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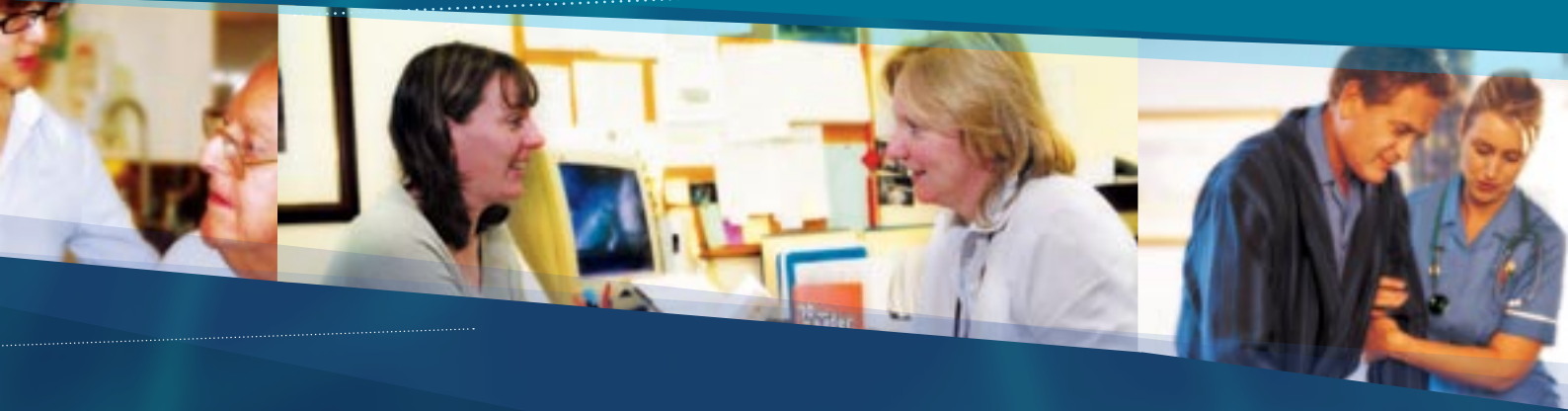
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Australian Council for Safety and Quality in Health Care

Partnerships for Health in Action: Promoting Consumer
and Community Involvement in Health Care Improvement



July 2005



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Acknowledgements

The Australian Council for Safety and Quality in Health Care (Council) acknowledge the efforts of all consumers involved in the Council's program of work and in improving patient safety more broadly. The Council thank the significant contribution made by its Consumer Advisory Committee, particularly Betty Johnson and Kate Moore, in their work in developing this paper.

The Council is also grateful to the people who agreed to have their stories presented in the case studies, which are published with their permission.

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ISBN: 0 642 82691 9

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The Australian Council for Safety and Quality in Health Care was established in January 2000 by the Australian Government Health Minister with the support of all Australian Health Ministers to lead national efforts to improve the safety and quality of health care, with a particular focus on minimising the likelihood and effects of error. The Council reports annually to Health Ministers.

Copies of this report can be found at www.safetyandquality.org or by contacting the Office of the Safety and Quality Council on telephone: +61 2 6289 4244 or email to: safetyandquality@health.gov.au.

Publication approval number: 3659 (JN9038)

Table of contents

<i>Introduction</i>	2
<i>Message from the Chair of the Council's Consumer Advisory Committee, Betty Johnson, AO</i>	3
<i>Council's Engagement with Consumers</i>	4
<i>Safety Innovations in Practice - Small Projects, Large Gains</i>	6
Dream, Believe, Achieve – stroke survivors getting their lives back on track	8
Patients Educating Clinicians – a new paradigm for reducing adverse medical events	9
Health Care Consumers – tapping our most valuable resource	9
<i>Better Communication for Safer Systems</i>	10
10 tips for safer health care - what everyone needs to know	10
Better Complaints Management – assisting health services translate complaints into better practice	11
Open Disclosure – health services in open and honest communication	13
<i>Making Medicines Safer</i>	14
When things go wrong with medicines – the Adverse Medicine Events line	14
Safer use of medicines – using the Breakthrough Collaborative approach	17
Clear labelling of medications	17
Informing and empowering consumers for safe use of medicines	18
POPPIES – preventing opioid problems by providing information to enhance safety	18
Medication Safety Innovation Awards Program – encouraging innovative solutions in a diversity of treatment settings	19
<i>Working with Indigenous Communities</i>	20
Safer use of medicines in Aboriginal communities	20
Falls Indigenous Storyboard – a resource for Indigenous people	20
<i>Keeping Consumers Informed and Involved</i>	21
Scholarships for health consumers	21
Consumer Update – a newsletter for consumers	22
Consumer Advisory Committee	22

Introduction

The Australian Council for Safety and Quality in Health Care (Council) was set up in 2000 by the Australian Government Health Minister with support of all Health Ministers.

Ministers recognised that access to safe, quality care is a priority for Australians. Ministers approved a terms of reference for Council to lead national efforts to promote systemic improvements in safety and quality in health care by working collaboratively with consumers, hospital administrators, government representatives, academic experts and international leaders, to achieve real change in our hospital systems and practices.

Council quickly identified that system change requires leadership in sensitive and complex areas such as disclosure and reporting when things go wrong with health care. Furthermore, it was recognised that strategies need to be in place to make improvements and involve patients in their own care.

The Council's focus over this period has been in the following areas:

- Supporting the workforce;
- Measurement for improvement (collecting and reporting data);
- Working with consumers;
- Improving clinical practice for safer care;
- Redesigning our systems and IT;
- Building awareness;
- Increasing effective governance; and
- Strategic partnerships and future directions.

