Southern Health Breast Services

Consumer Participation Project

Evaluation Report

January 2004

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Based on the placement report of 4th year RMIT Social Work student Belinda Mercuri

PROJECT BACKGROUND & REVIEW

Actively seeking the consumer view is more and more frequently relevant to health care organisations. Dr Chris Brook, Director of Acute Care, Department of Human Services says "… evidence suggests that increased community participation in systems planning and delivery can lead to improvements in the quality, safety and accessibility of health care …".

Consumer Participation can be defined as the process of involving health consumers in decision-making about their own health care, health service planning, policy development, setting priorities and quality improvement in the delivery of health services. (Draper, 1997)

In June 2001 Southern Health received BSEP funding for a 12 month consumer participation project, to establish effective and sustainable consumer participation for Southern Health breast services. Since the project status ended, breast services consumer support has been provided by the Monash BreastScreen Senior Community Education worker.

A final year RMIT social work student reviewed the status of consumer participation in Southern Health breast services. The initial project aims provided the baseline for measuring progress.

Project aims:

- To establish a productive role for consumers in Southern Health breast services practice review and policy planning activities.

- To effect an environment whereby breast health professionals at Southern Health accept and welcome consumer input.

- To establish a consumer reference group for Southern Health breast services which is knowledgeable about breast matters, and has the capacity to contribute effectively at a range of levels, from service delivery to policy planning.

SIGNIFICANT PROJECT ACTIVITIES

A consumer reference group (CRG) was considered an appropriate way to establish a baseline resource of consumer input for Southern Health breast services and to date the CRG remains the vehicle by which all consumer input to breast service activities is provided. At the start of the project a consumer advisor was appointed to help establish a Breast Services Consumer Reference Group. The advisor worked closely with the project worker (the Monash BreastScreen community education worker) to identify and recruit appropriate members. The CRG has a membership of women treated for breast cancer. Not all members were Southern Health patients and the time since diagnosis varied by a number of years. The project worker chairs that group and provides executive support. The group membership has ranged between 8-10 in the 2.5 years of its existence and formally meets four times a year, although much contact and project work happens outside those formal meetings. Membership has been sought which reflects some diversity in terms of residential area, ethnicity, age, and breast

disease status. Commitment to a consumer advocate role was an essential attribute for all prospective members.

A formal structure and terms of reference for the CRG was developed by the project team in conjunction with the consumer advisor. Formal processes have been developed and documented for membership recruitment and selection, role expectations and orientation. *[Appendix 1].* CRG members are not appointed as formal representatives of community organisations, but links with an appropriate constituency of women have been promoted and constitute evidence of an appropriate background for prospective consumers.

Orientation and training for all CRG members has been a high priority and members have been helped to identify their training needs and supported in gaining access to training opportunities. For example, most members have been supported to undertake the Breast Cancer Network Australia, Science and Advocacy Training Program. Consumers have also been assisted to attend a number of consumer and breast health related conferences both in Melbourne and interstate. Most of the resources needed to promote training and orientation have been provided within BreastScreen or BSEP, and the orientation process has been labour intensive for staff involved.

Consumers have taken an active interest in numerous breast services review activities such as:

- Patient Held Record Project review
- Breast Care Nurse Project review.
- Lymphoedema 'Early Detection may mean Prevention' project evaluation
- Monash BreastScreen complaints process review.
- Monash BreastScreen accreditation
- End of Treatment group review

Members of the consumer reference group are now being invited to join breast service and broader BreastScreen and Southern Health committees. These include the Southern Health Community Advisory Committee, Southern Health Integrated Cancer Centre Steering Group Committee, BreastScreen Victoria Consumer Advisory Committee, Breast Care Nurses Competencies & Standards working group.

PROJECT REVIEW PROCESS

Evaluation Planning

A reference group was established to oversee the progress of the social work student placement. The group consisted of two members of the CRG, a women's health social worker, the Monash BreastScreen community education worker and the BreastScreen/BreastCare manager. The reference group guided the review process, raising issues, developing methodology, and commenting on findings.

