Consumer Participation in
Australian Divisions of General Practice
A Case Study Report.

June 2002
Foreword

Consumer Participation in Australian Divisions of General Practice: A Case Study Report aims to describe the consumer and community participation strategies in three Australian Divisions of General Practice.

This Case Study Report is one component of the National Resource Centre for Consumer Participation in Health’s Primary Health Care Project. This project, funded by the Department of Health and Ageing (DoHA), will contribute to the knowledge base, literature and evidence supporting consumer participation in primary health care and the health sector more generally. The project will also develop resources and products for distribution by the National Resource Centre that are applicable to the broader health sector.

The National Resource Centre for Consumer Participation in Health (Centre) is a clearinghouse and centre of excellence for consumer participation in health. A consortium of the Health Issues Centre, Australian Institute for Primary Care and the Women’s and Children's Hospital, Adelaide sponsors the Centre, and it is funded by DoHA.

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- From North West Melbourne Division of General Practice, Victoria.
  - Carolyn Searle, Executive Officer
  - Emily D Amico, Health Promotion Program Coordinator
  - Dr Sue Hookey, Chair of the North West Melbourne Division Board of Directors
  - Dr Paula Sullivan, General Practitioner and former Community Action Forum Representative
  - Debra O’Connor, Consumer Representative
  - Rose Bushby, Consumer Representative

- From Southern Division of General Practice, South Australia.
  - Ian Dobbie, Executive Officer
• Dr Helena Williams, Medical Director
• Samantha Battams, Health Services Coordinator (1998-May 2002)
• Trevor Parry, Consumer Representative
• Tina Griffin, Consumer Representative

From St George Division of General Practice, New South Wales.
• Dr Klaus Stelter, Executive Director
• Vanessa Rivers, NESB Program Coordinator
• Leslie-Ann Pullen, Community Liaison Officer
• Linden Harper, Quality Use of Medicines and Enhanced Primary Care Program Officer
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• Elizabeth Martin, Consumer Representative on St George Division of General Practice Management Committee

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Introduction

Divisions of General Practice (DGPs) were set up in 1992 to enhance communication between individual GPs and improve integration within the wider health system. A Division is a local network of GPs. There are 123 of them across Australia. Many of these DGPs have involved consumers and the community in the planning and implementation of their work. This case study report: Consumer Participation in Australian Divisions of General Practice, documents the consumer participation approaches of three DGPs and in doing so endeavours to contribute to the knowledge base supporting consumer participation in the primary health sector.

Aim

The aim of this project was to describe consumer and community participation in three Australian Divisions of General Practice (DGPs) using a case study approach. This report explores the impetus for involving consumers, as well as enablers and barriers to consumer participation efforts.

The case studies:
- Document the rationale for involving consumers;
- Describe the desired outcomes of consumer involvement activity;
- Describe the methods employed to involve consumers, and;
- Describe the enablers and barriers to consumer participation efforts from both the DGP and consumer’s perspectives.

Rationale

There are two reasons why a case study approach was used. Firstly, although there are a number of reports examining the role of Divisions of General Practice, there are only a small number of examples describing the approach taken by Divisions to engage consumers. Secondly, the Centre has learned that referring health providers to examples of where others have successfully engaged consumers is a highly effective method of explaining the rationale and benefits of consumer participation in health. This approach has been reinforced by the Centre’s work with the Consumer and Provider Partnerships in Health project and its development of examples of consumer participation in practice.

Background

We began this study with a review of existing models of community and consumer participation in Australian DGPs. (Appendix 1.) This literature review outlines the history of the establishment of Australian Divisions of General Practice and details the models of consumer participation employed since the establishment of the Divisions program.

Methodology
The literature review showed that little information about consumer participation in General Practice was available, thus a qualitative methodology (Patton 1990; Yin 1989) based on the construction of case studies was used to explore and describe the issue in Australia.

**Sampling method**

A purposive sampling method (Patton, 1990) was followed for the selection of the key informants for the case study. Consultation with key stakeholder organisations that are engaged in working with DGPs served as the basis for the selections of the sample. These include:

- Australian Divisions of General Practice (ADGP);
- State-based General Practice Organisations (General Practice Divisions, Victoria; Alliance of New South Wales Divisions; South Australian Divisions Incorporated; Queensland Divisions of General Practice and Western Australian Divisions of General Practice);
- The Primary Health Care Research and Information Service;
- General Practice Branch, Commonwealth Department of Health and Aging; and
- The General Practice Partnership Advisory Council’s Consumer Standing Committee.

