

## Understanding and overcoming the barriers of implementing patient decision aids in clinical practice\*

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### Abstract

Patient decision aids (ptDAs) have been developed to assist patients with difficult health-related decisions. Despite their proven effects on decision quality in numerous efficacy trials, we lack an evidence-based approach for implementing them as part of the process of care. Pragmatic trials of ptDAs have uncovered a myriad of implementation challenges; therefore we need a better understanding of the barriers and strategies to overcome them to facilitate their widespread uptake. The following paper provides an overview of the barriers related to the uptake of ptDAs within the process of care and the strategies, opportunities and research priorities to overcome them. This report is based on our interpretation of the literature and our collective experience in implementing ptDAs within trials and other contexts.

### Introduction

Patient involvement in decisions regarding treatment, screening and/or investigations is widely advocated. In some cases, these health-related decisions

are straightforward however, when the evidence related to benefits and harms is unclear, or the decision is value-laden, they can be difficult. In order to facilitate the shared decision-making process, evidence-based patient decision aids (ptDAs) have been developed.

PtDAs are 'interventions designed to help people make specific and deliberative choices among options, including the status quo, by providing (at

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minimum) information on the options and outcomes relevant to a person's health status' (O'Connor *et al.* 2004a). In addition, ptDAs may provide information on the condition, probabilities of benefits and harms, methods for clarifying patient values, balanced examples of other's experiences and guidance or coaching in the steps of deliberation and communication (O'Connor *et al.* 2004a).

These decision support tools are meant to enhance, not replace, the traditional process of patient counselling by practitioners (O'Connor *et al.* 2004a). PtDAs can be self-administered or practitioner-administered and used in one-to-one or group situations. Their delivery may take on many forms including: decision boards, interactive videodiscs, information booklets, scripted telephone counselling, interactive computer programs, audio-guided workbooks, audio tapes, leaflets, structured interviews and the web (Molenaar *et al.* 2000; O'Connor *et al.* 2004a). Many developers use more than one mode of delivery and the use of the web is gaining popularity (O'Connor *et al.* 2004a).

Studies to date have focused on the development of ptDAs and their evaluation on the decision-making process and outcomes of the decision (Molenaar *et al.* 2000; Estabrooks *et al.* 2001; O'Connor *et al.* 2004a). The latest review of 34 studies (O'Connor *et al.* 2004a) shows that patients and practitioners who use ptDAs make better decisions. Patients participate more, know more, have more realistic expectations of benefits and harms and are more likely to receive an option with outcomes they most value. Furthermore, ptDAs reduce the uptake of invasive surgical procedures by 24% without affecting health outcomes and one study has demonstrated cost-effectiveness (O'Connor *et al.* 2004a). Therefore, they may have a role in reducing overuse of options that informed patients do not value. While we know much about the benefits of ptDA in improving decision quality compared to 'usual' care, we know less about how to increase their widespread uptake beyond the academic setting (Holmes-Rovner *et al.* 2000; O'Cathain *et al.* 2002).

In order to successfully implement ptDAs into the process of care within the real world we need to understand more about the barriers associated with their uptake and how these can be overcome. The *Ottawa Model of Research Use* presented by Logan

and Graham (Logan & Graham 1998) highlights six key elements on how to get research into practice that should be systematically monitored before, during and after any research transfer efforts. These elements include the innovation itself, potential adopters, practice environment, different methods of knowledge transfer, evidence that the adoption occurred and outcomes resulting from uptake of the innovation (Logan & Graham 1998; Graham & Logan 2004). The following review employs elements of this model to examine the barriers relating to the ptDAs themselves, the practitioners and patients who adopt them and the organization within which they are used (see Fig. 1). In addition, it explores the strategies and opportunities to facilitate their uptake into the process of care. Our interpretation comes from the literature and our collective experience in developing and implementing over 30 ptDAs and assessing barriers to their uptake (Graham *et al.* 2003, 2004).