Consumers, the health workforce and other stakeholders have been partners in this work.

To assist this process Council has relied on advice from a range of working groups and expert advisory bodies to oversee its initiatives and ensure that they are effective and sustainable.

Indeed Council sees a lasting achievement as the engagement of all stakeholders in working together to make achievements in safety and quality and consumers have played a key role in this.

The Council's Consumer Advisory Committee was set up in 2004 to replace the previously operating Consumer Reference Network and Consumer Working Group, to support the Council Consumer Representatives in their role on Council.

The purpose of this report is to highlight some of the achievements of Council's collaboration with consumers and to showcase the powerful role that consumer engagement can play in the health sector.

Message from the Chair of the Council's Consumer Advisory Committee, Betty Johnson, AO

Consumers *can* make a difference – but they need to be involved. Since Jane Phelan and I began working as part of Council in 2000, this principle has stood behind our work. And in that time, consumers have done much to further Council's aim to enhancing patient safety.

This has been achieved not only by consumers actively participating in their own health care, but through their effective participation in policy and planning for health services. In working with my colleagues on Council, the Consumer Reference Network, the Consumer Working Group and now the Consumer Advisory Committee, we have seen this demonstrated very clearly.

From a consumer perspective, I have seen the development of Council products and services such as the *10 Tips for Safer Health Care*, the *Open Disclosure Standard*, the *Better Practice Guidelines for Complaints Management* and the *Consumer Adverse Medicine Events Line*, all of which have a direct impact on the experience of health care consumers. Other current Council initiatives, such as the *National Patient Safety Education Framework* and the *National Falls Guidelines*, are also influencing the safety of the health care environment.

Consumers have been substantially involved in all these initiatives. Indeed, their very success rests on their ability to meet the needs of consumers – as defined by consumers.

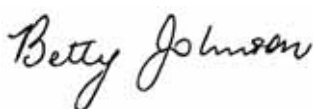
We know that the most critical success factors for involving consumers in patient safety are:

- a health care policy and delivery environment that is open and welcoming to consumers' participation, knowledge and views;
- a culture that supports open and honest communication, and belief in the importance of a two-way partnership between consumers and health care practitioners;
- a respectful relationship between providers and consumers, including acknowledged respect not only for the skills of health practitioners, but also for consumers' knowledge and perspectives; and
- consumer and provider understanding of how the health care system works and how it can work better.

The role of consumers on Council has been to identify mechanisms to create and support these success factors, and to integrate these mechanisms in daily practice in health care settings. This paper describes just some examples.

As a health care consumer, I am always grateful to the health professionals who devote their working lives to minister to others' needs in the health system. Our role is to work in partnership with health professionals to minimise harm from mistakes. However we know, not only from research but also from our own experience as humans, that it is impossible for mistakes *not* to be made in a complex system.

As the complexity of the health system continues to increase, the role of consumers in patient safety and improving the quality of health care will become even more important. It is clear from the success stories in this paper that both consumers and health professionals are up to this challenge.



Betty Johnson AO

Chair, Consumer Advisory Committee

Council's engagement with consumers

Council's vision for a safer health care system places consumers at the centre of that system; it harnesses the experiences of patients and their carers to drive improvement. To this end, Council's strategic work plan has articulated the aim in its third objective: *to promote consumer and community involvement in improvements in care.*

The involvement of consumers in Council's own work has been critical to achieving this. Council has developed projects and strategies to involve consumers in both improving the safety of their own care, and improving the policies, systems and practices that make health care safer for everyone.

Consumers have been involved in Council's activities:

- the [Consumer Working Group](#) in operation from 2000 to 2004 provided expert advice to Council on its specific consumer-oriented initiatives and more broadly;
- the [Consumer Reference Network](#) in operation from 2001 to 2004 involved a number of consumer organisations and individual consumer advocates providing advice to Council as needed;
- the Council sponsored a [national forum of consumers and workshop](#) (in 2001), which was a critical step in the process of developing a vision for consumers' role in a safer health care system;
- a Council-commissioned [review](#) (in 2002) [of the Consumer Reference Network](#);
- the Council sponsored consultation in 2003, conducted by the [Consumers' Health Forum of Australia](#) who consulted with consumer groups on how consumers could more effectively contribute to the work of Council;
- a [workshop with members of the Consumer Working Group and the Consumer Reference Network](#), in 2004, to determine the most effective way for Council to receive advice from consumers. The workshop advised the Council to replace the Consumer Working Group and the Consumer Reference Network with a single consumer advisory mechanism;
- the establishment of the [Consumer Advisory Committee](#) in 2004 as a result of the above advice; and
- the appointment of a [specialist Consumer Consultant](#) in 2004, to liaise with consumer organisations and to advise Council on issues of importance to consumers.

Consumer representatives are also included on Council committees and working groups. Currently, there are 15 consumers involved on 10 committees.

Consumers have thus had a significant influence on Council's work program and their advice has been the origin of many of Council's projects; for example:

- the *Open Disclosure Standard: A National Standard for Open Communication in Public and Private Hospitals, Following an Adverse Event in Health Care* – which was produced together with educational materials, to support greater openness between health professionals/providers and patients/carers when things go wrong;
- *10 tips for safer health care* – a booklet published and distributed by Council to encourage consumers to ask questions of their health care providers;
- the *Safety Innovations in Practice Program* – funding local projects that involve partnerships between consumers and providers, working to improve safety;
- *Turning Wrongs into Rights* – a project to improve the use of data from health care complaints;
- The piloting of the *Consumer Adverse Medicine Events Line* – commissioned by Council to encourage and enable consumers to report adverse events connected with medication use;
- *Charting the Safety and Quality of Health Care in Australia* – which brings together what is known about safety and quality in the Australian health care system;
- the *National Patient Safety Education Framework*;
- *The National Falls Guidelines* – for prevention of falls in older people in hospitals and residential aged care facilities; and
- scholarships to enable consumers to attend national and international conferences on safety and quality in health care.