Purpose

The social work student evaluation was designed to establish:

- The level of receptivity to consumer involvement across breast services health professionals and the degree of uniformity in response.
- How consumer participation has worked at different levels in Southern Health.
- Whether the consumer reference group has been an effective way to involve consumers.
- Whether consumers on committees is a positive experience for consumers and health professionals.
- The extent of Southern Health senior management commitment to consumer participation.
- Ways to improve or increase consumer participation.

Enquiries were made around:

- Knowledge within a professional area about consumer participation.
- Staff examples of working positively with consumers in breast services.
- Staff identifying where improvement in consumer participation could be made in their service area.
- Examples of active consumer participation in service planning .
- Staff awareness of the consumer reference group and how to engage with consumers.
- Consumer reference group members being able to identify where they have been influential.
- The level of understanding about the consumer role on a breast services committee (Radiographer Training Centre Advisory Committee) held by all committee members including consumers. Southern Health senior management approach to engaging with consumers at an organization-wide level.

Methodology

Semi–structured interviews were held with numerous key people *[Appendix 2*]. Members of the Consumer Reference Group and a range of key staff in Breast Services within Southern Health management were asked specific questions appropriate to their position.
Questions devised for the CRG were developed after a review of literature and discussion with consumers. Questions being asked of staff were reviewed by the CRG. Interviews were then formally conducted and tape recorded then transcribed and analysed for common themes and issues.

Interviews

<u>Southern Health Management</u>
Director of Operations - Moorabbin site
Business Manager - Moorabbin Site
Director of Clinical Services – Southern Health
Executive Officer Community Advisory Committee - Southern Health
Program Manager Monash BreastScreen & Southern Health BreastCare Project

Southern Health managers and breast services managers were considered pivotal to developing the future directions of breast services. questions focussed on the actions those individuals might take to build a culture which promotes and supports consumer participation.

Breast Services Clinicians
Medical Director of BreastCare
Head of Breast Surgery, Director Monash BreastScreen
Nurse Unit Managers – Chemotherapy Day Unit, Women's Health Surgery Ward.
Breast Care Nurses
BreastScreen Nurse Counsellors
Breast Care Social Workers

These staff work directly with women across the spectrum of breast disease diagnosis and treatment. Questions were asked about how consumers might have some input at a clinical level and about what role they feel consumers play or could play in improving services for women, where consumers could be involved where they currently are not, identifying positive examples of consumer participation, ideas for improving the staff / consumer relationships.

RTC Advisory Committee members
Program Manager Maroondah BreastScreen (Committee Chairperson)
Designated Radiologist Monash BreastScreen
Designated Radiographer Monash BreastScreen
Radiographer Training Centre Advisory Committee Consumer Representative
Program Manager Geelong BreastScreen

The BreastScreen Victoria Radiographer Training Centre (RTC) is managed by Monash BreastScreen. The RTC offers clinical and academic training to radiographers.

RTC Advisory Committee (RTCAC) comprises staff and consumers. Consumer representatives on the RTCAC are appointed from the Southern Health Breast Services Consumer Reference Group. Members of the RTCAC were interviewed to examine both staff responses to consumer presence and the consumer perspective of being on a committee. The questions for the RTCAC focused on the whether the consumer representatives have been active members on the committee, the support the consumer received, staff perceptions about consumer representatives on committees, ways to ensure consumer participation worked better and what attributes a consumer on a committee such as the RTCAC would possess.

Consumer Reference Group

Members of the Consumer Reference Group *(9 members)*

Interview Findings

Radiographer Training Centre Advisory Committee (RTCAC) members

Most reported that the consumer representative was not an active member of the RTCAC, recording very limited participation in discussion, and making very few relevant comments or other significant contributions. Members speculated that this may be due to a lack of understanding about issues placed before the committee. This was possibly complicated by the fact that the RTCAC was a newly established committee with several members new to, and somewhat unfamiliar with the field. A few respondents felt that the most appropriate consumer for such a committee was a radiographer, not a woman diagnosed with breast cancer.