### **Barriers, strategies and opportunities (refer to Table 1 for summary)**

#### **Patient decision aid**

##### *Quality and maintenance*

Graham *et al.* investigated doctors' perceptions of three ptDAs using qualitative research methods (Graham *et al.* 2003). Potential barriers to their uptake included practitioner concerns about the ptDAs' comprehensiveness and up-to-datedness (Graham *et al.* 2003). The issue of updating ptDAs is crucial to their quality. In our experience several ptDAs have required frequent updating because of the fast pace of new evidence (O'Connor *et al.* 1998; Cranney *et al.* 2002). For example, the number of treatments options for osteoporosis have increased dramatically (Neer *et al.* 2001). The use of hormone replacement therapy for postmenopausal women have been confined largely to those with symptoms attributed to the emergence of the research findings from the Women's Health Initiative that oestrogen increased the risk of heart disease, stroke and breast cancer (Rossouw *et al.* 2002). The treatments for osteoarthritis have been called into question because of new evidence on the risks of Cox-2 inhibitors as demonstrated by the APPROVe trial (FitzGerald

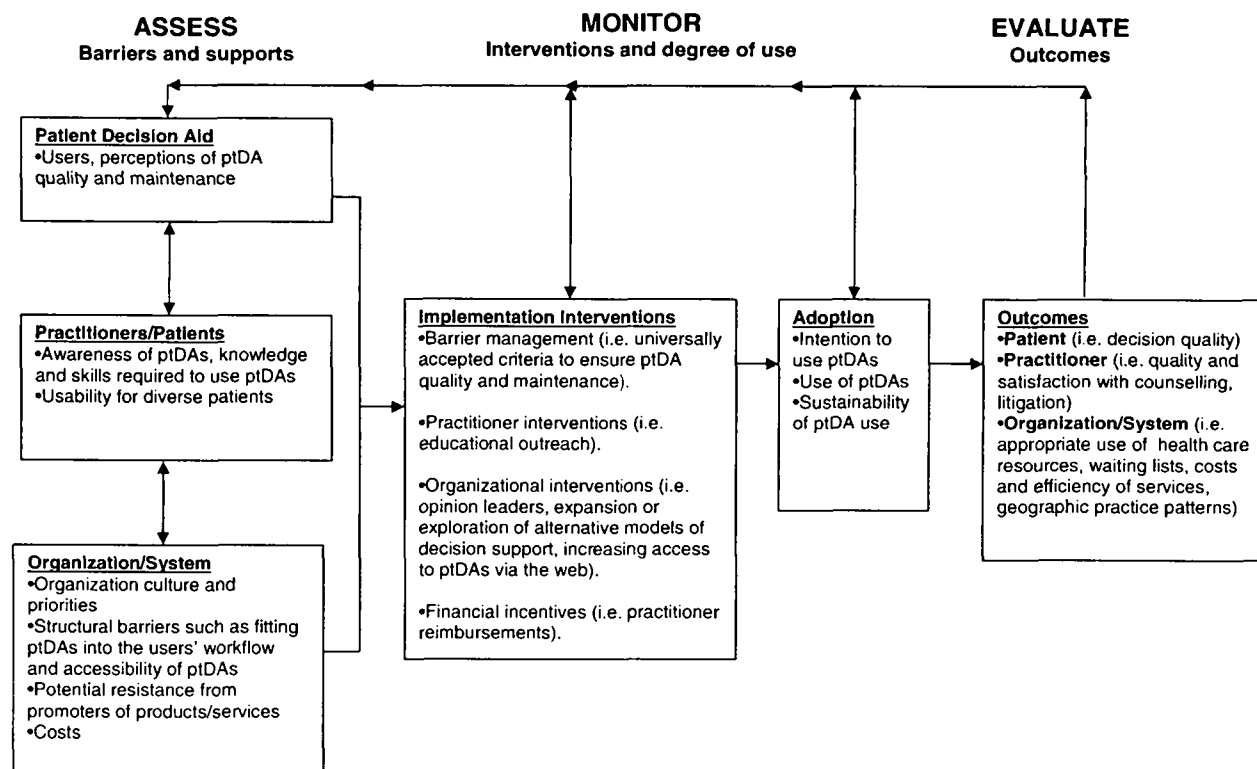


Figure 1 Ottawa model of research use [adapted from Logan & Graham (1998)].

2004; Juni *et al.* 2004; Bresalier *et al.* 2005). With the ever-shortening shelf life of scientific evidence, it is important that ptDA developers be closely linked to those who produce, summarize and analyse evidence. Our greatest success in the timely update of a ptDAs occurred when we had strong links to systematic review teams, epidemiologists or decision analysts with updatable models, or practice guideline groups. In another case, we were able to produce a ptDA to debrief study participants at the completion of the study (Man-Son-Hing *et al.* 1999). This strategy would have been very helpful for the millions of patients and practitioners affected by the results of the Women's Health Initiative and APPROVe trials.