This paper briefly describes some of Council's consumer projects in action.

Safety innovations in practice - small projects, large gains

Small, innovative changes can make powerful contributions to improving the quality and safety of health care. As Council's *Safety Innovations in Practice (SIIP) Program Mark II, Compendium of Project Reports, July 2004* show, the program makes clear that:

'Listening to consumers and their carers and empowering them to take the lead in their health care in partnership with care providers, leads to improvements in safety and quality of care'. (p.22)

'Taken together, the projects demonstrate the gains in both patient safety and quality of services that can be made by recognising that the experience of consumers and their perspectives differ from those of health professionals'. (p.22)

'Consumer needs took centre stage in many projects, with their perspectives often the catalyst for change'. (p.14)

'Consumers played a role in assisting change management where resistance to change by staff or organisational inertia were issues. Their positive feedback and improved outcomes were used to create momentum'. (p.14)

The SIIP program aims to encourage health care professionals to develop innovative and practical projects that will deliver demonstrated improvements in patient safety within their health care setting. The development, implementation, and evaluation of projects at a grassroots level ensures a 'hands-on' approach to patient safety, and encourages the exploration of 'good ideas' that could be implemented in other health care organisations. The program is now in its third phase, with two rounds of projects already funded by the Council in 2002 and 2003.

The SIIP program operates by the Council providing one-off grants for a limited number of projects throughout Australia that affect system improvements to enhance the safety of patient care. Altogether, the three rounds of SIIP have funded 176 projects which delivered innovations across seven categories: involving consumers, supporting health professionals to deliver safer care, systems redesign, using existing data and measurement to improve safe practice, safe staffing (the management of staffing variables to improve patient outcomes), health care associated infections (HCAI), and building on SIIP projects from previous rounds. The map on the next page illustrates a snapshot of consumer projects from all rounds of the SIIP program.

SIIP projects involving consumers

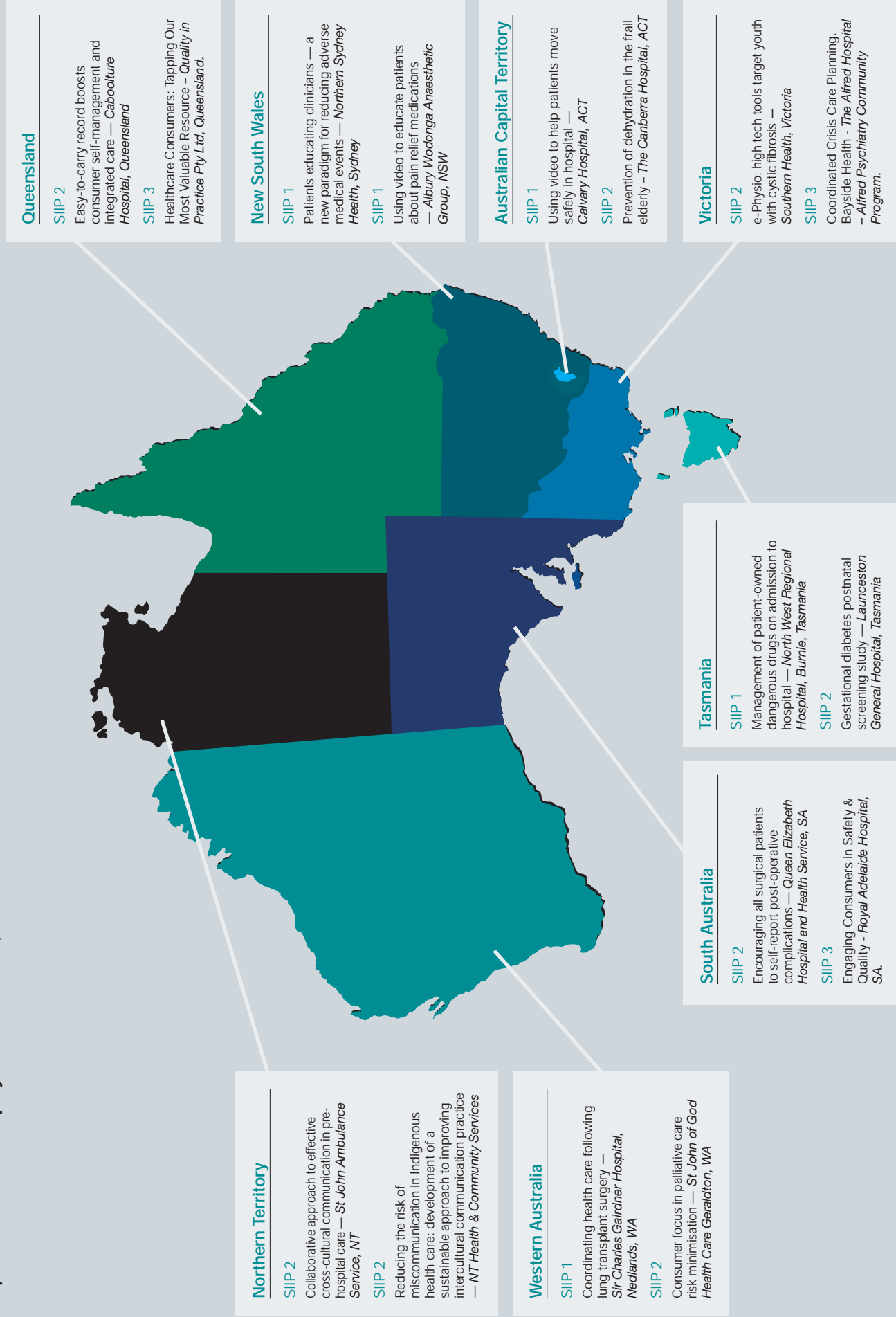
A total of 51 SIIP projects demonstrate innovations in areas of consumer involvement in health care as a means of improving patient safety in the following areas:

providing information

focus on projects to address specific health awareness issues (eg preventing dehydration in older people) or improve medication and treatment compliance (eg a hand-held client-specific discharge plan used by a hospital emergency department and information sessions on eastern and western medicine use).