The consumer representative said that although she was provided with reading material, an agenda and other relevant information prior to the meeting, some difficulties she encountered were due to the use of jargon during the committee meeting and the generally technical nature of the discussions. She stated that she saw her role as being more 'passive' and that of an observer. She felt she could not reasonably contribute to some of the things discussed at the committee.

Of note, the Terms Of Reference for the RTCAC specified two consumer representatives, one of which was to be nominated by the BreastScreen Coordination Unit (BCU). As BCU did not manage to recruit, the Southern Health Consumer Reference Group provided the only consumer, and that person changed during the course of the first 18 months of the RTCAC existence. The consumer presentative commented that although she was the sole consumer on the committee, it did not concern her, and that it provided an element of anonymity.

Overall the majority of members of the RTCAC, including consumers stated that a clearer definition of the consumer's role and obligations was needed. One staff member's reservations were expressed as follows: "problems could arise if the consumer role is not adequately defined, for instance consumers may have an agenda unrelated to the RTC". "Consumers raise issues they would personally like addressed, but this may not be the most appropriate place to address issues of a personal or individual nature".

Southern Health & Breast Services Management

Senior management suggested that building the 'culture' which encourages consumer involvement in health service delivery is 'essential' and 'vital', because it has advantages for professionals, consumers and patients alike. Respondents considered it important to understand both community needs and consumer wishes when service development planning activities were undertaken.

They also acknowledged that without senior management 'support' and 'drive', incorporating consumer participation into existing and developing structures would not be successful. Ways to encourage consumer participation should be attempted and 'pushed forward' opportunistically. Furthermore, one respondent felt that it was part of his role to 'help medical clinicians to understand that consumer input is positive, and not an imposition or some inappropriate challenge to their professional autonomy and authority'. This might be achieved by senior management modelling behaviour that they would like to see followed by others.

Consumer involvement is recognised by senior management as being still in its infancy in terms of development, with there being no agreed recipe for the best ways to incorporate consumers successfully into hospital structures. Respondents differed in terms of the most appropriate organisational level for consumer input at site level, with some believing input at senior management level is essential for real change and others believing input at the clinical level isthe most meaningful. Senior management basically all agreed that they must encourage and facilitate different approaches to see which is successful.

Senior management viewed the process of engaging with consumers as 'not a static exercise', and one which requires creativity, flexibility of timeframes and trial periods, and - importantly - appropriate resource allocation. Whilst senior management accepted that there are costs associated with engaging with consumers and that they held ultimate responsibility for resource allocation, the reality is that this is difficult. Setting aside scarce resources solely for the purpose of consumer involvement would bring difficulties given such strong competition for funds. Senior management identified some specific mechanisms they would use to encourage staff to engage with their consumers but which did not have significant ongoing cost implications. These included forums to provide staff, patients and consumers with information; surveys to better gauge opinion on the service being provided; informing staff of specialty weeks i.e. breast cancer week; having more consumers involved in review processes.

Service Managers felt they could both contribute to the development of a consumer focussed culture by being 'creative', and 'supporting creativity'. They considered questions they must address included: 'How might we best engage with our consumers?' 'What can they offer?' 'What can we try?' Additionally, one respondent commented that 'we need to encourage and support staff to respond to feedback and input from patients and consumers'.

Opportunities to explore different approaches to consumer participation were identified. One service manager believed that senior management needed to approach this issue in a slightly different way and instead of asking 'where are the opportunities for consumer participation', they might instead ask 'why would we exclude them? This manager also believed that as the value of consumer involvement becomes more recognised, its existence more prevalent and embedded into organisational structures, this changed focus is inevitable.

Service Managers acknowledged their responsibility for building and enhancing the consumer/ staff relationship, backed by their senior managers. This process might start by managers becoming aware of the strong role consumers can play and reinforcing this with staff. It was acknowledged that not all staff are as supportive or 'switched on' as they might be to consumer involvement. Therefore identifying and supporting opportunistic collaborations between staff and consumers was considered a vital management role in facilitating changed attitudes. Several respondents expressed hope that over time consumers are just 'accepted without being noticed', demonstrating that consumer involvement would not be 'token gesture' but in fact, an integral component of service planning and delivery.

