



## Health innovations in patient decision support: Bridging the gaps and challenges

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### REVIEW

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### Abstract

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Patient decision aids (PDAs) help to support patients in making an informed and value-based decision. Despite advancement in decision support technologies over the past 30 years, most PDAs are still inaccessible and few address individual needs. Health innovation may provide a solution to bridge these gaps. Information and computer technology provide a platform to incorporate individual profiles and needs into PDAs, making the decision support more personalised. Health innovation may enhance accessibility by using mobile, tablet and Internet technologies; make risk communication more interactive; and identify patient values more effectively. In addition, using databases to capture patient data and the usage of PDAs can help: developers to improve PDAs' design; clinicians to facilitate the decision-making process more effectively; and policy makers to make shared decision making more feasible and cost-effective. Health innovation may hold the key to advancing PDAs by creating a more personalised and effective decision support tool for patients making healthcare decisions.

#### Key Words

Patient decision aids; shared decision making; health innovation

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#### Introduction:

Expanding research evidence has made the practice of evidence-based medicine more challenging.<sup>1</sup> When making a

healthcare decision, patients, often guided by their clinicians, need to weigh the pros and cons of each option while considering their personal values.<sup>1</sup> This is a challenging task because patients need to acquire and understand the health information provided while clinicians need to be updated regularly with accurate information and communicate it to the patients in an unbiased manner. The decision-making process becomes even more complex when there is no single best option or when decisions are based on a patient's own preference (e.g., early breast or prostate cancer, insulin therapy).<sup>2-4</sup>

Over the past three decades, clinicians and researchers have started developing tools and interventions to improve patient decision quality and outcomes. Currently, the main decision support interventions include: (1) training clinicians to support patients in decision making; (2) decision coaching; and (3) patient decision aids (PDAs).<sup>5,6</sup> Among these, PDAs are the most well studied and found to be effective in: improving patient decision quality such as increasing knowledge and accurate risk perception; reducing decisional conflict; increasing participation in decision making; and helping patients to make a choice that is consistent with their own values.<sup>7</sup>

#### Patient decision aids: Historical perspective

PDAs are evidence-based tools designed to help patients participate in making specific and deliberated choices among healthcare options.<sup>7,8</sup> A PDA contains information on the healthcare options available as well as the risks and benefits of each option. It also helps to clarify patient values (what is important to the patient) and guide them systematically through the decision making process. The International Patient Decision Aids Standards (IPDAS) identify key components and standards of a high quality patient decision aid.<sup>8</sup>

In this review, we tracked the development of PDAs by extracting information from the 86 studies included in the recently updated Cochrane Review on the effectiveness of decision aids.<sup>7</sup> We limited the PDAs review to those published in the Cochrane Review because they have



been subjected to rigorous appraisal and are deemed to be of high quality.

Over the span of 26 years (1983-2009), PDAs have evolved from simple decision support tools to more complex ones. The format of the PDAs expanded from using pamphlets (1983), interactive multimedia (1995), script of option outcomes (1996), education and counselling on option outcomes (1997), audiotapes (1997), videos (1998), booklets (2000), CD-ROM (2001), computer programmes (2002), decision boards (2003), to internet (2007). Despite the advancements in the development of PDAs over the years, the challenge remains how to develop a decision support tool that suits individual needs. When choosing a PDA, it is important to consider the patient's age, gender, ethnicity, language, and cultural and education background.<sup>9</sup> Few PDAs take into consideration these factors and they are limited by the format of the PDA. There are, therefore, opportunities for health innovations to provide decision support according to individual clinical profile and needs.

## Potential areas for health innovation in patient decision support

### Use of information and computer technology (ICT)

There is an increasing number of web-based PDAs developed worldwide.<sup>7,10</sup> Web-based PDAs are easier and cheaper to update compared to other types of PDAs such as booklets or videos. However, the Internet may not be readily available in some parts of the world and not all users have access to computers. Mobile telephone technology is a possible solution to this problem as it is widely used even in underdeveloped or developing countries.<sup>11</sup> Mobile applications can be downloaded with minimal cost or for free and are, therefore, more accessible to target users.

PDAs are tools meant to supplement, not replace, clinical consultations. Computers, mobile telephone, and tablets are readily available tools that can be used by both patients and clinicians to discuss the options and decisions within or outside the consultations. There are concerns that this may marginalise older people who may not be IT-savvy. However, there is increasing evidence to suggest that older people are not averse to technology;<sup>12</sup> the use of the Internet among the elderly has increased in recent years and older patients who are making decisions about their chronic illnesses may benefit from PDA innovations using the latest technology.

In addition, the use of ICT can make patient decision making more interactive. The use of animation, videos, audio-visual aids, and personalised options allow patients, especially those with a lower education level, to be more engaged in the decision-making process. The amount of information

presented to the patient can be presented in stages or controlled by users to avoid information overload. The use of navigation function allows users to select information that is relevant to them. Moreover, developers can create mandatory fields to ensure that users read and understand key information provided in the PDA.

