

## **Consumer Views on Participating in the Austin Bowel Cancer Consortium Clinical Support Systems Program**

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*The Austin Bowel Cancer Consortium (ABCC) was one of the four sites across Australia chosen by the Royal Australasian College of Physicians (RACP) to test the Clinical Support Systems Program (CSSP) model. Conducted in 2000 – 2002, the Austin Bowel Cancer Consortium CSSP aimed to explore how to support clinicians and specialists to optimise the use of evidence in their practice and how consumers can be involved in the process. It focused on the treatment of bowel cancer. This article describes how consumers participated in the project, how they perceived the experience of participation, and to what extent they considered their participation empowering and effective in delivering more responsive health services.*

The CSSP was a \$5.5 million initiative of the RACP, funded by the Commonwealth Department of Health and Ageing and the Victorian Department of Human Services. Its aim was to test the CSSP model, which was an integration of clinical practice improvement and evidence-based medicine, to support clinicians in their practice.

Austin Health, Warringal Private Hospital, Bendigo Health Care Group, North-East Divisions of General Practice, Health Issues Centre and Swinburne University participated in the ABCC CSSP. The project used an action research approach to undertake a number of major interventions to achieve its main aims. These included an analysis of work culture in participating health services, engagement of clinicians and direct consumers, conversion of published guidelines for colorectal cancer treatment into clinician pathways and the development of an information technology tool for use in the clinic. Among the major outcomes of the project were the clinician pathways and an electronic tool that incorporated psychological and social aspects of consumer care, a report on the consumer and carer experience of colorectal cancer treatment and key information materials produced by consumers.

### **Process of Consumer Participation in ABCC CSSP**

Health Issues Centre, as a key member of the consortium, represented consumer perspectives throughout the life of the project. Their researchers carried out tasks of engaging consumers with experience of colorectal cancer.

#### *1. Consumers' and Carers' Experience of Care*

Information needed to be gathered concerning the consumers' and carers' experience of care during their diagnosis and treatment of colorectal cancer. As there was no existing colorectal cancer consumer group or advocacy group to consult with in order to gain a consumer perspective, the project took a grass roots approach by recruiting consumers who were bowel cancer patients at Austin Health, Warringal and Bendigo Health. In total, 33 consumers in Melbourne and Bendigo, including 25 patients identified by the clinicians engaged in the project and eight carers participated in semi-structured, qualitative interviews either individually or in small groups, which were taped. Health Issues Centre's researcher conducted all the interviews.

#### *2. Consumers Reviewed the Interview Report*

A report based on the interviews' findings was produced and provided to the consumers involved along with a letter inviting them to provide feedback on the report and participate further in the project. Comments from the consumers were received via letters and telephone calls. Some indicated their willingness to continue their involvement. The report was revised in light of the consumers' comments and sent to clinicians in the project and other interested parties. This report, *Interviews with Consumers and Carers about their Experience of Care for the Treatment of Colorectal Cancer*, can be obtained from Health Issues Centre.

### 3. *Establishing Consumer Reference Groups*

Consumers who indicated their interest in further participation were invited to join the two Consumer Reference Groups, one in Bendigo and one in Melbourne, representing rural and metropolitan consumers. The groups were convened to ensure consumer perspectives were present during the development of information technology documents and tools for clinicians, set out as the project's major interventions. The Bendigo and Melbourne groups consisted of six and eight members respectively, and were facilitated by a Health Issues Centre researcher and two project officers. Each group met regularly to work on tasks assigned to them. As a result, the two Consumer Reference Groups achieved the following outcomes:

Three key pieces of information materials initiated and developed by consumers which included:

- a patient pathway document for people undergoing a colorectal cancer operation;
- a poster on the warning signs for colorectal cancer and strategies for community education on this matter; and
- a booklet containing a list of questions a person diagnosed with colorectal cancer may want to ask their doctor.

### 4. *Consumers Participating in Other Project Activities*

One consumer from the Bendigo group and two from the Melbourne group later became members of the Implementation Group. The project's key operational team comprised of clinicians and service providers who represented the Austin Bowel Cancer Consortium members. Two Consumer Reference Group participants brought consumer perspectives to a meeting of the Psychosocial Group, another project team responsible for the study of clinician's work culture. Some consumers also participated in other project activities, i.e. the project review day, the CSSP workshop with visitors from United Kingdom, the project presentation for Austin Health Consumer Advisory Committee and the RACP conference on the CSSP dissemination.