Both senior and service managers spontaneously commented on the positive relationship existing between Breast Services and its consumer body. Terms used to describe this relationship were 'relevant', 'functional' and 'sensible'. It was also noted that management felt the breast services consumer representatives at Southern Health are 'knowledgeable', 'articulate', 'useful' and 'make a real contribution'.

Several respondents commented that despite there being few recognised indicators for effective consumer participation, breast services consumer engagement had so far been positive. Development of such indicators might be a helpful process, with one possible indicator being around consumers not only being 'welcomed' onto a range of diverse committees, but ensuring that consumer representation is heard on these committees. Another indicator might be for 'the current structures that are in place to reflect a consumer driven attitude'. The development of the breast services Patient Held Record might be a useful study to demonstrate such an attitude.

Additional comments made by respondents included that it was important that consumer representatives be 'robust' individuals. This means that consumers must be able to handle some of the challenges that come with the role such as rejection of ideas, and suggestions for change not being acted on, regardless of the intensity of a desire for that change. However, it was also considered important that consumers 'have some wins' as this allows consumers to feel validated and know that their contribution is recognised and effective.

Nurses, Nurse Unit Managers and Social Workers

Respondents reported that consumers play a 'significant' and 'essential' role at the service delivery level. They identified several specific service developments where consumer involvement improved service or enabled health professionals to better target service delivery or where it supported health professionals working for changes to service delivery. One respondent commented that the expectation of scrutiny from interested consumers also plays a role in the working relationship between consumer and staff, encouraging staff to routinely evaluate plans with a consumer in mind.

Southern Health breast services was credited with having some vision around consumer participation, which worked in practice when coupled with commitment and dedication from women. Specific improvements were cited, including the 'End of Treatment" group, the Patient Held Record, and the establishment of the Consumer Reference Group, as a point of consultation.

Future opportunities were many and included involvement with planning for an Integrated Cancer Centre and involvement in strategies to seek service feedback from users.

Most respondents suggested that increased benefits from this relationship will flow as staff increase their contact with consumers through project work and group work.

Consumer Reference Group (CRG)

Consumers were asked if they could articulate the drive to them becoming consumers in this field. All members were women with breast cancer, although not all had been treated in the Southern Health systems. Most expressed a desire to use their own experiences to help others. Some wanted to turn what had been a negative experience into a positive one, some felt their actions would result in a sense of personal achievement.

All considered they were providing a voice for women who have cancer. Having this voice heard by professionals and the wider community really made operational the notion that women can help other women. CRG members felt that the attributes of an effective consumer representative included commitment, passion, and the ability to listen and learn and a belief in the primacy of patient interests. Essential qualifications included having some knowledge about health services and the interest in and insight into hospital service organisation. Agitating for change was important and being a consumer at the health service level meant being engaged by the detail and understanding the boundaries and barriers whilst being able to identify real opportunities for change. Many of the CRG members are also members of consumer groups operating at different levels, with participation on one group being helpfully informed by participation at the other level.

Consumers believed their value to service review and planning lay in their bringing to the table the deeply personal nature of cancer, with one consumer commenting that their presence draws professional attention to the consumer voice. All respondents felt that a consumer group is a useful form of consumer involvement because issues that affect the consumer can be explored, while supporting other members and sharing information.

Most CRG members considered their good working relationship with Southern Health staff as a positive group achievement, with one remarking that being accepted onto other (than breast cancer related) committees signified real achievement. Others believed that making professionals and the community aware of the presence of the consumer group was a positive outcome.

Also acknowledged were some personal benefits such as friendships and support networks, as well as developing a better understanding of the hospital process and organisational structures.

The overwhelming majority of the group stated they felt supported by staff within the breast services areas and felt they all shared together frustrations such as funding insecurity for the breast care nurses and the lymphoedema service.