Purposive sampling was also aided by the identification of all DGPs that have formal mechanisms for consumer participation using the Primary Health Care Research and Information Service Annual Survey of DGPs 2000/2001.

Case studies were then selected from the list of potential sites based on the advice of the Commonwealth Department of Health and Aged Care, General Practice Branch and the Primary Care Project’s Steering Committee.

**Sample**

The Divisions selected to be part of the case study were:

1. The **North West Melbourne DGP (NWMDGP)** in Victoria. This DGP is classified as an urban Division with 350 GP members. Its consumer participation strategy currently includes a Community Action Forum, consumer representation on program committees and consumer and community members with voting rights on the Division’s Board of Directors.

2. The **St. George Division of General Practice (SGDGP)** in New South Wales. This urban division in South East Sydney has 200 GP members. Its consumer participation strategy currently includes a Non-English speaking background (NESB) Committee, a Community Liaison Officer, and a consumer representative on the Management Committee.

3. The **Southern Division of General Practice (SDGP)** in South Australia. SDGP is an urban-rural Division with approximately 450 GP members. Its consumer participation strategy includes consumer representation on program committees and two consumers as observers on the Division’s Board of Directors.
We compiled a profile of the selected Divisions was compiled from documents available at their Internet sites and preliminary informal interviews conducted with Executive Officers by telephone. This covered such matters as the background of the Division, its location, size and structures, roles and responsibilities of staff and a general overview of their consumer participation strategies. These telephone interviews also served as the first point of contact to identify the potential relevant participants in the study and to schedule the time and places for the interviews.

**Key Informant Interviews**

Eighteen face-to-face interviews were carried out with Executive Officers, Program Managers, Coordinators, General Practitioners and Consumer representatives of the three selected Divisions of General Practice. Triangulation at each site was achieved by conducting multiple interviews.

The interviews followed a semi-structured guide and each interview lasted between 30 and 60 minutes. The interview guide consisted of four main themes:

- The history of consumer participation in the Division;
- Processes for consumer participation strategies;
- Barriers and enablers to consumer participation in the Division, and
- The future of consumer participation in the Division.

The interview guide was pre-tested with people of similar background and in similar settings to those under study. Most of the interviews were conducted at the DGPs headquarters with two consumer representatives interviewed in their homes and one general practitioner interviewed in her surgery. Only consumers were remunerated for their participation in the study.

All the interviews were tape-recorded and fully transcribed. All participants were given an opportunity to comment and correct a draft version of this case study report.

**Analysis**

The analysis of the transcripts of interviews consisted in three stages:

1) Reading the full transcript of each key informant’s interview;
2) Conducting a thematic analysis (Patton 1990) of the contents of the transcripts; and
3) Writing a summary of findings under the four headings of the interview guide: history, process, barriers and enablers and the future of consumer participation in the Division.

The case studies also include emerging themes and a list of overall tips for DGPs planning to develop their own consumer participation strategies.

The information collected through interviews was complemented by relevant documents made available to the Centre by the participating Divisions of General Practice. This included: minutes of meetings, committee terms of reference, guidelines, annual reports and information distributed to prospective consumer members.
Case Study 1: NORTH WEST MELBOURNE DIVISION OF GENERAL PRACTICE.

The North West Melbourne Division of General Practice (NWMDGP) define themselves as “a network of local GPs working together to improve the health care in our community.” Its catchment area includes the northwestern suburbs of Melbourne. The local population is 258,156 and the Division’s current GP membership is 350.

The NWMDGP has a long history of consumer and community participation activities. General Practice Divisions Victoria (GPDV) nominated NWMDGP as the Victorian Division with the most experience in consumer participation. The Division is recognised by both providers and community/consumer organisations as leaders in consumer participation.

Interviews with six people involved in NWMDGP’s consumer participation strategies were held between 15 May and 30 May 2002. They were:

- Carolyn Searle, Executive Officer;
- Emily D Amico, Health Promotion Program Coordinator;
- Sue Hookey, General Practitioner and Chair of the NWMDGP Board of Directors;
- Paula Sullivan, General Practitioner and the former Community Action Forum GP Representative.
- Debra O’Connor, Community Action Forum member and Consumer Representative on NWMDGP Board; and
- Rose Bushby, Consumer Representative on the Community Action Forum.