Safety Innovations in Practice (SIIP)

Snapshot of consumer projects from SIIP 1, 2 and 3



involving consumers in continuity of their care

focus on projects that attempt to foster self-management strategies (eg a video series for chemotherapy patients and an education program for stroke survivors) or try to understand consumer perspectives in the management of specific chronic conditions (eg a study mapping consumer experience following gestational diabetes - *Gestational diabetes postnatal screening study*, and a CD-Rom/website strategy to improve physiotherapy compliance among young people with cystic fibrosis).

strengthening consumer involvement

focus on projects that use consumer experience as the focal point for developing strategies to improve health care delivery. Strategies include individualised and shared patient records (eg a diabetes care plan and risk minimisation protocols in a palliative care setting), encouraging a consumer role in reporting/managing health (eg bedside nursing handovers) and listening to consumer perspectives to determine how services could be improved (eg cross cultural guidelines for ambulance services to Indigenous Australians and safer, low cost transfer to home for patients following total hip replacement).

using consumer feedback to improve safety

focus on projects that explore these issues for example, through self-reporting of post-operative complications, and through changes to use of bedrails in order to reduce falls and increase patient mobility.

Poor communication or miscommunication between health providers and their clients is a recurring issue in the projects, particularly for culturally and linguistically diverse communities. The extent of miscommunication and the failure of each party to recognise that misunderstandings have occurred in their interaction have potentially dangerous consequences. Therefore, it is important that health providers and clients work together in the management of communication issues.

As a whole, the consumer-based SIIP projects demonstrate the gains in both patient safety and quality of services. These projects showed that it is important to recognise that the experience and perspectives of consumers differ from health professionals. Consumer satisfaction with their care and acknowledgement of consumer needs by their health carers appear to positively affect consumer perceptions of their care and potentially, the health care outcomes they achieve. Three specific SIIP projects, *Dream, Believe, Achieve*, *Patients Educating Clinicians*, and *Health Care Consumers* are outlined in more detail below.

Dream, Believe, Achieve – stroke survivors getting their lives back on track

Dream, Believe, Achieve, funded under SIIP 2, was based on work by two stroke survivors, John Norton and Peter Richardson. When these two men left hospital, they found that they had no 'road map' to help them live with their stroke's physical and emotional effects, and deal with its impact on their daily lives. They saw the need for a self-management program to help stroke survivors deal with the devastating impact a stroke can have on people's lives.

John and Peter live in Bendigo and worked in collaboration with the Bendigo Health Care Group in Victoria to refine their ideas and develop the program. Seed funding from the Council allowed them to pilot test it in 2003, and the excellent results of the Bendigo pilot attracted further funding from the Australian Government Department of Health and Ageing. The 'National Stroke Foundation Self Management Education Project' is now being conducted under the auspices of the National Stroke Foundation, who have employed John and Peter as Consumer Consultant Project Officers to the project.

The revised *Dream, Believe, Achieve*, which now includes a leader training program to teach health professionals and consumers how to deliver the program, is to be further tested in a larger pilot in Adelaide. It is expected that it will help stroke survivors develop practical strategies to get on with their lives, monitor their health in partnership with their health care providers, and enable the consumer to become the 'expert' in his or her long-term recovery.

Further information about the self management program can be found at www.strokefoundation.com.au.

Patients Educating Clinicians – a new paradigm for reducing adverse medical events

This project, which was run by Northern Sydney Health in New South Wales, was also funded under the SIIP 2 program and provided junior doctors with the opportunity to interact with patients who had experienced an adverse event, with the aim of increasing the doctors' understanding of the impact that these events have on patients.

This project used a three-hour education session to bring together junior medical officers and patients. The sessions were developed by a steering committee which included consumers who represented patients who had experienced an adverse event.

Patients were willing to speak about their traumatic experiences and showed great belief in the value and importance of the project. Many of them stated that participation in the project had helped them gain some closure to their experience.

The interaction between patients and doctors was considered very powerful for both parties. Some junior doctors were obviously moved by the experience and many expressed surprise that an adverse medical event could affect an entire family for many years.

Health care consumers – tapping our most valuable resource

Under this SIIP 3 project, run by a Queensland group – Quality in Practice – the proportion of general practices that engage consumers and use their experience and insights to improve patient safety is expected to increase.

Quality in Practice will work closely with consumers and general practitioners (GPs) on its *Consumer awareness campaign working party* – to develop ideas, scripting and production of an educational video. This video will promote the use of patient feedback and advise practices on how to use this information to improve safety and quality. The video will promote such messages as:

- the importance and benefits of engaging consumers as partners in their health care;
- examples of the difference that consumer/GP partnerships in health care can make for health outcomes; and
- techniques for gaining patient feedback such as surveys and consumer information sheets.