CRG members consider the composition of the group ‘unfinished’ in terms of diversity with one respondent expressing this as ‘not exclusion, but an ongoing process of inclusion’. Women with secondary disease, women with a disability and NESB women - particularly Asian women are notably absent.

DISCUSSION

Committee Roles for Consumer

This review found both consumer and staff unclear about the role and responsibility of consumers on the Radiographer Training Centre Advisory Committee (RTCAC). Most staff on the RTCAC queried what consumers were actually able to contribute to a committee that is focused on technical and strategic issues.

However, despite acknowledging these issues, CRG members consider they have a valid contribution to make. Despite their contribution being initially limited in terms of their technical knowledge, consumers have the capacity to develop a better understanding of the technical nature of RCTAC deliberations particularly if more lay language was used.

Further, consumers can add to committees of a technical nature an appreciation of how the changes in treatments or service associated with the strategic and technical issues may affect health outcomes for women (Consumer Focus Collaboration 2000). So, the contribution consumers make may not necessarily be of a direct nature, but the importance of maintaining their presence on such committees is significant.

The Consumer Collaboration Focus (2000) emphasises the importance of adequately defining the expected role of the consumer on a committee as well as every other committee member, and having this formally documented.
As the committee membership is being reviewed as part of the RTC pilot evaluation, the consumer input should be specially considered. Several staff commented on the definition of consumer being more appropriately a radiographer but there is reluctance from both management and CRG to changing the consumer role at this early stage.

Staff/Consumer Collaborative Opportunities

Nursing and social work clinicians had the least difficulty identifying opportunities for collaboration and expressing unconditional enthusiasm for working closely with consumers. Nurses, (particularly the breast care nurses) and social workers believe it is in everyone's interests that they work more directly with consumers. These two groups of staff generally accept a liaison role between patients and clinicians, and as such are perhaps best placed to see real and potential benefits of such a close working arrangement.

There are many ways a more direct relationship between clinical staff and consumers might manifest itself. Staff identified real interest in more routinely and possibly even informally using consumers as a sounding board for specific change. This is evidence of a significant level of trust and respect for the existing CRG members. Setting up a process which resulted in open dialogue and free information exchange is an exciting opportunity in terms of developing an environment which is receptive to real consumer input. However also recognized is the reality that the consumer resource is small and needs 'protection' in that CRG members already donate significant amounts of time in the interests of the women following them. This probably

means that communication between staff and CRG members is probably best organized more formally in the first instance.

Staff also suggested that specific project or group activities may enhance the staff/consumer working relationship and expressed interest in engaging with consumers at every opportunity.

Consumer Representation & Diversity

“Many health services are limited in their capacity to provide appropriate and accessible services to the diverse community in which they exist” (Consumer Focus Collaboration 2000). In light of this information it is important to consider how to better engage and include community members who are not being adequately represented.

Senior management believes that seeking input from their community is important, but defining the community is not always easy. Geographic borders are insufficient, but are those most often used to broadly describe a community. Those who are offered treatment constitute one boundary of consumer, and breast cancer affects women primarily. Yet women are mostly part of wider groups – partners, family and friends all of whom might be affected by such a diagnosis. Stage of disease is a unifying feature of some diseases, and the needs of people at different stages of breast cancer treatment are known to be significantly different. Ethnic diversity is a significant feature of the community in which the breast services of Southern Health operate, yet CRG members felt strongly the absence of women from diverse backgrounds, such as women from Non-English speaking backgrounds (NESB). Similarly at different times the CRG recognized that they needed to hear from women with progressive disease, women who are diagnosed at a younger than average age and so on.

The importance of diverse consumer representation in groups such as the CRG is vital to being able to successfully represent the needs and views of different sectors of the community, leading to a richness of women’s experiences being shared and acknowledged. Furthermore, it allows for communication around some of the barriers to consumer participation to be identified and addressed.