HISTORY

Consumer participation strategies: an overview

The North West Melbourne Division of General Practice has the following Consumer Participation strategies in place:

1. Board of Director Level: The NWMDGP Board consists of 10 Directors; two of these positions are held by non-GPs. The first is a consumer representative and the second is a community representative. Both the consumer and community Board members have full voting rights and the same conditions and terms of reference as the GP members. The Board is responsible for the overall direction setting for the organisation.

   The consumer representative was appointed by the GP membership to the Board in 1999, and the community representative was appointed in September 2001. Prior to the consumer representative becoming a full Board member with voting rights, she attended Board meetings as a representative of the Community Action Forum and had observer status.

2. Community Action Forum (CAF). This group has up to ten members and is formed from a combination of both community and consumer members. It was established in 1996. The aim of the Community Action Forum is to advise the North West Melbourne Division of General Practice on matters and issues from a consumer/community perspective. Their roles and responsibilities are to:

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2 ABS 1996 Census.
• Provide information and advice from a consumer perspective to enhance the role and work of the North West Melbourne Division of General Practice
• Discuss and comment on the needs of the community and issues related to general practice;
• Advocate on behalf of the community on health issues;
• Actively work toward strengthening the communication links between consumers and GP's;
• Comment on current and future programs and activities of the Division
• Advise on the content and planning of education sessions;
• Share experiences and support other consumers who are working with Divisions of General Practice; and
• Report to the GP membership through the North West Courier; the Division's monthly newsletter. ³

The CAF includes members and network members from a variety of groups including: Moreland Carer's Association, Centrelink – Multicultural Service Officer, Council of the Ageing, Men's Health and Wellbeing Association, Consumer Health Forum, Mental Health, Women's health in the North and Broad Insight Group Northern Suburbs Lupus Support Group.

3. **Consumer Representatives on Program Committees.** Members of CAF determine whether there is a need to be involved at program level and they appoint a consumer representative to participate. Not all of the NWMDGP committees have consumer representation.

4. **Community Participation.** The NWMDGP is also involved in community festivals and external activities where they engage the broader community. For instance, they have GPs who do regular radio interviews and write articles for local newspapers.

This case study will focus primarily on the development and integration of the Community Action Forum in the work of the NWMDGP.

**Origins**

In 1996, the Commonwealth Department of Health and Family Services provided funding to the NWMDGP to undertake a Community Liaison Project.

Paula Sullivan is a general practitioner who was involved in setting up the Community Action Forum in 1997. She was employed by NWMDGP for 20 hours a week along with a Community Liaison Project Officer. She was involved in building awareness of the need for consumer participation within the Division:

*We had a very small Board at that time. So we started off just within the organisation, by exposing the Board members to the concept of consumer participation and how important it was. We then worked with the project officers and the staff. They got to come along to CAF and talk about their projects and by doing this they realised its value and the things that they might not have considered otherwise. Then we started writing articles in the newsletter about what the consumers were doing and the value their perspective had brought to the Division.*

³ www.nwmdgp.org.au
When the funding finished in 1998 it became the role of the Health Promotion Officer to continue to engage with the CAF and the CAF has remained a core part of the NWMDGP’s management structure since this time.

**Model for consumer participation**

Paula Sullivan remembers:

*From the start we were very keen on having a committee that was properly consumer based. The Consumers Health Forum had put out a publication⁴ that talked about different models and how and where to find consumer representatives. We also talked to the Health Issues Centre in Melbourne.*

Debra O’Connor is a founding member of CAF and the current Consumer Representative on the Board. When asked about the model on which the CAF was based, she notes:

*It was based on a standard representative advisory group model. We did a needs analysis and this identified people from different demographics that were particularly vulnerable. We determined that an advisory group was a way to understand their needs. There were some fairly innovative and thoughtful GP’s who were prepared to listen to the idea. It wasn’t accepted by them all.*

The CAF has both community members and representatives appointed by consumer and community organisations.

**Initial invitation to consumers**

The process of inviting consumers to participate in CAF was time intensive and involved personal approaches to organisations. The outreach process also included the production of written material about the Division and the purposes of the CAF.

