

Consumer involvement in the Centre for Health Services Research

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Abstract

Consumer involvement in health decision making has become widely established as both a necessary part of our democratic process and part of the broader move to improve health outcomes. Many consumers are now expecting to be involved in decisions about their own health care. The partnership approach has led to the formal involvement of consumers and their groups in a large number of health initiatives. In keeping with these trends, the Centre for Health Services Research (CHSR) appointed a part time Consumer Liaison Officer (CLO) in January 2000. The position was established in conjunction with The Health Consumers' Council of WA.

Consumer participation in the CHSR has become an integral part of the research program and the CLO was involved in the strategic planning process for the CHSR covering the period 2001–2005. Dissemination of the research outcomes from the Centre's research program has been a pivotal role of the CLO. During 2000 the CLO undertook a Survey of Consumer Research Priorities which found that consumers want to participate in meaningful informed consent and an opportunity exists for health service researchers to assist them to achieve this goal. Consumers seek clear communication from health providers and they are keen to be involved with research from the ideas phase through to the dissemination of research findings in understandable language. The CLO has also given a number of talks on "How to Involve Consumers in Health Decision Making".

This paper will explore the consumer liaison role in the CHSR and examine the role it played in the successful launch in October 2001 of "Duty to Care: Physical Illness In people With Mental Illness". This study used the WA Data Linkage System to determine the extent to which users of mental health services, who comprise 8 % of the WA population, had different rates of physical illness compared to the general population for the period 1980–98. The dissemination framework for this report will be discussed. This included the publication of a technical report and stakeholder and consumer summaries. The involvement of the CLO in this project greatly increased the profile of the study and ensured that both researchers, stakeholders from government and provider organisations, and consumers were well informed of the outcomes. The CLO has continued to communicate the research outcomes to the community whilst the project has entered a plateau phase. The presence of the CLO with the support of CHSR, together with community groups has helped to ensure that stakeholders, par-

ticularly the government, remain focussed on changing the health system to better meet the needs of people with mental illness.

Introduction

Community participation is part of the World Health Organisation's "Health for All Strategy" and supports the goal of moving to greater public accountability¹. In recognition of this, the Department of Public Health (DPH) at the University of Western Australia (UWA) has employed a part-time Consumer Liaison Officer (CLO) for the past two years. In doing so, it has met some of the objectives of the Consumers' Health Forum policy document "Developing a Statement on Consumer and Community Participation in Health and Medical Research"². The policy is written to support consumers and researchers working in partnerships based on understanding, respect, and shared commitment to research that will improve public health.

This paper explores a number of models for consumer participation in health decision making. It also discusses some practical examples of consumer involvement in the Centre for Health Services Research (CHSR), a research unit within DPH.

Some models for consumer involvement

Consumer involvement in health has grown in the past decade and is now more widely accepted as part of health decision making. It takes place in a variety of different ways and many models are effectively used. Examples include consumers working together to provide input into the Consumer Reference Group of General Practice Divisions of Western Australia (GPDWA) Ltd³, the Mental Health Services of the Fremantle Hospital and Health Services through the South West Metropolitan Consumer Advisory Group⁴. Consumers have direct input into the Cochrane Collaboration through the Collaborative Review Groups, the Consumer Network⁵ and membership of the International Steering Group. There is consumer involvement in the National Prescribing Service Ltd (NPS)⁶ from board level through to working groups. NPS is committed to involving consumers in a wide range of activities to strengthen the message about the wise and quality use of medicines in Australia. The Medical Services Advisory Committee (MSAC)⁷ has a consumer representative as part of the specialist supporting committees and Australia's peak national health consumer organisation, the Consumers' Health Forum of Aus-

tralia⁸, has just appointed a project officer to oversee its involvement in the activities of MSAC.

The Health Consumers' Council (HCC) of WA (Inc)⁹ is the independent, community based organisation representing the consumers' voice in health. It advocates on behalf of consumers to government, doctors, other health professionals, hospitals and the wider health system. It provides consumer representation in health policy, planning, financing, research and service delivery. The HCC is one of only two state based health consumer organisations in Australia. It has a unique structure that allows consumer members and interested consumer citizens to bring health issues to its peak consumer group the Health Issues Group⁹ that meets monthly. This allows consumers with concerns to have a direct forum in which to discuss health issues. The author as a consumer of numerous health services became an active member of the HCC in 1994 and represents them and CHF on a range of state and national committees.

Principles of health consumer representation

The "grass roots" approach to health consumer representation is important as consumer representatives with this background should not exist in isolation and should be nominated by and connected to relevant consumer groups. This has many advantages as the consumer group trains consumers in the basic principles of participation and has a democratic, layered, process for selecting consumer representatives. Consumers move away from personal opinion and when sitting on committees balance the views of health professionals, government and other stakeholders. The consumer participation in health decision making has followed a widespread trend to far greater consumer involvement across a range of consumer activities. There is general acceptance that there should be a far greater focus on the needs of people served by health care however, there is often far less commitment and clarity as to how to go about it¹.

Consumers can also be recruited through projects such as the Cancer Foundation of WA's Consumer Participation Project¹⁰. This project trains and coordinates the involvement of a number of consumers placed on different cancer committees. It has close links with the HCC and is managed by an interdisciplinary team.