A key strategy to overcome barriers associated with the quality and maintenance of ptDAs is to develop and gain widespread acceptance of minimal quality standards specifically designed to evaluate these decision support tools. As part of the Cochrane Systematic Review of ptDAs, a standardized assessment known as the CREDIBLE criteria (Compe-

tently developed, Recently updated, Evidence-based, Disclosure of conflict of Interest, BaLanced and Efficacious) was developed (O'Connor *et al.* 2004a). This set of criteria provides a summary of key indicators that provide confidence in the credibility of a ptDA (O'Connor *et al.* 2004a). Currently, these criteria are being updated by the International Patient Decision Aid Standards (IPDAS) Collaboration, involving ptDA developers, evaluators, practitioners, consumers and policy makers. Their goal is to establish an internationally approved set of criteria for evaluating the quality of ptDAs, including criteria to address updating and expiry dates. Other issues that need to be addressed are policies regarding implementing standards and identifying relevant accreditation groups (O'Connor *et al.* 2004b).

#### Practitioner/patient

##### *Awareness, knowledge and skills*

Lack of awareness of existing ptDAs for a particular clinical decision has been viewed by practitio-

**Table 1 Barriers, strategies and opportunities related to the implementation of PtDAs into the process of care**

<i>Barriers</i>	<i>Strategies and opportunities</i>
<b>Patient decision aid</b> <ul style="list-style-type: none"> <li>• Users' perception of quality and maintenance</li> </ul>	<ul style="list-style-type: none"> <li>• Stronger links between ptDA developers and evidence producers, systematic reviewers and guideline developers.</li> <li>• Universal acceptance and employment of internationally defined criteria developed to establish confidence in the credibility of the ptDA.</li> </ul>
<b>Practitioner/Patient</b> <ul style="list-style-type: none"> <li>• Awareness, knowledge and skills</li> <li>• Usability for diverse patients</li> </ul>	<ul style="list-style-type: none"> <li>• Educational and skill building initiatives in the use of ptDAs and decision support are gaining momentum.</li> <li>• Further research required on how PtDAs work to improve decision quality for people who vary by demographic characteristics and baseline decisional needs for better health outcomes.</li> </ul>
<b>Organization/System</b> <ul style="list-style-type: none"> <li>• Organizational culture and priorities</li> <li>• Structural (i.e. failing to fit ptDAs into the users' workflow and accessibility to ptDAs)</li> <li>• Potential resistance from promoters of particular services or products</li> <li>• Costs to purchase and implement; develop and maintain ptDA</li> </ul>	<ul style="list-style-type: none"> <li>• Obtain administrative buy-in to incorporate use of ptDAs for the purpose of informed consent, a quality indicator and/or as a cost-saving measure.</li> <li>• Explore care pathways to determine moments in care in which decision support may be helpful. Investigate and evaluate alternative decision support service models, that is, <i>free-standing, clinic/hospital-based, insurance-centred-based models</i>.</li> <li>• Improve access to ptDA inventories, tools and reviews via the use of the web.</li> <li>• Program accreditation teams need to emphasize use of best available evidence.</li> <li>• Provide user incentives; further research required on the cost-effectiveness of these tools.</li> </ul>

ners as a unique barrier to their implementation within general and specialty practices (Graham *et al.* 2003). Also, while practitioners may agree with involving patients in health-related decisions, they do not always acquire the knowledge or skills to successfully practise shared decision making (Holmes-Rovner *et al.* 2000). Advances in shared decision making and the uptake of ptDAs are dependent on improving awareness of the available tools as well as, developing the knowledge and skills of health professionals in decision support (Elwyn *et al.* 1999). One strategy is to develop training in decision support in a variety of forums (Towle & Godolphin 1999; Godolphin *et al.* 2001; Thistlethwaite 2002; Edwards & Elwyn 2004; Legare 2005; Stacey 2005). Our group (Legare 2005; Stacey 2005) has developed initiatives such as credit courses in clinical epidemiology, nursing and medicine as well as continuing education that includes online autotutorials, interactive workshops, performance feedback and structured protocols in providing decision support. Details regarding these training initiatives in decision

support and other resources can be found at <http://decisionaid.ohri.ca/training.html>.

