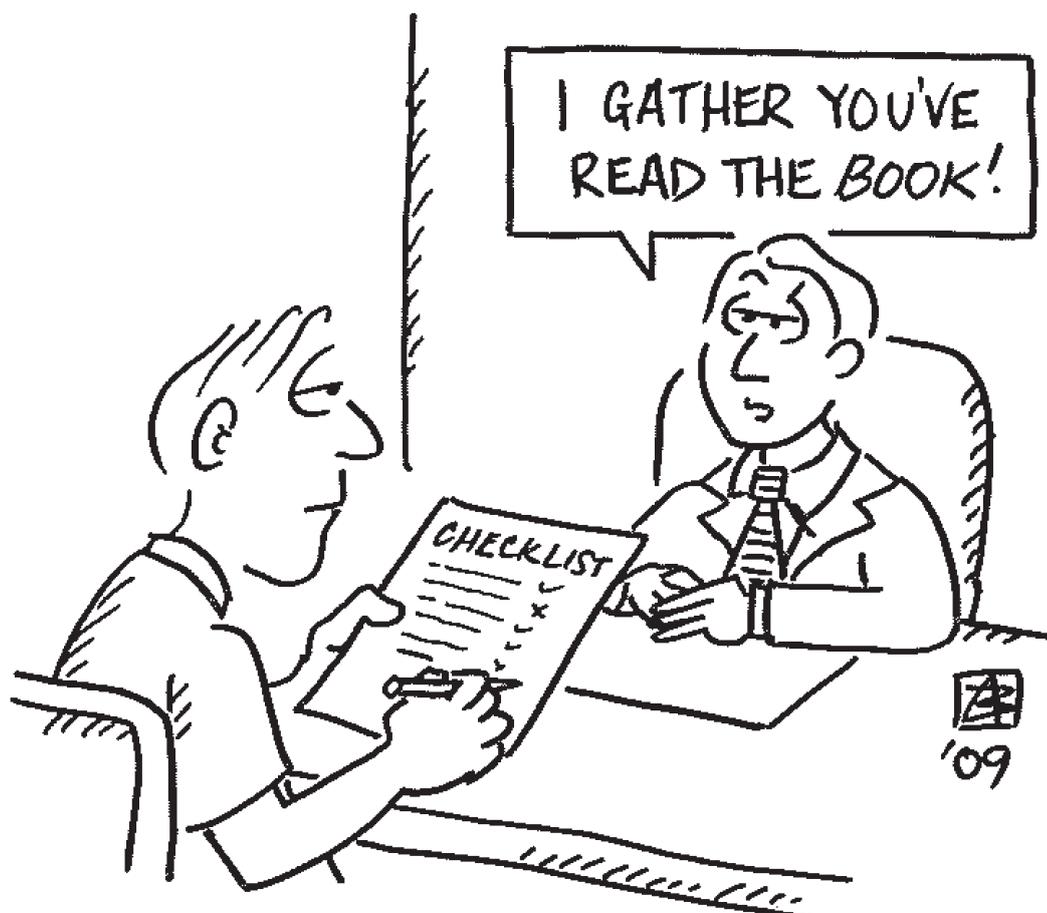




# Western Australia Health Consumers' Council: Patient First Ambassador Project

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**The Patient First Ambassador project is a unique initiative that encourages health consumers in Western Australia (WA) to become more informed and involved in their health care and management, with the potential to reduce health-related errors in the health system and result in less anxiety and stress, a quicker recovery time and less cost. The project, now in its second year, has volunteer consumers distribute the Patient First booklet directly to health consumers.**



The concept of using a Patient First Ambassador (volunteer), who is dedicated to the rights of the health consumer, is unique. The author and members of the Western Australia Health Consumers' Council believe that, in this context, the idea of a consumer talking to another consumer is a powerful tool; a volunteer ambassador, who is not affiliated with the hospital or health department, identifies themselves with the health consumer and is therefore able to discuss the topics in the Patient First booklet in a non-threatening manner. Most volunteer ambassadors are current health consumers.

The results of this project, after six months, demonstrated that health consumers readily accepted information that would empower them to become more proactive in the management

and treatment of their health. As well, with this information, consumers appeared more confident to ask appropriate questions and seek more information. The initiative to increase consumer understanding of a health condition, allow better decision-making through informed consent, and increase awareness of the risks inherent in health care, has the potential to have a significant impact on the reduction of preventable adverse events in health care in Western Australia. An additional aim of the Patient First Ambassador project is to increase health literacy and the ability to self-manage health conditions. The latter being factors included in the Federal Health Minister, Nicola Roxon's, discussion paper on Australia's National Primary Health Care Strategy.