The video will be presented and distributed through a national workshop series in September 2005 which will target 1200 practices in the first instance. Interest in the video has also been expressed from outside the general practice sector by health services.

Better communication for safer systems

10 tips for safer health care - what everyone needs to know

10 tips for safer health care is a booklet produced by Council, for consumers, to help them to become more actively involved in their health care. It explains how and why things can go wrong, and how consumers can work in partnership with their health care professionals to get the best possible care. The booklet:

- gives 10 tips for improving health care, including questions to ask of health care professionals;
- outlines what people can expect from their health care professionals;
- lists some sources of information for finding out more about particular conditions and how to manage medicines; and
- explains what to do if people have concerns about their health care.



10 tips for safer health care available for patients at the Intensive Care Unit of the Calvary Hospital, Canberra

In April 2004 all Australian Health Ministers agreed that, by 2006, all health care consumers should be receiving *10 tips* at or before admission to hospital.

In most States and Territories the booklet is now given to patients in public hospitals, and some jurisdictions are distributing it through general practitioners.

Health services are finding innovative ways to bring *10 tips* to the attention of their patients and families. For example, Northern Territory Hospitals have placed laminated copies of a *10 tips* poster in each patient locker. In Tasmania, Western Australia, South Australia and Queensland, *10 tips* materials have been delivered to all health services. The Stawell Regional Health Service in Victoria has not only made the booklets available in all hospital reception and waiting areas, it has also extracted the 'tips' and placed them in a self-standing photo frame on each bedside table.

Also in Victoria, the Mildura Base Hospital features the *10 tips* in its annual Quality of Care report, which is in the form of a calendar for 2005. The hospital reports positive feedback from staff and patients. Some respondents said the *10 tips* were what they liked best about the report, and there were comments such as:

'Consumer tips a great idea'

'Loved the 'Tips for Consumers' – a big step in the right direction for patient choice and information.'

The *10 tips* have also been promoted by private health insurers Medibank private, HCF and GMHBA Ltd to their membership through newsletters and stand-alone reports.

10 tips has been translated into 15 different community languages. Copies of the English and translated versions can be obtained through the Council Secretariat, or downloaded from Council's website <http://www.safetyandquality.org/>.

Better Complaints Management – assisting health services translate complaints into better practice

Consumer complaints are an important source of information about adverse events and how they might be prevented. Council is committed to making sure that complaints are acknowledged and used to improve quality and safety, and that they form an integral part of critical incident reporting and review – something that does not always happen.

The Complaints Management Handbook for health care services, developed by Council to be released in 2005, provides practical information and assistance to people who manage complaints in health care services. It will supplement Council's *Better Practice Guidelines on Complaints Management for Health Care Services*, released in 2004.

Traditionally, complaints processes in the health care sector have focused on the individual consumer or carer, and the health care providers directly involved. The outcomes of complaints are not routinely examined and translated into broader lessons for the health service, the health system and the community.

Good complaints management can promote quality improvement by recognising the systemic nature of most adverse events and promoting open communication with patients and carers, while supporting both health professionals and consumers during the complaints process.



Case Study

The following case study illustrates the value of consumer complaints in improving patient safety.

'Asking for access to my medical records was one of my ways of trying to regain control and understanding of what had happened. When that was blocked, my distress turned to anger and fear.'

Ms C, a long time member of the Health Care Consumers' Association of the Australian Capital Territory, spent eight days in hospital following complications from a procedure that should have taken only two days.

Understanding the issues

'My main concern was that there were several days between my first reporting concerns about new symptoms and receiving any medical attention to find out and remedy what was wrong. It took about a month after I came home to recover fully from the physical harm that resulted from this.'

After recovering fully, Ms C wrote to the hospital's Chief Executive Officer (CEO). She identified five main areas of concern about her treatment and the difficulties accessing her medical records, and asked for an appointment to discuss the issues with the CEO.

Direct negotiation

The hospital's Customer Liaison Officer called the next day and offered Ms C a meeting with the CEO. She met the hospital CEO, Director of Nursing, Quality Control Manager and Customer Liaison Manager. The Liaison Manager had prepared a full briefing of issues and the results of the hospital investigations. These issues were discussed at the meeting and Ms C was provided with a copy of the briefing.

Collaborative solutions

As a result of Mrs C's complaint, it was agreed that the hospital would work with consumer representatives on the issues arising from the complaint, including:

- development of new pain management protocols for Accident and Emergency and other service areas in the hospital;
- a review of procedures on patient-reported symptoms relating to fluid;
- development of guidelines for administration of time-specific medicines;
- improvement of patient access to medical records; and
- improved information in the wards to patients about access to complaints procedures.

The letter reassured Ms C that her concerns about not being heard were well understood, and that her experience would be used to improve the system for other people.

'Generally, I felt satisfied with the way the hospital handled my concerns.'

Complaints Management Handbook, Australian Council for Safety and Quality in Health Care 2005

Open Disclosure – health services in open and honest communication

Doctors and other health professionals realise that even with the best of care, things can sometimes go wrong, but patients do not always understand this well. Doctors and other health professionals often have very little understanding of the emotional impact that an adverse event can have on a patient, even if there are no long-term physical effects. The impact is made worse if communication after an adverse event is poorly handled.

The Council's Open Disclosure Standard was developed as a result of advice from consumers about their need to receive open and honest communication when things go wrong with their health care.



The standard sets out the elements of a response to an adverse event or near miss:

- an expression of regret;
- a factual explanation of what happened;
- a discussion with the patient about their concerns; and
- steps being taken to manage the event and prevent it happening again.

Case Study

The following Case Study illustrates the power of open disclosure to enhance patient well being and improve patient safety management.