#### *Usability for diverse patients*

In Graham *et al.*'s study, several doctors felt that the ptDA was not appropriate (27%) and/or too complex (19%) for some groups of patients and their use of the ptDA would depend on their patients' literacy levels, desire to be involved in decision making, motivation and health status (Graham *et al.* 2003). To date, there is no evidence on the assessment of readability of ptDAs and their suitability for particular audiences; however, most of the 131 ptDAs in the Cochrane review inventory were developed for general audiences such as grade eight reading level (O'Connor *et al.* 2004a). Future research is required on how ptDAs work to improve decision quality for people who vary by demographic characteristics (age, sex, education, ethnicity) and baseline decisional needs (stage of decision making, preference for participation in decision making) for better health outcomes (International Patient Decision Aid Standards Collaboration 2004).

## Organizational/system-related

### *Organizational culture and priorities*

The organizational culture, which is shaped and influenced by health care administrative leaders, can either hinder or facilitate the uptake of ptDAs. In our experience, the introduction of a tangible tool such as a ptDA may have policy implications, which often serve as a barrier in their implementation into the process of routine care. One approach to facilitate a shift in organization priorities is to mandate the use of a ptDA as a requirement for obtaining informed consent (Holmes-Rovner *et al.* 2000). Another possibility is to negotiate a guideline or develop a medical directive for the routine use of ptDAs as a quality indicator for the purposes of achieving higher funding or accreditation rates (Holmes-Rovner *et al.* 2000).

The realignment of organizational priorities in order to implement the use of a ptDA most often requires facilitation from an opinion leader or champion. For example, in the 2004 Improvement Plan of the UK National Health Service (Department of Health 2004), patients will have 'greater choice and shared decision making between patient and clinical team over treatment and care'. An implementation strategy to imbed ptDAs into the process of care is being evaluated as part of a urology initiative of the Modernization Agency. In four geographic regions, patients facing treatment options for prostate cancer and benign prostatic hypertrophy are receiving ptDAs and follow-up coaching by urology nurses trained in decision support as part of routine care.

### *User's workflow*

Structural barriers such as failing to fit into the general practice context (Holmes-Rovner *et al.* 2000), scarcity of time (Elwyn *et al.* 1999; Holmes-Rovner *et al.* 2000; O'Cathain *et al.* 2002; Graham *et al.* 2003; Edwards & Elwyn 2004) and pre-existing clinical care processes (Holmes-Rovner *et al.* 2000) have all been cited as barriers in the uptake and/or the appropriate timing of ptDA administration into the process of routine care. In order to overcome these structural barriers, consideration may need to be given to expanding existing or alternative educational and/or decision support models. There is no single accepted model for how the decision support

process should unfold; however, it is important to explore care pathways to determine moments in care in which decision support may be helpful. O'Connor *et al.* have identified three models for implementing ptDA into clinical practice. These include: (i) *free-standing models*, for example, web resources or BCNurseLine; (ii) *clinic- or hospital-based models*, for example NHS Urology initiative and; (iii) *insurance-centred models*, for example call centres such as Health Dialog (O'Connor *et al.* 2004b). Regardless of the model, it should be tailored to ensure that the timing of administration of the ptDA adequately prepares patients for the practitioner-patient counselling session (Holmes-Rovner *et al.* 2000). Currently, evaluations of these models for implementing ptDAs into clinical care settings are underway.

### *Accessibility*

Practitioner access to ptDAs has also been identified as a structural barrier in ptDA uptake and, in order to ensure widespread use of ptDAs, it has been recommended that their access be made easy (Graham *et al.* 2003). The availability of ptDAs is expanding as a result of the web. Of the 131 ptDAs identified as being available and updated within the last 5 years in the Cochrane Review of ptDAs, 73% were web-accessible only (O'Connor *et al.* 2004a). Web-based ptDAs have many advantages including increased availability, decreased costs, ease of updating and improved access either within patients' homes, public libraries or practitioners' offices (Deco 2000). While the web may prove to be a practical medium of delivery (Edwards *et al.* 2003), not all patients have the skills or access to the computer resources required; therefore downloadable versions of materials are needed for those providing information to patients using other media. Since the most recent review of trials of ptDAs did not use web-based platforms, this delivery medium needs to be evaluated (Edwards *et al.* 2003).