Being expected to represent all consumers is acknowledged as a difficult task but as a baseline it means particularly aiming to include those sections of the community who may find that their particular needs are not even acknowledged by health services . Such known barriers include cultural and socio-economic factors, and issues of power and attitude. Other areas identified by consumers include a lack of community awareness or knowledge of issues women are facing.

This process of identifying and engaging with the community is ongoing and slow. There are no quick fixes. It will involve engaging service users and identifying potential consumers in an appropriate manner.

CONCLUSION

The positive nature of the early stages of consumer participation in breast services at Southern Health is readily acknowledged by consumers and a broad range of health service staff and managers. Further, senior health service managers knew about, or reported active involvement with the breast services CRG and universally welcomed and applauded the attempts of breast services to develop real partnerships with its consumers. Both consumers and staff also acknowledged that real resources had been allocated to supporting the development of this system of care which is trying to be more formally respectful of its consumers.

Breast services were acknowledged by Southern Health senior management as being leaders in the organization in terms of developing systems of care which reflect consumer engagement and which are receptive to consumer input.

Whilst there was general agreement across all management groups that service review and development will increasingly include engagement with consumers, the degree of appreciation and enthusiasm with which that understanding was expressed, varied somewhat. There was no strong agreement or any real common understanding of what active consumer engagement might look like. This may simply mean that at different levels of the organization, approaches to consumer input are appropriately varied. It may also reflect the limited experience many staff reported about formal engagement with consumers.

The CRG was considered a useful and essential baseline from which to develop processes for positive consumer engagement. The group itself was able to reflect on its own membership and terms of reference and members seemed to feel unconstrained by the group's formal framework. Indeed they felt the group structure supports the individual consumers involved and strengthens their recommendations for change. Whilst it might demonstrate solidarity to members, having a supported group process also demonstrated safety to senior management, enabling them to make requests for representatives from that group to serve on some significant and senior planning groups in Southern Health.

Whilst the group composition might need some modification from time to time, it is fair to say that general opinion was that the group members were responsible, interested, intelligent and unafraid and that the group process and structure was a factor in its success. Clearly a group does not survive without the commitment of management for resources. However resources alone are not an indicator of success. Establishing such a group requires the commitment of an individual who will push to find the best way for consumer interests to be met , who will push to find the best consumers, who will push to support the individuals and the group and who will act as the liaison person between the consumer group and significant others.

Ongoing support, including financial support for the group is essential for it to maintain the momentum developed over the past 2 years. That the CRG is as successfully identified with breast services is a significant reflection of the commitment of the Monash BreastScreen community education worker.

It seems fair to say that whilst no staff rejected the legitimacy of consumers having a place around the table, there was some uncertainty about the actual value resulting from individual consumer activities. Some staff interviewed for this review formed their opinions about the

success of consumer engagement on their participation on the RTCAC where the single consumer was unsure of her role and the other members were no clearer, it being a new and evolving committee involving new knowledge for all members.

This review would suggest that there are likely to be other processes and projects which might serve to better link consumers and staff than those which revolve around committee membership. Projects which involve consumer input and specific review activities whereby consumers accept responsibility for undertaking certain tasks are likely to prove valuable in demonstrating the benefit of consumer engagement to those staff who have had no opportunity to see this in practice. For example, it is hope that consumers will take a more active role in reviewing service complaints in BreastScreen. This task is unlikely to be time consuming for consumers, is likely to educate consumers as to the sorts of complaints women make about the services they receive, and so allow consumers to consider driving service reforms for repeating problem areas.

Activities where the consumers are freed from the restraints of committee structure, meeting process, terms of reference, technical jargon etc are likely to serve all interests.

The staff who had no doubt that engagement with consumers would be helpful and who simply wanted more of it, were those staff with direct responsibility for taking up the liaison role between patients and medical clinicians. These staff, generally nurses and social workers are those who hold enormous knowledge about the impact of treatment on individuals and families and who more or less automatically take a consumer viewpoint and who are unafraid to check their viewpoint against a consumer's reality. They report back to clinicians on the acceptability of various treatment or care systems and as they often bridge the gap between hospital and home or community care, they are repositories of knowledge about ongoing problems post acute care. The synchronicity of purpose between these staff and the consumer is clear. To link the consumer with such staff is likely to result in significant improvements in patient care. Staff understanding, when coupled with the experience and drive of consumers is likely to result in a mutually energizing and fruitful arrangement when visions for change are shared.