Paula Sullivan remembers:

*Kim (the Community Liaison Project Officer) and I went around and actually door knocked organisations. We were very much met with the feeling of suspicion. Organisations needed to be convinced that GP’s were serious about talking to consumers. I think it helped to have a GP actually be part of the team that approached these groups because it meant that it wasn’t just people saying GP’s were interested, it made it a bit more personal.*

Rose Busby was recruited to the first CAF meeting back in 1996 and has been a member of CAF since this time. She was then a representative for the Council on the Ageing (COTA). COTA asked her to participate in the first CAF meeting. Rose tells this story of what she thought would be involved:

*She (The COTA representative) said, well look Rose it will be straightforward: if they bring a new bandage out, you’ll be asked to try them and say what you thought of them. But we got there Paula outlined what she wanted, and I just sat there in a daze. Because as you know, all*

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these health people talk in acronyms, and I didn’t have a clue what they were talking about. So I went back to COTA the next day and I said look I can’t do this. I said its got nothing to do with bandages, they’re talking about bringing the consumer and the doctor closer together, and to advise doctors and get doctors to talk more freely to the consumer. I said “I don’t know what they’re talking about”. They said, don’t give up after one meeting.

Rose did continue to attend, and she is a valued contributor to CAF 6 years later. Both the Division staff and the consumer representatives on CAF learned together what both sides needed to make the group work and to support the membership.

Based on feedback from their consumer representatives and Division staff, the NWMDGP have refined their processes to recruit consumer and community members to CAF. Emily D’Amico is the Division’s Health Promotion Officer. Her role includes supporting the group. Now when new members are required, there are processes and policies in place to provide accessible and easily understood information about what CAF do and what is required from members. As Emily explains:

There’s the CAF brochure, which says a bit about what CAF do, who can be a member, how to become a member. But there have also been articles in the local paper about CAF. Some of the members are people who’s GP has said, you should think about joining CAF. The Division want a broad member base with people from different backgrounds to get the most input from all sorts of areas.

Rose also argues that participation based on an individual’s own agenda is not acceptable:

We don’t want people who are going to push their own barrow. One of the big issues is they have to be community minded.

**Funding arrangements**

The original Community Liaison Project which established CAF was funded by the Commonwealth Department of Health and Family Services. This included a budget for staffing a Community Liaison Officer and a GP to work on the project for 20 hours per week. Money for infrastructure was included and this covered items such as administration support, venue and catering allowance and travel for consumer representatives. Consumers were paid for their time at a rate of $25 per hour.

When the funding for the Community Liaison project ceased, the Division recognised the value that CAF added to the management of the Division and continued to provide staffing and support, although this became part of the Health Promotion Officer’s role.

Rose Bushby remembers that when the funding for the initial project finished, the CAF membership had some ideas about how to continue to fund the Community Liaison Officer’s role:

I’ll tell you this is how highly we all thought of Kim. We offered to withdraw our payment, if they would keep Kim in a job. Because she was terribly dedicated, along with Paula, two excellent people.
This did not happen, but helps to demonstrate how much mutual respect existed between the CAF members and the Division staff. Instead the CAF has continued to be funded through the Division’s infrastructure budget. Members continue to be paid for their involvement at a rate of $25 per hour. Carolyn Searle underlines the importance of providing budget resources. She notes:

*Divisions must have voted allocation for it. The CAF budget is approximately $10,000 each year.*

**Equal payment to all participants**

Another innovative approach taken by NWMDGP is that all Board members have the same conditions and are paid at the same rate. Carolyn Searle notes that:

*All the Board members have an annual retainer of $4000.*

This is quite different to other Divisions of General Practice who usually use different payment rates for general practitioners and consumer representatives. It underlines the equal status of all Board members. As Debra O’Connor states:

*I have the same conditions and am not seen as a second-class Board member in any way. It’s really important.*

**PROCESSES**

**Communication strategies**

NWMDGP and the CAF publish a regular newsletter called *Health Links*, which is distributed to community groups, patients and health consumers in North West Melbourne. This newsletter provides an update to the community on the work of CAF and invites feedback and comment from the community.

**Community participation and core business**

In *Joint Forces – GPs and Consumers*, Dr Ralph Audehm states: “Consumer input is important to ensure project direction is relevant to both GPs and the local community.” He also emphasises “the need for consumer input and involvement in all Divisional Projects.”