Ms G nearly died after an adverse event during a caesarean. Ms G didn't want to sue. What she wanted was to receive an explanation that made sense to her, have the hospital express regret about what had happened, and know that there were appropriate review mechanisms in place to minimise the likelihood that it would happen again.

Ms G ultimately received a full explanation of the adverse event and an apology, and these were critical in assisting her come to an acceptance of what had been a very painful and frightening experience. But this took 12 months and she found it far from a straightforward experience.

Ms G notes, *"Having an incident that is unresolved, particularly over something as important as nearly dying, can take over your life. I had felt so angry and was even becoming very bitter."*

"For me, no amount of money that I could ever achieve from legal action could have taken away my pain and anger the way access to information and that wonderful apology did. It felt so wonderful to get rid of that horrible burden of anger."

Many people would say that open disclosure already happens in Australia's health system, but it is not necessarily done well. As the story above and that in the *Better Complaints Management* section show, the extent to which open disclosure is practised can have a major influence on consumers' health outcomes and quality of life.

Open disclosure also provides an impetus for putting in place processes to investigate and correct deficiencies in the system. As with complaints information, adverse events can be used by health services to inform them about system changes that may be needed. It is vital to include consumers in the process, and some health services are making sure this happens.

Health Ministers have now agreed to a national pilot of the Open Disclosure Standard in hospitals across Australia and will use the information from the pilot to support ongoing use of the Standard by health services.

Making medicines safer

When things go wrong with medicines – the Adverse Medicine Events (AME) line

If medication safety is to be improved, it is vital to appreciate consumer experiences in relation to medications. It has been suggested, therefore, that consumers should be able to contribute to adverse medicine event reporting systems. The potential benefits include first-hand accounts of adverse events, early warning of potential drug toxicity problems, and increased reporting on over-the-counter and complementary medicines. Consumer reports can complement those submitted by health professionals and may partly address the problem of under-reporting by health professionals.

The Consumer Adverse Medicine Events (AME) Line was set up as a Council pilot project, in October 2003, to examine the contribution such a system can make in practice. The line is operated by pharmacists of Mater Health Services Brisbane, and offers consumers the opportunity to report both adverse drug reactions and errors related to medicines.



Case Study

The following case study illustrates the value of medicine labelling.

Mrs CB, aged 58 years, rang the AME line and asked:

“Can my antibiotic be causing fatigue, slow pulse and heaviness in the chest?”

These symptoms are not usually side-effects of the antibiotic Mrs CB was taking, so the AME line pharmacist reviewed all her medication. Mrs CB had recently visited a mole scan clinic where she was diagnosed with a form of acne and prescribed – as she understood – an antibiotic. The local pharmacy dispensed the prescription but provided no consumer information. Mrs CB took the tablets for 21 days until she developed the troubling symptoms. Her only other medicine was verapamil, prescribed by her regular doctor for a heart condition.

In talking with Mrs CB, the AME line pharmacist discovered that the medication Mrs CB had been prescribed was not, in fact, an antibiotic, but metoprolol, a beta blocker that slows heart rate. The brand of antibiotic that was probably intended appears in prescribing software beside the brand of metoprolol that Mrs CB was accidentally prescribed.

The AME Line pharmacist advised Mrs CB that this error was most likely the cause of her symptoms, through a reaction between the verapamil and metoprolol that worsened her heart condition. The pharmacist contacted Mrs CB’s GP, who visited her within the hour and rectified the error. Her symptoms resolved over the next 48 hours.

Mrs CB was keen to prevent others experiencing this medication error. She commented that she could have detected the error herself *“if there had there been something on the bottle or label to suggest that ...[it]...was a heart medication, not an antibiotic.”*

The AME line has received over 2,500 calls concerning medicine safety.

About half of these calls were reports of adverse drug reactions. Of these, 50% were reported to the Australian Adverse Drug Reactions Advisory Committee (ADRAC), as they met the following defined criteria:

- were serious or novel incidents;
- had a strong causal association; or
- were related to recently marketed drugs.

Whilst the other half of these reports failed to meet ADRAC criteria, they also provide valuable information about more common adverse drug reactions (ADRs). This information can identify trends or clusters of ADRs that may eventually be of significance to ADRAC; in particular the different range of ADRs reported by consumers as opposed to those reported by health professionals.

The remaining half of total calls involved:

- medication errors or problems with medication quality (7%);
- symptoms that were more likely to be the result of disease than of medication (20%); or
- no symptoms, but a need for information on medicine safety (23%).

These data suggest that the AME line provides a useful triaging function, potentially diverting up to half of all calls away from standard reporting procedures, and thus reducing the workload of services that do not focus on these events. Perhaps more importantly, the service provides a unique opportunity for consumers to pose questions and seek advice on adverse reactions, which in some cases could prevent serious harm.

Case Study

Ms YC, aged 57 years, rang the AME line and asked:

“Can my cranberry tablets be upsetting my sleep?”

The AME line pharmacist established that Ms YC had depression and had been stabilised on her antidepressant medication for three years. She usually slept well. About two weeks before her call, she developed mild urinary burning and began taking cranberry tablets to treat herself for cystitis. Within a week she found it was difficult to get to sleep, and to stay asleep. She was reluctant to discuss this with her doctor as she felt guilty taking over-the-counter medications without consulting the doctor.

The pharmacist could not find any published link between cranberry and insomnia. He did, however, explain that cranberry is acidic and antidepressants similar to that taken by Ms YC had been shown to work less well when taken at the same time as acidic substances such as ascorbic acid (Vitamin C). He suggested that she stop using the herb for two weeks as a trial.