Working with consumer groups

Consumer involvement in health decision making is occurring in a variety of ways. On occasions, direct input is sought on a case by case basis by asking the consumer groups for an opinion on a topical health issue. This method of communication with the consumer groups is effectively used by The West Australian Newspaper for its general news and "health + medicine" supplement. In these instances, consumers are given a voice but the media is not actually seeking to establish a long-term relationship about this issue with the consumer group. The media regularly consults the HCC and seeks input on current issues such as a person dying in an Emergency Depart-

ment, the review of the Medical Act of WA, and ambulances regularly being placed on bypass from major tertiary hospitals. Only comment may be sought or a feature article may be being written. The HCC may be one of a group of stakeholders whose opinions are canvassed.

In contrast with the short, direct input sought by the media, requests by providers, government and other health organisations require a longer term consumer involvement. Consumers are then selected by the groups that they represent and placed on committees for varied lengths of time. They become a valued part of the committee and regularly report to their respective consumer groups.

Consumer representation in the Centre for Health Services Research

Consumer representation brings a range of views and is an integral part of CHSR. The CLO position was set up in 2000, initially on a part time basis. It was recognised very early by CHSR that health consumer participation in research is part of the wider commitment to dissemination of research outcomes to the community. Additionally, it is part of public accountability for money allocated to research.

One of the first tasks of the CLO was to survey chronic illness groups to ascertain what they wanted from health services research. The "Survey of Consumer Research Priorities – Report on Outcomes"¹¹ published in late 2000 shows that consumers are very keen to be involved in health services research. The partnership of consumers and researchers has the potential to strengthen and influence health policy. Health services researchers have an important role to play in assisting consumers to give informed consent. Consumers seek clear communication from health providers and they want to be involved from the ideas phase through to the dissemination of research findings in understandable language. Consumers are concerned that the behaviour of professionals is more in accord with both the results of research and service priorities¹².

After a short time during 2000, it became apparent that consumer involvement was an activity that should be pursued by CHSR and DPH. The CLO was therefore offered a two day a week appointment in 2001. Effective dialogue takes time to build up and the CLO position has been gradually extended to a point where consumer participation is one of six major themes incorporated into the Capacity Building Grant recently submitted to the National Health and Medical Research Council. Entitled "Improving Health Outcomes With Population-Based Biological, Social And Environmental Information And Research Methods" this grant if successful will expand the CLO role within DPH. The Institute for Child Health Research (ICHR) is the other collaborator in the capacity grant and if successful there are plans to develop a consumer reference group within ICHR. This would allow better communication and the seeking of direct input from stakeholders including parent groups. "Supported" teenage research participants would also be invited to "have a say" as they are long-term research subjects.

There are also plans to expand the teaching role of the CLO to include postgraduate programs of the DPH and undergraduate courses run by the Faculty of Medicine and Dentistry and the Health Science degree program. This will enable undergraduates, PhD and postgraduate coursework candidates, to be informed in the basic principles of consumer participation and community partnerships concepts and professional working relationships with research subjects.

The "Duty to Care" Project

The CLO will maintain a consumer library and continue dissemination of the main findings of research projects. The "Duty to Care" project is a case study of how to effectively use the CLO to assist with dissemination of the findings of a research project.

In 2001 the technical, stakeholder and consumer summaries of "Duty to Care" were completed. These summaries aimed at targeted audiences were launched with the project in October 2001 when the PhD "Duty To Care Preventable Physical Illness in People With Mental Illness"¹³ by Dr David Lawrence was completed. The project was based on the Data Linkage System¹⁴ from the WA Data Linkage Project using de-identified data of people who had had some contact with the mental health services.

"Duty to Care" reports on a major study of the physical health of 240,000 people with mental illness in WA who represent about 8% of the population. This group has a life expectancy in the 50's and a range of problems including dramatically increased rates of heart disease, respiratory problems and infectious diseases. The results highlight inequalities in health care for people with mental illness. A very bleak picture of the health of people with mental illness emerges, and one of the CLO's duties has been to ensure consumers are informed of the results. The technical report from the study, along with the stakeholder summary and the consumer summary can be down loaded from DPH's website at www.dph.uwa.edu.au by following the links:

Research programs

Centre for Health Services Research

Duty to Care

(If there are any problems with the website contact the CLO at this email address rcoghlan@dph.uwa.edu.au who will send you the PDF files of the reports).

The CLO role also involves influencing policy and practice, by ensuring all relevant stakeholders are given every opportunity to address the issues identified in "Duty To Care". Consumer organisations were heavily involved with the planning for the launch and a consumer was invited to address the audience on the day. There was considerable media coverage and the results were published in many peer review, consumer and community journals. The Health Report on Radio National on 5.11.01 reported on the main findings of the project. Pro-

fessor D'Arcy Holman and Ms Cobie Rudd from GPDWA were interviewed. Service changes, particularly those involving better primary health care, have the potential to improve the health outcomes of those people with mental illness who have physical illness.

Conclusion

The CLO role within the DPH is still developing, however, early signs are that it is working well thereby meeting many of the objectives in the CHF document Developing a Statement on Consumer and Community Participation in Health and Medical Research² which has been adopted in principle by the Australian Health Ethics Committee of the NHMRC. The CLO has been able to develop links with others consumers both within and outside WA covering the wider health system. Consumers are effective networkers and their involvement is part of the social justice movement for greater community participation in health decision making. There is an increasing interest in how money is spent in health services research and consumer involvement contributes to the greater transparency that is required. Consumers are also interested in health information and the moral philosophy of the research experience.

The CLO project at DPH has raised the profile of consumer involvement in research and currently is the only one of its type in Australia. It is hoped that future and existing data linkage projects will also involve consumers in accordance with CHF's policy on Consumer and Community Participation in Health and Medical Research.

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