In *Making consumer participation an integral part of a Division of General Practice* Kim Hider writes:

*The establishment of a CAF model as a channel for consumer involvement and participation into a Division of General Practice will always prove challenging. However from the North West Melbourne Division of General Practice’s experience, the CAF model offers an excellent way for consumer integration into general practice. It offers an effective mechanism for the Division to gain input from the wider community on local health issues, and is establishing itself as an extremely valuable and integral part of the Division.*

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6 *Making consumer participation an integral part of a Division of General Practice*, Kim Hider, North West Melbourne Division of General Practice, 1997, p 2.
The NWMDGP have a number of strategies in place to ensure that consumer participation is linked to the core business of the Division. Including:

- A GP Board member who is the GP representative on CAF.
- The Board requires that each new Board member attends one CAF meeting. So that they can see at first hand how CAF works.
- The Board and CAF have a combined strategic planning day.
- CAF are involved in the evaluation sub-committees
- CAF members have strategic input into the Continuing Professional Development (CPD) program for GPs. CAF members are invited to attend and if CAF members deem it appropriate, have a consumer speak to provide a consumer perspective into the program.
- CAF are always involved in the development of business plans and strategic plans.
- Consumer Representatives participate in the Program Committees.

Paula Sullivan explains some of the philosophy behind the evolution of these strategies:

*I think it was important that there was that liaison between the CAF and the Board. Now we’ve got someone from the CAF on the board, which was always the committee’s aim. Though I must admit I was skeptical about whether they’d achieve it at the start, but we got there, probably because our CEO was really on board with it. I think the more positive the experience at the start the easier it was to move people through those changes. Importantly, CAF were involved in projects from inception through to completion.***

Rose Bushby confirms this:

*We’re all on the different committees of the program areas and we all report back to CAF. I myself am involved in Illness Management, Chronic heart disease and diabetes programs.*

**Champions for consumer participation**

The consumer participation strategies in place at NWMDGP appear to be strongly embedded in the values of the Division. Efforts to establish the CAF and its continuation for six years has been the work of particular individuals.

When the original funding for the CAF finished, there was a strong view from one of the GP members of the Board that the CAF continue.

Carolyn Searle commented:

*She (Dr Paula Sullivan) was really the driving force with keeping it going. My individual perception was that the majority of the other Board members didn’t necessarily have a strong view either way. But because Paula was there with a very strong view about the value of engaging the community, it was allowed to continue.... You absolutely have to have a GP champion.*

In addition to this GP champion, the Executive Officer had a sound background in community and consumer engagement:

*I had very strong views about the value of engaging consumers in health issues and what was required to ensure that your engagement with consumers was meaningful engagement. I encouraged the management to*
think about including the consumers in the Board and to actually set the priorities for the strategic plan. Then when I took over as executive officer I put a recommendation to the Board about restructuring all of the committees. Because a number of different committees were meeting, but none were related to one another and they actually didn’t report to the Board. So it was a very, very poor governance structure. I developed terms of reference for each of the committees and made the reporting and accountability lines very, very clear. This included that the consumers actually need to report directly to the Board. That is the model we have continued to use.

This illustrates that in addition to a GP champion, management structures and support are required to inform and sustain the process. While writing this report, the Centre received an email from Rose Bushby requesting to add on the record that the Executive Officer had been a 'staunch supporter of CAF'.

Culture clash

Each of the people interviewed had a different perspective on this notion of a clash of cultures between consumers and general practice. Interviewees identified past conflictive episodes involving particular individual styles, but also there was acknowledgment of culture clashes that have been overcome in time.

Carolyn Searle, commented:

We had an occasion last year where there was a member of CAF that was a single-issue person and who had a very strong dogmatic personality. Arising out of that there was tension within CAF itself because the Division operates in a very cooperative way. My perception was CAF was finding it very difficult to deal with this member. In the end she resigned. Everyone breathed a sigh of relief. This was unfortunate because she did have something to contribute but she was dealing with it in an aggressive way. So it was more to do with the way she was dealing with it rather than the processes of CAF.

Debra O’Connor noticed an initial clash of cultures, but this has become less of an issue for her both as a CAF member and Board member with the cross fertilisation between both groups:

What’s broken that down a bit is having a GP member of the Board on CAF, and having the consumer on the Board.

Paula Sullivan talks about this in terms of initial perceptions and how these were broken down as the consumer participation strategies evolved over time:

GP’s had a perception of consumers being these loud lobbyist’s. So they just needed to be exposed to the reality of people having information to share.