In a follow-up phone call, Ms YC reported that her normal sleep pattern had returned within a week of stopping the cranberry tablets. It would appear that a drug interaction had made her antidepressant less effective, and this possible drug interaction was reported to the Australian Adverse Drug Reactions Advisory Committee.

The AME line is valuable in flagging issues raised by consumers – for example, Mrs CB's suggestion about how medication information could be communicated better, or in the case of Ms YC, the need for innovative approaches to address the complex issue of complementary medicines used without the involvement of the primary health carers. The challenge is to find ways to translate this information into system changes that improve medication safety.

Consumer adverse drug reaction reporting agencies have recently begun operating in North America and Europe. None, however, has extended their brief to include collecting medication errors or near-miss reports directly from consumers, as does the AME line. In this pilot project Australian consumers are leading the world.

Safer use of medicines – using the Breakthrough Collaborative approach

A Breakthrough Collaborative is an improvement method that relies on the spread and adaptation of existing knowledge to multiple settings. The collaborative methodology produces improvement by harnessing the collective wisdom of participants, an advisory panel of experts and a literature review to develop strategies to aid implementation of evidence-based best practice.

Participating teams are required to attend learning sessions and maintain continual contact with each other and a collaborative project management team through email, conference calls and site visits. Reporting progress and hearing how colleagues have made changes and overcome problems can be motivating and provide practical ideas that can be implemented locally.

Council's *National Medication Safety Breakthrough Collaborative* (NMSBC) brought together 100 health care teams from across Australia to design and implement projects aimed at reducing harm by 50% through the safer use of medicines in hospitals and in the interface between hospitals, general practice and community care.

Three of these projects, described below, illustrate how consumer representatives have contributed to significant improvements in patient safety.

Clear labelling of medications

On the Mornington Peninsula, south of Melbourne in Victoria, Peninsula Health set out to improve the communication of discharge medication information to community health providers, and to patients, recognising that consumers do not always remember information provided at the time of discharge.

The team developed more patient-friendly medication labels, which specified, in simple language, what the medication was for. After introducing the labels, the team conducted a customer survey to check their usefulness. They were disappointed by the results: patients had not noticed the new patient-friendly labels. In consultation with consumer groups, the team put the label in capitals, and pharmacists were instructed to point it out. A second customer survey showed a positive response to the revised labels.

The consumer representative on the team was integral to the discussions, and was actively involved in conducting patient surveys and in formulating the patient information brochures and the medication labels.

The report of the project notes that *'It was enlightening to listen and appreciate the consumer's view of the health system and processes around patient safety. The consumer representative also ensured our efforts focused on the benefits for patients through his refreshing perspective'*.

Peninsula Health, NMSBC Final Report

Informing and empowering consumers for safe use of medicines

Community Health, a community-based organisation providing community health services to people in the ACT, aimed to increase their clients' understanding of their medicines. Their target group was people aged over 65, who were taking five or more medications – a group at high risk of hospitalisation from an adverse medication event.

The project involved talking to community groups about safe medication use. A key message in those meetings was: 'taking the right medicines, the right way and in the right dose improves your health and helps you maintain your independence'.

Two consumers, Anna Saxon-Taylor and Lynn Skinner, were involved from the outset. They were part of the initial planning, helped develop the information for consumers, and worked with other members of the team in talking to the consumer groups.

'Having the two consumers involved in our team was our greatest strength. It helped us connect with consumers, and to keep the language and intent of the project focused on the consumers.'

ACT Community Health, NMSBC Final Report

The project demonstrated the benefits that consumer involvement can bring and ACT Community Health is now continuing to engage with consumers in a wide range of activities.

'It was reassuring to see how keen and interested the consumer groups were to receive information about medication safety, and in particular to have the information delivered by one or both of the consumer representatives on our team in conjunction with the Project Coordinator.'

ACT Community Health, NMSBC Final Report

POPPIES – preventing opioid problems by providing information to enhance safety

Neringah Hospital in Sydney NSW, specialises in offering an integrated inpatient and comprehensive community palliative care service to people in the northern suburbs of Sydney – aiming to help their incurably ill clients to benefit from the best potential quality of life. This includes control of pain and alleviation of symptoms as well as a support system that addresses the psychological, social and spiritual needs of patients, families and carers.

A medication and pain diary were developed through consultation with patients and staff to assist patients and their carers to better manage their medication. Information brochures were also developed.

The diary also prompted an increased communication flow between patients and their carers including extensive use of brochures.

The overall result has been a significant and sustained increased quality of life for 40% of patients.

The project has also had significant interest from local GPs, home nursing services and other health services with a roadshow being conducted to promote the findings.

Medication Safety Innovation Awards Program – encouraging innovative solutions in a diversity of treatment settings

Under the Medication Safety Innovation Awards Program, Council sought to identify sustainable ways to ensure medication safety in a range of treatment settings and for a range of medical populations.

The Royal Hobart Hospital project, jointly managed by the School of Pharmacy at the University of Tasmania and the Pharmacy Department in the Hospital, demonstrated the importance of providing consumers with a range of information to help them take their medicines safely after they are discharged from hospital.

The project targeted patients who were at high risk of a medication related adverse event – people who were aged 60 or older, were taking five or more medications, and had two or more chronic conditions.

High risk patients were divided into two groups. On discharge from hospital, the first group received standard medical care while the second group received a package of medication information, including numbers of telephone help lines, and access to a medication information website. They also received discharge medication counselling sheets and verbal counselling from a clinical pharmacist. Their list of discharge medications was faxed to their general practitioner and community pharmacist within 24 hours of discharge; and they were telephoned 5 days after discharge to provide added medication-related support.