### **Evaluation of Consumer Participation**

In April and May 2002, Health Issues Centre conducted an evaluation of consumer participation in the CSSP. The main aims of the evaluation were:

1. To gather information on the methods and outcomes of the consumer participation strategy.
2. To reflect on how consumers were involved in the project and how this could be improved.
3. To assist in creating a model of consumer participation for acute care settings where there is no existing consumer group.

Qualitative research methods were used for the evaluation so issues could be examined in depth. Data was collected through semi-structured interviews, involving the consumers in two steps.

1. Telephone interviews with those who had participated in the interviews about their experience of care but not the Consumer Reference Groups.
2. An evaluative discussion at the end of the last session of the two Consumer Reference Groups.

In total, 18 out of 33 consumers and carers participated in the evaluation. Of the 19 consumers who were not involved in the Consumer Reference Groups, seven participated in telephone interviews. The remainder did not participate in the evaluation for a number of reasons. One had indicated earlier that he did not want further involvement in the project, two had died, and the remainder were not contactable.

Of the 14 participants involved in the Consumer Reference Groups, 11 participated in the evaluation. One consumer in the Melbourne group had died, one consumer in the Bendigo group stopped attending, and another had moved interstate.

## **The Consumers' Perspectives on Participating in CSSP**

### *Why Participate?*

Having had cancer, the majority of consumers reported that they agreed to be involved in the project because they had been contacted and asked to participate. They wanted to influence change in health care and were curious about what other people had gone through. All of the participants in the Consumer Reference Groups reported that they decided to become involved to assist others and/or to support change in health care.

*"I think having had the disease you want to make some usefulness out of it."*

Some consumers participated because they felt that the interview would be helpful for them.

*"Well, talking about it helps you."*

It would appear that the health providers' invitation to participate and in particular doctors' encouragement were both critical in consumers' decision to participate.

*"I think the recommendation from the doctor was the influence."*

### *Why Others Did Not Participate*

The majority of participants attributed other consumers' reluctance to participate to the individual's situation, that is, consumers would have experienced the project as confronting or they were having difficulty adjusting to their cancer diagnosis and/or management of pain.

*"It's that stage of adjustment to the fact that you are a cancer client would put a lot of people off. Because if you can't cope with the idea that you've got cancer, then how could you be in a group where every body is going to be talking about it. It would be very confronting."*

*"It's very scary."*

The silence surrounding cancer within the Australian culture probably prevented other consumers from participating in the project. This is something some consumers in the Consumers Reference Groups have experienced.

*"People just don't want to know about you for some reason. They are scared of catching something, I don't understand. I have lost a lot of people. I say I have got cancer and they just shy past you. All the people you know, they don't even come to see you at home."*

### *Being Involved in the Interview*

All of the participants in telephone interviews reported feeling okay about the first interview to gather information for the report based on consumer and carer experience of colorectal cancer treatment. The members of the Consumer Reference Groups felt that the initial interview was very good, because it was calming and informal. For some, being

interviewed in a group particularly made them feel more comfortable.

*"Because you are coming in with your peer group. It's not that you're a one off."*

Consumers, who went on to join Consumer Reference Groups, saw being involved in the first interview as good preparation for the tasks and responsibilities involved in the Consumer Reference Groups.

*"Questions from the first interview, from my point of view, it made you think about what happened, and what should have happened. So the first interview was an introduction, which was good."*

#### *Reviewing the Interview Report*

The majority of participants in the telephone interviews commented that the findings in the report on consumer and carer experience were good because they were based on their experiences. One participant had not read the report. Members of the Consumer Reference Groups said that the information and knowledge developed through the consumer interviews was excellent. Some participants stressed that the report increased their understanding about colorectal cancer and treatment options.

Upon receiving this report, some of the consumers expressed great interest in the findings and found learning about others very supportive.