## Background

In March 2002, the US Joint Commission for Accredited Healthcare Organizations (JCAHO), together with the Centres for Medicare and Medicaid Services, USA, launched a national campaign to urge patients to take a role in preventing health care errors by becoming active, involved and informed participants on the health care team. One of the initiatives developed to advance this agenda was the Speak Up initiative. In February 2008, Myrl Weinberg, President of the International Alliance of Patients' Organizations (IAPO), stated that:

*[T]o meet patients' needs, decisions that affect a patient's healthcare should not be taken without the full involvement of the patient at all levels of care, whether that be in the choosing of treatment options, developing healthcare policy or designing healthcare systems.*

Based on the Speak Up initiative, the Western Australian Council of Safety and Quality in Health Care developed the Western Australia Strategic Plan for Safety and Quality in Health Care 2003–2008 (2003). A core strategy of the plan is a commitment to engage consumers as partners at all levels of health care.

In November 2005, as part of this commitment to enhancing consumer participation, the Western Australia Council for Safety and Quality in Health Care, in partnership with the Health Consumers' Council of Western Australia, developed the Patient First Ambassador project for consumers in the Western Australia health system. This was done in consultation with and the involvement of consumers in each step of the way. A Patient First booklet, based on the Western Australia Charter of Patients Rights and Responsibilities, was published.

The challenge of promoting, distributing and discussing the Patient First resource appeared insurmountable, until the possibility of Patient First Ambassadors (volunteers) was raised by the Health Consumers' Council Western Australia. The project commenced at Sir Charles Gairdner Hospital, Perth, in November, 2007. The Health Consumers' Council of Western Australia accepted responsibility for the recruitment, training, placement and support of the Patient First Ambassadors for the length of this project.

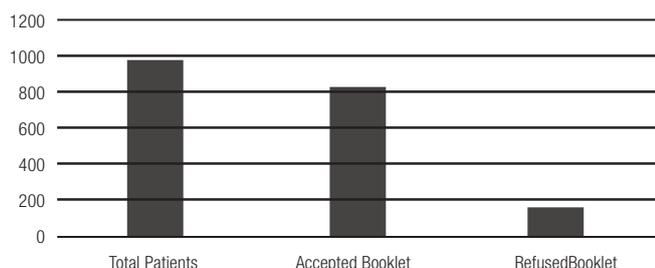
## Method

Eleven members of the Health Consumers' Council become ambassadors for this project. Two training days were offered. These covered the role of the ambassador and the topics in the Patient First booklet, using relevant scenarios and role-play to familiarise volunteers with the booklet. An orientation day was conducted at Sir Charles Gairdner Hospital before the sessions started in the Outpatients Departments. The Patient First Ambassadors, wearing distinctive corporate livery, were rostered to cover the Outpatient clinics at Sir Charles Gairdner Hospital, with each session lasting three hours and each volunteer usually allocated two sessions per month. A collection data form was developed to record comments made by the consumers.

## Results

Over the six-month project a total of 978 outpatients were approached at 66 sessions. Eight hundred and twenty-four patients received at least one Patient First booklet over the six-month project, with several patients taking more than one. One hundred and fifty-four patients refused to accept a booklet; the most common reason being that they had already received one or had read one previously.

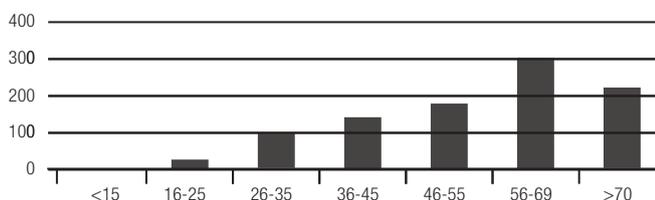
Figure 1: Total patients who accepted or refused the booklet



There were 764 comments from the patients recorded by ambassadors on the collection data form. Comments ranged from identifying those outpatients who were interested in the booklet, those who made very positive comments about the usefulness or helpfulness of the information, to comments about the reasons the booklet was refused.

The majority of the patients participating were within the range of 56 to 69 years old. The aged distribution is shown below.