It might be helpful for management to consider constructing opportunities for other staff to engage with consumers in a way which can highlight the known and well recorded benefits of such liaison.

CRG members were not appointed as representatives of other organizations. However to be effective, they must be able to take a step away from simply representing their own experiences and so seeming to meet their own personal needs. The CRG can itself help in this regard, with group process being a strong safety mechanism. Another way this can be facilitated is for consumers to have associations or links with others, either in individual connections or via organized groups or associations.

However it happens, it is clear that for consumers to be trusted and accorded respect they must be able to represent those whose experience is different from their own.

The future of consumer participation in breast services at Southern Health is looking healthy. Those with the capacity to help or hinder seem mostly helpfully intentioned, albeit not always clear about what will constitute helpful action. This means that the original project aim of

facilitating an organizational environment receptive to consumer input is not yet achieved. However the senior management interviewed are respectful of this ambition and strongly supported it at a theoretical level. Resources to support and nurture this early stage development in breast services have been allocated but if those resources were withdrawn it is doubtful that the consumer gains made to date will be sustained. Staff who work with patients directly are enthusiastic and are likely to continue to be welcoming of such involvement. Finally and most significantly, the consumers are committed, both personally and as a group to representing the interests of women to service providers, and to engage in whatever activities are likely to bring about necessary change in service delivery.

This total combination of factors and approach meets the starting requirements for successful consumer engagement.

References:

1. The Consumer Focus Collaboration (2001) *The Evidence Supporting Consumer Participation in Health*. Australia

2. Draper, M. (1997) *Involving Consumers in Improving Hospital Care*: Lessons from Australian Hospitals. Commonwealth Department of Health and Family Services

3. L. Innes, L. Bowen, N. Bruce, L. Scott and P. Williams (2003) *An evaluation of Consumer Participation in Hospital Breast Services.* Blackwell Publishing

4. National Resource Centre for Consumer Participation in Health (2003) *Methods to Consumer Participation*. Fact Sheet No 2. Latrobe University.

RECRUITMENT AND SELECTION PROCESS
FOR CONSUMER REPRESENTATIVES IN SOUTHERN HEALTH BREAST SERVICES

Selection Criteria

As far as possible the group will include women from culturally and socially diverse population groups and age groups, women living in the Southern Health and Mornington Peninsula health regions, and those who have an awareness of the consumer advocate role. Women with a particular interest in breast services or breast disease will be sought. Ideally one or two women with a breast screening perspective will be included.

Recruitment

Women meeting the above criteria are sought through the following channels:
Breast Cancer Network – formal nomination process
Cancer support groups
Community Health Services
Neighbourhood Houses
Specialist agencies eg. disability organisations
Suggestions from current consumer reference group

Terms of Reference and a Role Outline will assist in recruiting and informing potential consumer representatives.

Selection Process

An initial interview will be held with a potential consumer representative to discuss the role. The interview is undertaken by two of the following: the Monash BreastScreen Senior Community Educator, the BreastCare Project Worker and the Consumer Advisor. The aim is to provide an informal forum for discussion of expectations, meeting schedules and processes, orientation and training. The meeting is held in a venue which is acceptable to the potential consumer representative.

At this meeting an information package is provided which includes information about Southern Health Breast Services, role outline, terms of reference, breast cancer information websites and the Little Purple Book of Community Rep-ing. A BCNA folder is also available.

The two interviewees will make recommendations based on the interview, which will be discussed with the third project member and the BreastCare Project Manager. Women who can demonstrate a sound understanding and commitment to health concerns will be selected.

A letter of offer from Monash BreastScreen and Southern Health BreastCare Program Directors is sent to suitable consumer representatives.