*"I found it very interesting to read about other people's experience, and to realise that my situation was not unique."*

#### *Being Involved in the Consumer Reference Groups*

The Consumer Reference Group members reported their involvement and participation as having been very good for them in many ways. They described the experiences as enjoyable, increasing their confidence, taking away fear, and helping them learn to cope.

*"This group served a bit of purpose of debriefing for a lot of us. ... I think that was very helpful for us probably. ... It was helpful in more ways than just getting the tasks done."*

*"I think preparing the documents was useful too because there was considerable consensus about what was needed and the sorts of questions people would suggest that others ask in hindsight, because at the time, you are in a state of shock."*

All members in the Consumer Reference Groups were satisfied with their involvement. One suggested that the project information sent out to consumers at the beginning should have stated clearly what the project expected of consumer representatives. The consumers felt that the processes utilised by the Consumer Reference Groups were very informative and relaxed, and every member of the group contributed.

*"You are relaxed and there is no tension."*

It was apparent that consumer commitment and motivation greatly contributed to the success of the Consumer Reference Groups.

*"Most of us came to the meetings. I think that is the case. There was quite a lot of motivation ... because you didn't give us gorgeous morning teas. So I think that way you are quite lucky because you asked us to do a job."*

Paying consumers for their participation was seen as positive. However members of the Consumer Reference Groups did not see it as a necessary incentive for participation. The consumers provided affirmative comments on the structure of the Consumer Reference Group's meetings, including frequency and length of meetings, information provision before each meeting, and availability of parking.

### *Being Involved in Other Activities*

Consumers who participated in meetings and other project activities beyond the Consumer Reference Groups reported that their involvement was a learning experience for them, although sometimes they found the subject of discussions rather professional, or not directly relevant to them.

A consumer from the Melbourne Consumer Reference Group thought that some of the meetings she had attended did not function effectively from a consumer perspective.

*"No, I'm not saying that my views weren't important. They weren't properly utilised. There were so many other people who seemed to have a far more concern than just talking to the patient. ... Professional people want to talk to other professionals. ... Just professionals against non-professionals. I think if there were more of us there, it would have had more of an impact. More of a group than singularly."*

Other consumers who were also at the same meeting felt the need to establish middle ground if effective dialogue between consumers and clinicians was to take place.

*"Naturally we have to try to lift ourselves up to the language of the clinicians and they've got to drop down. ... Eventually in 12 months you'd probably have felt very relaxed there."*

### *Being Involved in the CSSP and Impact on Health Services*

All of the participants in the telephone interviews reported consumer feedback in the CSSP was vital in the development of accessible and relevant health services. However, they were not clear about how useful consumer involvement in the CSSP would be, and felt unable to comment about it. It would appear participants had difficulty foreseeing at that time what contribution consumers could make to improve health care services. However, the majority of participants felt that health services had much to learn through consumer feedback and participation. They emphasised the need for health service providers to take into account the perspectives of consumers/patients, and make changes based on consumer feedback.

All of the participants in the telephone interviews reported that they hoped that Austin Health, Bendigo Health and Warringal would note their views, but expressed scepticism/lack of confidence about the development and application of change based on consumer feedback.

The Consumer Reference Group members realised that consumer involvement in CSSP would be useful in helping other colorectal cancer patients.

*"I think what I have learned over the last four months I can possibly feed it back into other future consumers."*

Consumers in both groups felt optimistic about the impact of their involvement on the health care service. They were pleased with the specific tasks they had completed, for example, the three pieces of information materials to be distributed to other consumers using the health service, namely the patient pathways for colorectal cancer operation, a colorectal cancer warning signs poster, and a list of questions to ask doctors booklet.

*"I feel that if those three documents are launched, that will be wonderful. I think that will make me feel that my input has been more than rewarded."*

*"By developing people from the ground floor to help other people, and naturally that will feed through to the clinicians and they'll sort the chaff out from the grain."*

*"I think if anyone is prepared to listen, you can always learn."*

## Lessons Learnt

All of the consumers interviewed expressed willingness to participate and contribute to the project activities at various stages of implementation in spite of their illness. The recruitment of consumers was a sensitive process and required skilled staff, as it involved addressing consumers' emotional, as well as physical issues, related to cancer diagnosis. Further, an important prerequisite for recruiting and engaging consumers is the setting out of the terms of reference of their involvement.