For Rose Bushby, breaking down perceived cultural differences was about building trust over time:

That was a big thing at the very start. That we weren’t there as a group to bash them. At every meeting we invited one of the doctors from the Division to come and sit in on our meetings. In terms of different cultures Rose says: I grew up in an age where the doctor was a god. You did exactly what that doctor told you. But now I see doctors as human beings. When you work with them you do gain more insight into what they have to put up with and what they do.
Education and support for consumers

The Health Promotion Officer is responsible for supporting the CAF and this includes assisting with functions such as minute taking, setting the agenda in consultation with the CAF chair, distributing relevant papers and newsletters to the group between meetings, organising the venue, catering and payments. CAF members are encouraged to contact each other and are provided with contact details for CAF, Divisional staff and the Board.

A Community Action Forum Information Guide has been developed which clearly outlines the following:

- CAF Terms of Reference;
- CAF Terms of Membership;
- Meeting Schedules;
- Background documents on General Practice Representation across Australia;
- The NWMDGP Committee Structure;
- A list of Divisional Staff, their role and how to contact them;
- An outline of the Division’s Strategic Plan;
- The CAF Annual Report;
- A list of Consumer participation in health organisations at both State and National level;
- A list of acronyms used in health care; and
- Brochures on both NWMDGP and the CAF itself.\(^7\)

Paula Sullivan, reflecting on the early days of CAF notes:

Support was required, initially informal, but has become more formal as CAF has evolved. The members weren’t just new to Divisions, they were new to committees and new to the jargon of politics and all the funding arrangements. So there was a lot of just walking through it together and getting a feel of what people were interested in doing, and what was achievable.

Carolyn Searle discussed the education and support mechanisms:

Any consumer activities the GPDV are put on we’ve always encouraged the consumers to go to that. We use the annual planning day, partly as personal development and partly as developing CAF’s plan. We’ve sent a few CAF members to consumer conferences.

Debra O’Connor notes that there is a gap between the support consumer representatives receive through their involvement with NWMDGP and the broader Divisional organisations:

Consumers feel supported within the NWMDGP structure but not within the wider Divisional movement. I’ve been trying to lobby to get some sort of network of consumers involved in divisions across the state set up.

Emily D’Amico has watched individual consumer members of CAF become more confident in their role over time:

Now we have a rotating chair, whereas for the first five years there was just the one chair the whole time. Also there was the one CAF Board

\(^7\) Community Action Forum Information Guide, North West Melbourne Division of General Practice.
member for the last five years, and now some of the member are thinking,

oh yes I might be able to give that a go, and they’re going to go along to
the training and try to get someone else to take over, which I think shows

signs of maturity of the group.

In terms of training and support for the Board, Sue Hookey notes:

Board members all participate in the same training. So I just see us all as
Board members, not people with particular hats on.

**Evaluation**

In 1997 the Health Issues Centre evaluated the CAF\(^8\). The evaluation reports pointed out:

*Within the NWMDGP the CAF has established the foundations for continued consumer involvement and participation. The high level of participation and commitment of the CAF consumer members and the project team in the establishment and running of the CAF has resulted in widespread benefits. However, the establishment of the CAF is only the first step to consumer participation. Within the NWMDGP, the CAF currently holds a peripheral position in relation to the board and the Division. If consumer involvement is to become integral to the working of the Division, consumer input must extend beyond the CAF. Mechanisms must be adopted which enable consumers to become involved in the Division’s policy formulation and decision making on consumer concerns, in the development of projects and in extending the links between the Division and the community.*\(^9\)

This conclusion was considered by the Division, and following this, steps were taken to close the gaps identified by both introducing consumer representation on to the Board and involving consumer representatives at program and project level.

This has been the only formal evaluation to take place to date. Informally however, NWMDGP have continued to fund and support the CAF due to the added value and perspective it brings to the business of the Division.

**BARRIERS AND ENABLERS**

**Enablers**

Interview participants were asked what elements within the Division make consumer participation work. The universal theme was the need for commitment to the strategy and the need to have supporting structures in place.

Carolyn Searle said:

*I would suspect that there wouldn’t be a single Board member that would advocate ever dismantling CAF. This commitment comes from seeing examples of how it works, so you can really recognise the value of*

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engaging consumers. The other thing to recognise is that it is hard. You can’t just set it up and then walk away from it. It will have its ups and downs. I know some people have said to me they don’t want to do it just in case they get that really dogmatic consumer. You have to be very clear about what you’re expecting out of it. That clarity then has to be transferred to the consumer members themselves so they’re very clear about what their role is as well.

