementation theory and health equity need to be considered. On the one hand, delivery of PtDAs on the Internet is currently less accessible for communities that lack either high-speed access of cellular phone service. However, telehealth clinics in rural communities can extend healthcare access for patients who otherwise may be limited by travel times/costs (Fox 2012). Other communities may benefit specifically from PtDAs delivered on the Internet, such as working adults who cannot attend daytime doctor visits, home-bound individuals, and older adults who no longer drive. In addition, emerging evidence (see below) suggests a shift from personal computers to mobile phones, with disadvantaged groups becoming the largest users of smart phones for Internet access. New efforts are being made to address health equity gaps by developing culturally-tailored mobile health websites. Lastly, current trends indicate that retired adults are the fastest growing group of new Internet users, but it remains unknown whether the working generation will increase their Internet use once they retire. During this transition period in Internet use, theories of implementation and health equity will need to be operationalized with consideration of potential short-term versus long-term approaches for an evolving patient population.

There is a rising need for multidisciplinary theories and frameworks to address the multifaceted and changing needs and preferences of patients with chronic illnesses (Rogers 1983, Krueter 1999, Li 2012). In addition to traditional healthcare decisions, such as surgical versus medical management, patients are increasingly offered self-management strategies, family-based interventions, and community programs. Self-management theories support the use of technology for documentation of personal experiences over time, and social learning theories discuss the saliency of shared experiences. As patients are openly reporting their testimonials on the Internet, issues remain about how to consider these rapidly-growing banks of patient-reported data and testimonials within the theoretical frameworks associated with decision support and evidence-based medicine. The expanding market of health technologies shapes the expectations of patients, raising issues around incorporating user-directed marketing strategies within implementation frameworks (Brownson 2012). An integrated framework of chronic care, implementation, marketing, and knowledge translation theories may be needed to create effective decision support programs that assist with self-management of progressive illnesses, the inclusion of family decision makers, and rapidly-evolving online health technologies.

## **SECTION 5: EVIDENCE BASE UNDERLYING THIS QUALITY DIMENSION**

### **a) Updated Evidence Base**

#### *Use of The Internet For Decision Support*

For 2007-2011, Worldbank.org indicates that an average of 74.2% of individuals in the United States, 76% in Australia, 81% in Canada, 83% in Germany, and 85% in the United Kingdom used the Internet. A 2011 survey in the United States indicates that 80% of Internet users search for health information, making it the third most popular online activity (behind using e-mail and search engines) (Fox 2011). Most individuals search for information about a specific disease (66%) or treatment procedure (56%).

In recent years, studies by the Pew Internet & American Life Project reported a continuation in the upward trend in mobile phone usage (Smith 2011, Fox 2012). Over 83% of U.S. adults reported owning a mobile phone, with 35% using a smart phone to access the Internet. Mobile Internet usage was most common among individuals who were 18-29 years old, African American, and Latino. Qualitative analyses suggested a growing preference for social connectivity (e.g., high rates of texting and social websites), and for searching for health information on the Internet prior to making an appointment with a doctor.

However, it is unknown how many individuals seek decision support on the Internet, due largely to the breadth of terms used to describe patient DAs and the variety of formats available.

#### *Inventories of Decision Aids Delivered on the Internet*

The Ottawa Hospital Research Institute maintains a Decision Aid Library Inventory (available at: <http://decisionaid.ohri.ca/AZinvent.php>) that provides searchable and browseable lists of PtDAs



by: clinical topic; contact and availability information; and scoring on each of the IPDAS Checklist criteria. As of October 2012, this library contained 270 PtDAs, 198 of which were available in some form on the Internet. A systematic review is currently being conducted to a) identify which of these PtDAs are Internet-available, Internet-adapted, or Internet-based, and b) report the extent to which their effectiveness has been evaluated. Results will be incorporated into this IPDAS chapter as they become available.