Databases of ptDAs have been made available to the public by several academic institutions that specialize in shared medical decision making via the web. The Cochrane Collaboration Systematic Review Team created two databases of ptDAs. One contains a global inventory of over 500 ptDAs at various stages of development (<http://decisionaid>).

ohri.ca/cochinvent.php), whereas the other is an A–Z Global Inventory of available and evaluated ptDAs using the CREDIBLE criteria with links to their authors (<http://decisionaid.ohri.ca/AZinvent.php>). The *British Medical Journal* introduced the online Evidence-Based Rheumatology text book, part of their Clinical Evidence series, containing ptDAs and consumer summaries that can be downloaded (<http://www.blackwellpublishing.com/medicine/bmj/rheumatology/decaids.asp>).

#### *Promoters of products/services may strongly resist*

If patients end up choosing less aggressive treatment as a result of informed choice (Man-Son-Hing *et al.* 2000; Kennedy *et al.* 2002) negative financial implications for device manufacturers, pharmaceutical suppliers or surgeons could ensue. On the other hand, in situations where the utilization rates of such services or products are low, the use of a ptDA could actually increase use. While the majority of promoters of services or products would likely agree with the appropriate usage of ptDAs, criticisms from those whose utilization may be affected by well-developed ptDAs could become a barrier to ptDA development and/or uptake (Deyo 2000). In order to avoid any potentially impeding influences regarding the uptake of well-constructed ptDA (or the uptake of poorly constructed, biased ptDAs) health care accreditation teams need to endorse the use of ptDAs that are balanced in their presentation of the options and reflect the best available medical evidence (Deyo 2000).

#### *Costs*

The lack of infrastructure to cover the costs of purchasing ptDAs and to finance their distribution, that is, ordering, storing and tracking the ptDAs were perceived by doctors to be a barrier in their uptake (Graham *et al.* 2003). Furthermore, concerns have been expressed about the costs associated with developing and maintaining ptDAs and whether their benefits are important enough to warrant the financial backing (Deyo 2000; Estabrooks *et al.* 2001). One solution to overcome users' costs would be to reimburse practitioners or clinics/hospitals for providing decision support services (O'Connor *et al.* 2004b); however, to justify costs from a health care perspective, evaluations of the overall cost and benefits must be conducted.

To date, the evidence suggests that the use of ptDA reduce rates of major elective surgery by 24% without unfavourable effects on health outcomes or satisfaction (O'Connor *et al.* 2004a). Knowledge that ptDA may result in an overall reduction in demand for more invasive procedures, which ultimately may reduce workload, waiting lists and/or costs could motivate health care professionals, administrators and organizations to use them (O'Connor *et al.* 1999; O'Cathain & Thomas 2004). However, in areas where more intensive procedures are not offered routinely or have a very low rate of use, ptDAs may lead to informed choices that increase their rate of use (O'Connor *et al.* 2004b). Despite this, health care 'resources saved by preventing unwarranted overuse of one option could be used to rectify inappropriate under use of another' (O'Connor *et al.* 2004b).

A landmark randomized control trial by Kennedy *et al.* (2002) evaluated the effects and costs implications of three different interventions: ptDA, ptDA in addition to counselling versus usual care in women with uncomplicated menorrhagia. Results demonstrated that hysterectomy rates and mean costs were significantly lower for women who received the ptDA as well as counselling when compared to those who received the ptDA only and those who received usual care. Neither intervention had an effect on health status (Man-Son-Hing *et al.* 2000; Kennedy *et al.* 2002). However, further confirmation of the cost-effectiveness of providing systematic decision support for other preference-sensitive decisions is warranted. Future economic evaluations should be both population-based and include incentives to determine the overall balance of cost and benefit of ptDA within the health care system (O'Connor *et al.* 2004b).

#### **Conclusion**

In summary, the majority of the work to date has involved the development and evaluation of ptDAs; however, less attention has been paid to the barriers and facilitators associated with their implementation into the process of care within clinical practice. The success in implementing ptDAs into the process of care hinges on many factors including the attributes of the ptDAs itself, the practitioners and patients who use them and the practice environment in which

they are used. In order to help health care professionals and administrators overcome the barriers associated with the widespread uptake of ptDAs, an evidence-based implementation strategy is warranted. Future research is required to develop and evaluate strategies that aim to facilitate the implementation of ptDAs into the process of care. Ongoing collaboration between researchers in the field of ptDA development, implementation and evaluation, and researchers in the field of knowledge transfer, such as through the Canadian Institute of Health Research's Group Grant held by this joint Ottawa team is a step in that direction.

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