Women who are not considered suitable will be contacted to explain that their help is not needed at the moment and to thank them for their time.

Checklist

An orientation checklist has been developed to guide the selection and orientation process.

Position Review
Members will be appointed initially for a two-year period and may be re-appointed. An individual interview will be held with representatives close to the end of their two-year term to review their role. A letter will be sent inviting members to make a time for this interview.

Vacancies

Where a vacancy exists in the group we will try to replace current members with one with similar background/representation.

Women who have been identified as interested and suitable for the group but no current vacancy exists will be placed on a waiting list.

Terms of Reference

Breast Services Consumer Reference Group

Responsibility
To inform the Monash BreastScreen and Southern Health BreastCare projects on matters of relevance to women with breast disease, particularly those matters relating to service provision, gaps in service provision and service delivery.

Membership

Monash BreastScreen Community Education Worker (Chair)
BreastCare Project Worker (Deputy Chair)
Breast Services Consumer Advisor (Minutes)
10 Consumer Representatives
Additional people may be co-opted to the committee from time to time

Consumer representatives

As far as possible the group will include women from culturally and socially diverse population groups and age groups, women living in the Southern Health and Mornington Peninsula health regions, and those who have an awareness of the consumer advocate role. Women with a particular interest in breast services or breast disease will be sought.

Term of Appointment
Members will be appointed initially for a two-year period and may be re-appointed.

Quorum
At least 5 people

Meetings
At least quarterly, and more frequently as issues arise

Reporting Lines
Responsible to BreastScreen Community Education Worker. Communication with BreastCare and BreastScreen Management will be through minutes of meetings and written reports.

Representation
BreastCare Steering Committee (Consumer Advisor represents group)
BreastScreen Management Executive (one consumer appointed by BreastScreen Manager)
Statewide BreastScreen Consumer Advisory Committee (one consumer appointed by BreastScreen Manager)

Decision making
Decisions will usually be reached by consensus but if such efforts fail, a vote may be taken and decisions carried by majority vote. The chairperson will have the casting vote.

Interviewees

Southern Health Management
Mr. Peter Faulkner - Director of Operations at Moorabbin site
Mr. Ying Can - Business Manager Monash Medical Centre Moorabbin
Dr. Syd Allen - Director of Clinical Services Southern Health
Ms. Claire Murphy - Executive Officer Community Advisory Committee at Southern Health
Ms. Louise Bowen - Program Manager Monash BreastScreen & Southern Health BreastCare Project

Breast Services Clinicians
Mr. Derek Richmond - Medical Director of BreastCare
Mr. Stewart Hart - Head of Breast Surgery, Director Monash BreastScreen
Nurse Unit Managers – Ms. Nicole Kinnane -Chemotherapy Day Unit, Ms. Sharon Roberts (acting) Women's Health Surgery Ward. Ms. Gemma Sacco – Breast Services
Breast Care Nurses – Ms Jenny MacIndoe, Ms. Fran Bell, Ms. Katie Evans
BreastScreen Nurse Counsellors - Ms. Rani Perera,
Breast Care Social Workers – Ms. Gaylene Reid, Ms. Laurel Warhurst

RTC Advisory Committee members
Ms. Michelle Muldowney - Program Manager Maroondah BreastScreen (Committee Chairperson)
Dr. Jill Evans - Designated Radiologist Monash BreastScreen
Ms. Jayne Mullen – Designated Radiographer Monash BreastScreen
Ms. Sandra Taylor & Ms. Barbara Bursztyn – Radiographer Training Centre Advisory Committee Consumer Representative
Ms. Yvonne Hewitt – Program Manager Geelong BreastScreen

Consumer Reference Group members

Ms. Barbara Bursztyn
Ms. Pam Williams
Ms. Mary Macheras-Magias
Ms. Tina McDevitt
Ms. Joan McDonald
Ms. Suzanne Phillips
Ms. Caroline Petrakis
Ms. Nicola Bruce
Ms. Margaret Dikes