### ***Randomized Controlled Trials of Decision Aids Delivered Using the Internet***

The 2011 update of the Cochrane Collaboration's Review of Patient Decision Aids searched for randomized controlled trials published between 2006 and 2009 that compared a PtDA with usual care or an alternative intervention with individuals who were actively making a treatment or screening decision (Stacey 2011). Among the 86 studies that met these criteria, 2 studies focused on PtDAs that were delivered on the Internet.

In the first study, Frosch and colleagues (2003) randomly assigned 226 men to view a 23-minute videotaped PtDA ( $n = 112$ ) or to access a website-based PtDA ( $n = 114$ ), prior to deciding whether they wanted to be screened for prostate cancer at their next physical examination. The video-based PtDA had been developed and evaluated in several previous studies. The Internet-based version was created by adapting the video content into a series of slides (e.g., selected images and audio from the video) to maximize download speed. Individuals randomized to the video group were offered the opportunity to watch the video at the clinic prior to their scheduled appointment. Individuals randomized to the Internet group were asked to access the slides on a website using a personal or public computer prior to their appointment. Internet access was not made available at the clinic and 24.7% had to download software to view the slides.

Results indicated that men rated the video and Internet presentations equivalently in terms of effort required, perceived convenience, and satisfaction. Men who viewed the video were more likely ( $\chi^2 (1) = 73.29, p < .001$ ) to view the entire video than those who viewed the Internet site. However, knowledge scores were equivalent between the video group and the Internet group who viewed the entire set of slides. These results must be interpreted cautiously, given that no usability or accessibility evaluation was reported for the Internet version prior to evaluation for effectiveness. There also exists potential confounding by location and timing of availability relative to the clinical appointment. This study highlights the importance of purposefully integrating health technology and decision support research methods and outcome measures.

In the second study, Frosch and colleagues (2008) randomly assigned 611 men to one of 4 versions of an Internet-delivered PtDA: a) traditional didactic PtDA providing information about prostate-specific antigen screening options and outcomes; b) chronic disease trajectory model for prostate cancer followed by a time-trade-off exercise; c) both the didactic PtDA and the chronic disease trajectory model; or d) links to public prostate cancer-specific websites from credible sources. Reminders were sent prior to the patients' appointments, which increased website usage to 84.3% from the previous trial. On a 10-item information comprehension quiz, men who viewed the traditional didactic version scored the highest (mean 8.65; SD.18), and those who viewed the public websites scored the lowest (mean 7.49; SD 0.19);  $p = .005$ . Differences were observed between groups in preferences for screening ( $p = .047$ ). The authors concluded that

guiding patients to a structured PtDA on the Internet was more effective than health information websites.

### ***Additional Studies in 2011-2012***

In addition, the authors are aware of at least three additional studies conducted in 2011-2012.

First, Li and colleagues (2011) developed and field-tested an Animated Self-serve Web-based Research (ANSWER) tool to provide decision support for rheumatoid arthritis patients considering methotrexate therapy. The PtDA consisted of narrated information about methotrexate, 6 patient stories, and interactive questionnaires to clarify treatment preferences. Participants ( $n = 15$ ) in the field test took an average of 56.1 minutes ( $SD = 34.8$ ) to complete the program and provided positive ratings using the System Usability Scale (mean 81.2 out of 100;  $SD 13.5$ ). The Think Aloud technique was used and content analysis revealed three themes: 1) user engagement (e.g., relevance of the design and content to the user), 2) information quality (e.g., clarity and credibility), and 3) user-tool interaction (e.g., ease of use). This study illustrates the importance of quantitative and qualitative usability testing. An ongoing follow-up study (ANSWER-DC) is investigating the potential added value of combining the web-based ANSWER PtDA with a 20-minute structured telephone consultation with an arthritis therapist.