### Risk communication

One important function of a PDA is to present risks and benefits of each healthcare option to patients in an unbiased manner. Currently, PDA developers use numbers, texts, and pictures (e.g. 'smileys') to communicate risks to patients.<sup>8</sup> However, recent studies have found that users may not be interested in the figures presented, probably because they have difficulty understanding the information or they feel that the risks and benefits may not be applicable to them.<sup>13</sup> Using ICT, patients' clinical information can be incorporated into PDAs and used to assess their clinical risks. This will more accurately predict the risks and benefits of choosing each of the treatment options. Using interactive audio-visual presentation, complex information, including statistics, could be made simpler and clearer to users, particularly for those with a lower education level.<sup>14</sup>

### Value clarification

Value clarification is a unique and important feature of a PDA and this differentiates itself from health education materials.<sup>15</sup> Value clarification exercises help patients to express what is important to them when making a decision. Clinicians should be aware of patients' concerns and priorities in order to guide them to make a decision that aligns with their preference. Value-based decisions are more likely to be followed through.<sup>8</sup> So far, value clarification exercises in PDAs have used a 'weighing scale' approach where patients weigh the pros and cons of the treatment options by indicating their level of preference.<sup>16</sup> These exercises become more complex when there are more than two options to choose from and/or there are multiple risks and benefits in each option. The use of ICT may help to simplify the value clarification process by allowing patients to select their preferred options; identifying the risks and benefits that are important to them; and visualising the significance of these options and their attributes.

For patients to make an informed decision, they should be able to forecast what they are likely to experience if they were to choose a particular option.<sup>17</sup> To achieve this, PDAs can use videos or animation to present personal stories about the pros and cons of each treatment option.



By imagining 'what life would be like' living with the choice, patients are more likely to adhere to the treatment and less likely to regret their decision.

### Language and culture

In a multilingual, multicultural society, it is crucial to develop a decision support tool in different languages and tailor it according to different cultural contexts. Previous studies have found that patients and clinicians tend to perceive 'imported' PDAs as irrelevant to their needs.<sup>18</sup> Therefore, PDAs that are sensitive to patients' preferred language and culture are more acceptable and, hence, more likely to be used by patients and their clinicians. This can be achieved more easily by using health innovations, for example, by presenting the information in different languages and using culturally sensitive texts and visual aids.

### Database on decision-making process

While using a patient decision aid, individual patient data can be captured using ICT. These data are important in helping clinicians and researchers to understand how patients make decisions. For instance, we can identify the pattern in decision making by documenting: the web pages that patients browse; the time users spend on each page; which options they prefer; what their concerns and priorities are; their readiness to making a decision; and their preferred choice. These data could then be summarised and reviewed by: (1) patients to facilitate discussion with their clinician or family about their decision; (2) clinicians to better understand and address patients' concerns and, hence, make the consultation more effective; (3) researchers to improve the design of the PDA; and (4) policy makers to devise cost-effective strategies to promote shared decision making.

### PDA clearinghouse

Currently, the most comprehensive PDA inventory that collects and classifies PDAs is the Decision Aid Library Inventory (DALI) (Canada) which archives more than 300 PDAs.<sup>19</sup> Other independent organisations, such as Healthwise (USA),<sup>20</sup> Health Dialog (USA),<sup>21</sup> Foundation for Informed Decision Making (USA)<sup>22</sup> and National Health Service (UK),<sup>23</sup> also produce and disseminate PDAs developed by its own institution. However, the registration of PDAs are entirely voluntary or institution-based and there is no systematic approach to capture PDAs that are available or under development worldwide. As a result, there are significant overlaps in the development of PDAs. For instance, there are currently 10 PDAs on prostate cancer treatment registered with DALI, some from the same country; this has resulted in duplication of work and wastage of time and resources. Therefore, a web-based PDA clearinghouse that coordinates the collection, appraisal and dissemination of PDAs would

help to make PDAs more accessible to developers, clinicians and, more importantly, patients.

### Opportunities and challenges in PDA health innovations

Despite the significant advancement in decision support technologies in the past 30 years, there are still significant gaps in finding effective ways to support individual patients in making informed healthcare decisions. Health innovation may form part of the solutions to bridge these gaps. Potentially, health innovations using ICT can save costs in terms of cutting down printing and reprinting as regular updates are necessary with rapidly emerging clinical evidence. Current PDAs lack flexibility in terms of personalisation of data, interactiveness and accessibility. The use of ICT can overcome these limitations by capturing individual clinical data, transforming them into interactive risk communication tools, and offering language and format that patients prefer.

However, the development and implementation of health innovations have their own limitations. Firstly, it requires ICT experts and infrastructure, which may not be readily available or affordable in some countries. Secondly, users, including patients and clinicians, need training on how to use the PDA, particularly if it involves complex navigation through the web site and if users are not IT-savvy. Thirdly, ICT has inherent security issues and this requires careful planning as confidential patient data are collected, stored, and used by different stakeholders. Fourthly, as with all innovations, the stakeholders may resist the diffusion of new technologies such as decision support tools. Finally, health innovation is a means to an end: patient decision aids should not replace face-to-face interaction with a clinician, particularly when making complex decisions. Guidance by the clinicians, supplemented by a patient decision aid, will help patients to make a more informed and value-based decision.

### Conclusion

Supporting patients in decision making is an important part of patient-centred care. This can be achieved by using decision support tools to assist clinicians in their busy practice. Using health innovations, rapidly changing evidence can be incorporated into the decision support tool; patients can learn about their illness and treatment options more interactively; and they can express their personal values and clinical risks to the clinicians more directly. Individual data can then be collated using ICT to improve design of PDA and understand the patient decision-making process. This may be the key to developing more personalised and cost-effective decision



support tools that could improve patients' decision-making experience and outcome.

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## PEER REVIEW

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### **CONFLICTS OF INTEREST**

The authors declare that they have no competing interests.