Figure 2: Patients by age range



It was notable that female patients (421) almost doubled male patients (284) receiving the booklet. It is interesting also to note that 220 couples received the booklet. The inclusion of 'couples' as a separate item was necessary as often both displayed an interest in the Patient First booklet

## Discussion

The majority of outpatients approached were very interested in the information contained in the Patient First booklet. The most discussed issues were informed consent, making decisions, risks, medications, and privacy. As evidenced by the comments collected, many patients feel that they are not given enough information about their management, treatment, and care. For example, one patient noted that he was not told about a complication he was currently experiencing before consenting to the treatment, and an 85-year-old patient did not feel listened to by the medical staff. For many, asking for more detailed information was not an option they believed was available to

them, until it was pointed out in the relevant section of the Patient First booklet. Many commented that having a better understanding of their rights as a health consumer would enable them to ask for more detailed information about health issues.

The majority of patients who accepted a booklet thought that the booklet was interesting and would be useful and/or helpful to them in the future. Evidence for this was cited in comments such as the following, provided by an ambassador: “the patient thought reading it would be useful before agreeing to major back surgery”, or “patient was concerned about going blind after recommended procedure and would be encouraged to ask for more information”, and “patient who was not informed about potential complication of surgery will now be more vocal about asking for information in the future”. Many comments highlighted the fact that had the patients received the information previously, problems may not have occurred. It was notable that had several patients been aware of the information in the booklet before they agreed to their procedure and /or treatment, they would not have agreed or would have approached their health management and /or treatment differently. For example, the patient who said the Patient First booklet would have been very useful to her if she had had it before her surgery—as she had many issues post-operatively—or the patient who had some bad experiences in hospital, would have liked to have received this resource earlier.

Very few negative comments were made by outpatients over the six months. These related mostly to the scarcity of resources in the health sector and the wisdom of using them on this booklet. Very few outpatients refused the booklet. Those who refused cited already reviewing the booklet or had received it as an inpatient as the reason for refusing. It is notable that many of the patients who had previewed the booklet commented that it led them to alter their behaviour in regard to involvement in their own management and care. For those who had not seen the booklet previously the following reasons were offered for their lack of interest: they were of the opinion that nothing will change in the health environment; patients did not have any rights; or they were quite confident to speak up already; some were non-English speaking.

As expected, the majority of patients approached were in the 56 to 70+ year age group (N= 520), with the smallest group younger than 25 years (N= 35). This is significant, as the older age group is the largest health consumer group that traditionally appears less inclined to take an active role in their health management and care. Therefore, this project successfully targeted those health consumers who would benefit most from being encouraged to take a more proactive role in their own health care. The more these consumers are aware of the issues in the Patient First booklet, the more potential adverse events may be prevented. Many of the elderly consumers’ comments suggested they could not willingly challenge medical and nursing staff about their health care or treatment, and many consumers did not feel confident or were not aware that this was an option they had. When shown the relevant section addressing these issues in the booklet, many consumers took the booklet to

use this knowledge; a few suggested showing the medical practitioner the relevant information from the booklet.

It was notable that those health consumers in the younger age group mostly felt that they were well-informed and would not hesitate to ask for more information if required. Overall, they appeared to be more confident.

More women than men received the Patient First booklet; no doubt a reflection on the demographics of the study participants—older women predominate in the population at large.

Some groups offered unique challenges, such as the visually impaired consumer, consumers whose first language was not English, adolescent consumers, Indigenous consumers, and mental health consumers. Some of the needs of these groups are being addressed in the continuing project.

## Conclusion

The six-month Patient First Ambassador project was successful, as evidenced by the number of health consumers approached and the number of Patient First booklets distributed and the positive comments received. Each ambassador was usually well-received by the consumer and useful discussion and information was passed on in the form of the booklet. Therefore, it appears there is a need to develop the health consumers’ awareness of this type of information and to encourage them to become more proactive in their health management, treatment, and care.

The Patient First information needs to be made available to all public and private health consumers. Other hospitals in WA have already expressed an interest in this project and Sir Charles Gairdner Hospital reported that the project was considered very successful; other departments within the hospital could be used to distribute the information to the health consumer. Methods of distributing the information are under review, such as using existing hospital staff and/or volunteers, Community Advisory Councils or utilising other interest groups. Other possible strategies include the development of a standard curriculum for the training of Patient First Ambassadors to support these groups and the development of a package on the Patient First concept to offer to interested parties.

The Patient First Ambassador project has shown, as evidenced by the numbers who received a booklet and the comments given, that health consumers do have an interest in ensuring the health system delivers the safest and highest quality health care possible, with the rights of consumers to participate and make choices about their own health care paramount.

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