In the second study, Simon and colleagues (2012) evaluated the effectiveness of a web-based, individually tailored PtDA (known as Patient Dialogue) on depression or acute low back pain for insureds of a German sickness fund. The Patient Dialogue system was compared to the non-tailored Static Patient Information in an online randomized controlled trial. The primary outcome was decisional conflict; secondary outcomes included knowledge, preparation for decision-making, preference for participation, involvement in decision-making, decision regret, and adherence. Out of 2,480 randomized participants, 657 (26.5%) provided analyzable data immediately after using the system. Three months later, data from 131 (5.3%) participants could be included in the analysis. The group who viewed Patient Dialogue reported significantly lower levels of overall decisional conflict than the group who viewed the Static Patient Information (38.7 vs. 45.1;  $p = 0.028$  via multiple imputation estimator). The largest standardized effect (Cohen's  $d = 0.56$ ) was observed on the preparation for decision-making scale (PD = 59.4 vs. SPI = 46.8;  $p < 0.001$ ). The authors concluded that the interactive Patient Dialogue PtDA may be an effective tool to reduce decisional conflict and prepare participants for treatment decision making. However, the large dropout rate needs to be taken into account. Furthermore, this study shows how a health insurance fund can support shared decision making, and how a web-based PtDA can be evaluated in a randomized controlled trial under routine care conditions.

Third, at the 2012 Society of Medical Decision Making Annual Meeting, Hoffman and colleagues presented the results of the ENGAGE study of an Internet-based PtDA to assist patients in choosing between non-surgical and surgical therapies for knee pain from chronic osteoarthritis. Using a multidisciplinary theoretical framework, they developed the PtDA to provide up-to-date clinical evidence about the treatment options, using a rich media format that allowed viewers to interactively select "More Information" to learn more about each clinical topic. The PtDA then provided guidance in 4 deliberative steps. To investigate the role of implicit versus explicit deliberative guidance, 2 versions were created. The *implicit* guidance

version presented the clinical evidence followed by standardized statements describing the process of becoming well-informed, considering which risks/benefits are most important personally, considering one's resources, and forming an action plan. The second version *explicitly* led viewers through each deliberative step, offering an optional interactive personal activity at each step.

One hundred and twenty-six participants from diverse background and locations in the United States were randomly assigned to either version. Notably, 100% of participants preferred to view the PtDA on their home or local public computer rather than at the clinic. Overall, participants reported that: the Internet-based PtDA was easy to use (98%), the information was clear (90%), the length was appropriate (100%), it was appropriately detailed (90%), and it held their interest (97%). Participants scored an average of 75% correct responses (min. 60%; max. 100%) on 5 Information Comprehension items. The median Preparation for Decision Making score was 74 (interquartile range = 30). The median Decision Self-efficacy score was 100 (interquartile range = 13.6). Viewing the PtDA reduced mean Decisional Conflict scores from 31.1 to 19.53 ( $p < 0.01$ ). These results were comparable to the performance of the video-based PtDA currently used in clinical care.

Overall, no differences were observed between the group who viewed the implicit version and those who viewed the explicit version. However, 46% of viewers in both groups chose to interactively engage with the clinical information or with the deliberative steps. Multiple regression analyses indicated that interactive engagement was significantly associated with increased self-efficacy ( $b = -9.08$ ; 95% CI =  $-15.95 - -2.21$ ;  $p = 0.01$ ) and decreased decisional conflict ( $b = -13.29$ , 95% CI =  $-22.75 - -3.83$ ;  $p = 0.007$ ). These results suggest that a) an Internet-based PtDA is acceptable to users and feasible for research, and b) patients may exhibit different "deliberative styles" that benefit more/less from different opportunities for interactivity, engagement, and support. Therefore, Internet-based PtDAs may offer additional gains when careful attention is given to their use of interactive and tailored information and support.

**b) Changes from Original Evidence Base**

The updated evidence base provides additional research studies up to July 2012.