The initial interview was a good experience for all, and was a necessary step to encourage the consumers to participate, in particular for them to consider joining the Consumer Reference Groups. The Report on consumer and carer experience of colorectal cancer developed through the interviews with consumers has been a powerful educational tool for all consumers participating in the project, influencing their understanding of colorectal cancer and providing psychological support.

While the project was effective and successful in enlisting consumer perspectives about their experience of care through the interview phase, the telephone evaluation interviews pointed to an ambiguous consumer relationship to the project. Because the interviews were a one-off event to gather information from consumers, some participants were left feeling unclear about the wider consumer input into the project. These consumers were involved in only one aspect of the CSSP, the information-gathering phase. It is important that this group receive feedback on their participation and on the later developments in the project, by way of a copy of the final project report.

The Consumer Reference Group members' involvement in CSSP was more certain, covering a longer period and a range of activities, and providing guidance for the project staff. This group of consumers not only developed and completed specified tasks; they also clearly expressed the personal benefit gained from their involvement. The involvement process provided them with knowledge and skills regarding the health care system. It increased their confidence, enabling them to comment on issues relating to care and information dissemination, as well as the roles of consumers in health service development.

The project's expectation of consumer participation was achieved, especially through the Consumer Reference Groups' activities. Consumers' personal gain in terms of emotional and educative support was evident. Key members of the consortium have explored processes for ongoing and sustainable consumer involvement through other mechanisms. It appears the members of the Consumer Reference Group were uncertain about their position and ongoing capacity to contribute as consumers within the health service but were interested in opportunities for this to occur.

Finally, the evaluation of consumer participation for those consumers who participated in the initial interviews for the report could have been scheduled earlier in the project, as some were unavailable later in the project. In the case of the Consumer Reference Groups members, evaluation of their participation would have been more valuable if it were done later to give them time to reflect on the process.

## Key Recommendations

To make the process of consumer participation in health services more effective and empowering, it is recommended that:

1. Further training and support for consumers be provided to help sustain their capacity to act as consumer representatives/advocates in activities beyond the scope and life of the project.
2. Consumers' confidence regarding their participation be developed through:
  - informing the consumers involved of the project's outcomes that resulted from consumer involvement;

- informing consumers of changes made in health services due to consumer involvement; and
  - inviting consumers to participate in dissemination of the work to which they contributed, for example, the launching of the three key pieces of work on patient information materials that were part of the CSSP project.
3. Evaluation of consumer participation should be planned as an ongoing process, not a 'one off' activity at the end of the project.

The results of this evaluation have formed the basis for the development of a model for consumer participation in an acute care setting where there is no existing consumer support group. An article explaining the model will be prepared and published in relevant publications. When ready, the model will be available on the National Resource Centre for Consumer Participation in Health's website at [www.participateinhealth.org.au](http://www.participateinhealth.org.au)

## Conclusions

Consumer views about their participation in the CSSP were generally positive. They found the consumer involvement process, from the initial semi-structured interviews to their involvement in the Consumer Reference Groups and joining other project activities, good and educational experiences. For consumers who were engaged longer in the project, such as members of the Consumer Reference Groups, the experience had clearly built self-confidence and knowledge about their condition, health services and participation in health services. They felt empowered to look forward to longer-term outcomes of their participation in the project in several ways, such as the launching of the three key information materials that they developed, so future colorectal cancer patients will be better informed.

Twelve months after the evaluation of consumer participation in CSSP, the consumers still felt their experience of participation in the CSSP satisfying and rewarding. However, being empowered to make changes to the health services did not seem to be their focus. A member of the Melbourne Consumer Reference Group who reviewed this article reflected on his experience and made a comment which summarised the consumers' view of being involved.

*"We were doing a job, and at my age it is good to be wanted and doing something to help others. As a group we had information to pass on, and through debate, we always came up with the goods, putting it into simple words, and helping future consumers with their illness."*

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## Reference

Health Issues Centre 2001, *Clinical Support System Project Austin Consortium: Report on Interviews with Consumers and Carers about their Experience of Care for the Treatment of Colorectal Cancer*, Health Issues Centre, Melbourne.