Twenty-eight days after discharge, people in both groups were telephoned and interviewed to assess the outcomes. People in the first group, who had only received standard care, had a significant decline in their knowledge of their medicines. However, those in the second group showed a significantly higher level of confidence in managing their medicines, and were more able to comply with their medication regime. The Hospital now has put in place measures that were used for the second group.

Working with indigenous communities

Safer use of medicines in Aboriginal communities

In 2004, Council funded a project to support the safe use of medicines in Aboriginal communities in the Katherine West Health Board Aboriginal Corporation (KWHB) region of the Northern Territory. The region extends west of Katherine to the Western Australian border and south to the Tanami Desert, an area of 165,000 square kilometres, where many different languages are spoken across the area. KWHB, governed by representatives from the remote communities that it serves, is the sole provider of primary health care services.

Data collected by the KWHB quality program showed that 57% of incidents involving medicine management over the past 12 months might have been avoided if clients had been more informed and empowered, and could question health practitioners about their medicines. KWHB wanted to give their clients the opportunity to be more informed, and so more involved in their health management.

While some information about medicines is available for consumers, it is not tailored to the needs of Aboriginal communities. Language difficulties and the literacy levels – including non-literacy of some of the community members – limit the opportunities for use of this information to promote a partnership between consumers and health professionals for medicine safety.

With the help of a SIIP grant, KWHB is developing culturally appropriate tools to increase safe medicine usage by building consumer awareness of medicine safety issues, and to empower clients to question providers and raise issues about their own and their family's medicines.

The information being used is based on existing English language quality and safety of medicines material, and Council's *10 tips for safer health care*, for consumers.

Extensive consultation with Aboriginal health workers and community members has begun, to ensure that the end product will be culturally appropriate and that communities will have ownership of the messages.

Falls Indigenous Storyboard – a resource for Indigenous people

National guidelines to help prevent falls have been developed by the Council in association with Queensland Health. *Preventing falls and harm from falls in older people: best practice guidelines for Australian hospitals and residential aged care facilities* will promote a nationally consistent approach to reducing falls harm among older Australians in both hospitals and residential aged care facilities. A range of support materials will assist the implementation of the guidelines, including information brochures for consumers.



Consultations with Indigenous specific hospitals and residential aged care facilities during the development of the Guidelines identified that there were no Indigenous specific falls prevention resources in Australia. As such, the Council has developed the *Falls Are Not for Me* storyboard for use by older Indigenous Australians, their carers and Indigenous health workers. Through a culturally appropriate means, the storyboard aims to raise awareness of the preventability of falls in older Indigenous Australians, and what can be done to minimise falls and their harm.

Keeping consumers informed and involved

Scholarships for health consumers

For several years the Council has provided scholarships for consumers to attend significant national and international conferences. The benefits are two-fold: strengthening the consumers' knowledge about reforms to the health system, and helping to ensure that debate at the conferences considers consumers' perspectives. An added benefit is that the consumer scholars are able to take the knowledge gained from the conference back to their local communities and health services to assist in improving patient safety.

In July 2004 the Council sponsored nine consumer scholars to attend the 2nd Australasian Conference on Safety and Quality in Health Care. Their response to the Conference was overwhelmingly positive, and more than six months after the Conference they continued to report benefits in their work to improve local health care services.

Some comments from consumer scholars

"I am using the knowledge gained to bring this subject forward to the consumers in my health area. I have managed to introduce the idea to our Quality Council to include consumers in root cause analysis and to have accreditation included on our health council forum."

"I guess I have been fortunate to have learned about systems. Contact with the Council as consumer scholar is a great opportunity to find out more, particularly for those who do not have backgrounds in health, or even knowledge of how governments function."

"The whole experience of attending the conference increased my confidence to speak out on consumer issues, knowing that there are such a large number of like-minded consumers out there, so I am not a lone voice but really a voice for a silent majority of Australians."

"I learned a great deal and gained a lot of information about the health system. This has helped me on a local level. It has also assisted me to get through some doors and create some new networks."

More scholarships have been offered for consumers to attend the 3rd Australasian Conference on Safety and Quality in Health Care in July 2005. That Conference will be addressed by a prominent American consumer, and by a number of Australian consumers who are active in improving safety in health care.

Consumer Update – a newsletter for consumers

Council publishes a regular bi-monthly newsletter for consumers, *Consumer Update*. Available to consumers throughout Australia, it contains short, sharp news and information about the Council's programs and activities. Copies can be obtained from the Council's website: <http://www.safetyandquality.org>.

Consumer Advisory Committee

The Council receives advice on consumer issues from its Consumer Advisory Committee. This committee was formed in May 2004, and is a successor to the Consumer Working Group and the Consumer Reference Network. The current membership is:

Betty Johnson, Chair – a consumer member of the Council, New South Wales;

Jane Phelan – a consumer member of the Council, Victoria;

Helen Hopkins – Executive Director of the Consumers' Health Forum of Australia, Australian Capital Territory;

Maxine Drake – Health Consumers' Council of Western Australia;

Myrtle Green – a consumer from Queensland;

Tony McBride – from the Health Issues Centre, Victoria; and

Merinda Epstein – a consumer with expertise in safety in mental health care, Victoria.

In the past year the Committee has provided advice to the Council on a range of the Council's activities, including:

- reducing health care associated infections;
- medication safety, including the Adverse Medicine Events line;
- a Patient Safety Checklist;
- the National Patient Safety Education Framework;
- falls prevention;
- appropriate selection of consumer nominations for Council committees and working groups;
- consumer input to the 3rd Australasian Conference on Safety and Quality in Health Care; and
- consumer scholarships program.

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