**c) Emerging Issues/Research Areas in Evidence Base**

As patients and families increasingly seek healthcare information and decision support on the Internet, additional research will be needed to address several fundamental questions:

- What are the best methods for providing decision support using the Internet? Which technology features are most helpful for patients and families?
- What are the advantages and disadvantages of different learning environments, such as linear and open designs?
- Should Internet PtDAs "stand alone" or do they need to be supplemented with other materials, such as paper-based tools? For which populations?

- What are the potential harms of providing decision support on the Internet?
- What are the costs of developing and maintaining Internet PtDAs (e.g., updating graphic/video components when new evidence emerges), and how do they compare to aids developed and delivered using other media?
- How can the features of Internet PtDAs be used to facilitate informed decision making by patients from disadvantaged groups or with low health literacy?
- Which technology features are most usable? Which are most preferred? By whom?
- What are the strengths and weaknesses of delivering PtDAs on the Internet, and how can they be adapted for other platforms such as smart phones, as applications for devices such as tablets, smart phones, and e-book readers (e.g., iPads, iPhones, Kindles), or via social media applications such as Facebook, Twitter, etc.?
- How might delivery of decision support using the Internet foster long-term engagement of patients and families facing chronic diseases? For example, how could decision support via websites best support communication with caregivers in other locations?
- How can Internet-based PtDAs be designed to adapt to the rapidly-evolving expectations of an increasingly technology-savvy population?

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**APPENDIX:  
ORIGINAL CHAPTER H**

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**Original Definition**

The Internet is one of several ways in which patient decision aids are made available. Other methods include video-cassettes, computer programs, decision boards, booklets, and audio-guided workbooks.

**Original Rationale/Theory**

The use of the Internet for making patient decision aids available is becoming more popular because of the increased accessibility for patients and the decreased costs for producing and distributing them. Patients go increasingly to the Internet to find answers to their health concerns and to get assistance in making health related decisions. However, information on the Internet needs not only to be valid and reliable, but also easily accessible and comprehensible. The design, usability, interface, logical organisation, and interactivity of an Internet site are crucial factors to enable patients to obtain the information they need.

**Original Evidence Base**

***Inventory of Available Patient Decision Aids***

Although patient decision aids have been available since the early 1980's, the use of the Internet as the medium of delivery has dramatically increased over the last 5 years. However, there has been little evaluation of the effectiveness of the Internet as the medium of delivery.

Of 131 patient decision aids that were available, updated within the last 5 years, and registered in the Cochrane Review of patient decision aids inventory (O'Connor et al., 2003):

- 73% (of 131) were available only on the Internet. Several other patient decision aids developed and evaluated as booklets or leaflets were also available on the Internet.

***RCTs Involving Patients Facing Actual Choices***

None of the 29 individual patient decision aids that were evaluated in 34 RCTS included in the Cochrane review used the Internet as the medium of delivery in the study (O'Connor et al., 2003).

A recently published trial by Frosch and colleagues (2003) compared men considering prostate cancer antigen (PSA) screening a) who viewed a patient decision aid video in the clinic immediately prior to their practitioners' appointment with b) those who accessed the Internet-



based patient decision aid at home. There was no difference between the groups in terms of participants' ratings of the convenience, effort, or satisfaction related to using the patient decision aids. Compared to the Internet group, men in the video group were more likely to use the patient decision aid (98.2% versus 53.5%), had significantly improved knowledge, and were more likely to decline PSA screening. Men in the Internet group who reviewed the entire online patient decision aid showed knowledge improvements similar to the video group.

### ***Other Relevant Literature***

The National Cancer Institute (NCI) provides Web design and usability guidelines based on research studies and supporting information from the field. Each guideline provides:

- A brief statement of the overarching principle that is the foundation of the guideline
- Comments that further explain the research/supporting information
- Source(s) of the research/supporting information
- A score indicating the "Strength of the Evidence" that supports the guideline
- One or more graphic examples of the guideline in practice.  
(<http://usability.gov/guidelines/intro.html#1>)

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