Emily D’Amico agrees:
Consumer participation strategies take time to develop because it involves building up all that level of respect and trust, until it becomes part of the culture that people accept.

Debra O’Connor underlines the importance of allowing consumer representatives to have time to settle in to their role:
You can’t expect consumers to get up to speed in the first 12 months. Most of our consumers, at the end of six months they’ve said, oh this is too hard, I don’t understand what’s going on. At the end of 12 months they’ve said, oh I’m beginning to understand a bit. Divisions need to realise, it actually does take time, it takes time for Divisions to become used to the idea of consumers being involved, and not worried that they’re going to be angry, attacking consumers. Also for consumers to understand what their role might be in Divisions.

When asked about the characteristics of success of the consumer participation strategies at NWMDGP, Paula Sullivan said that having consumer involvement as part of the core structure of the Division and having good communication mechanisms in place are paramount:
You need really good liaison between the CAF and the Board, and some sort of formal reporting between the two. Then it needs to be incorporated into the structure of the organisation so that it’s no longer considered an extra, but its part of the core business of the Division.

For Sue Hookey the characteristics of success were related to an openness to the reality of the community and a stepping outside of the doctor’s role:
The added value is not being so doctor centric. It can really open up a new dimension. So CAF helps us think about the broader community and its needs.

Rose Bushby characterises this in terms of what the Division and the community gets from CAF:
I think the Division gets a true sense of what the community out there is feeling about them, because we’re in such a diverse population.

**Barriers**

Each participant had a differing perspective on the barriers they encountered as the consumer participation strategy developed and evolved.

From Carolyn Searle’s perspective, lack of clarity around the role of the CAF was a barrier initially:
I think CAF had its major hiccup when we were having trouble with engaging people. It was because the role of CAF wasn’t really clear.
This was addressed through the development of an engagement strategy, terms of reference for the CAF and structuring the committee to be part of the Division’s management.

Emily D’Amico focused more on the physical constraints that setting up meetings sometimes entailed:

Some people do have disabilities and this needs to be accommodated. People have got to be aware that consumers may need transport and additional support to attend meetings.

For Sue Hookey, the constraints had to do with the perceptions of some of the general practitioners in the Division. Her comments relate to consumer representation on the Board:

A lot of the barriers are in the minds of the doctors. How do you put a price on the participation of consumers, so that there is not a divide between first and second-class citizens? That’s where I think a lot of boards would have stumbling blocks- with paying the consumer representatives or the non-medical reps the same as the other board members.

Debra O’Connor sees the barriers from the perspective of broader community participation. She argues for a need to think about broader consultation mechanisms so as to breach the situation that having a CAF prevents the Board of Directors from reaching and seeking feedback from the wider community:

Sometimes having a CAF absolves the Board from thinking more broadly about other public consultation processes.

**Tips and recommendations from the Division**

Participants were asked to give their tips to other Divisions who may be considering setting up consumer participation strategies

Debra O’Connor’s tips were:

- To have a three year time line not one.
- Ensure there is some infrastructure support and particularly funded support for consumers.
- A budget to support extra activities.
- As well as having an advisory group, include a consumer representative on the Board. This is critical to give credibility to the activities of the group.
- Be very clear about what the Division wants from consumers.

Emily D’Amico agrees that an advisory group needs time:

The Group itself needs time to bond and GP’s need time to get used to having consumer groups. We’ve got this situation where the consumers really feel like the Division want them and are looking after them and supporting them, and they know its not just a token effort.

Emily D’Amico noted in her review of a draft of this document, that DGPs setting up similar models for consumer participation need to recognise the amount of time that the designated staff member puts into maintaining the group.

Paula Sullivan recognises the importance of evaluating the process:
Set some goals and then have some structure in place for allowing an unbiased look at what you’re doing and what works, both from the point of view from the Board and the GP’s, but also the consumers, because it’s very easy for them to not feel like they’ve got a voice at all.

Sue Hookey has the following tips:
Certainly tips are things like head hunting, or getting credible consumers. Its getting people to think using a team approach and that you are looking at a skills analysis of the board and where the gaps are. You need to get a broad range of skills.

THE FUTURE

All of the people interviewed believe that the CAF has a strong ongoing role in the Division’s activities. All spoke about the added value that CAF had bought to the Division’s work and believe that the CAF will continue. There are however, some ideas about how the role of CAF could evolve in the future, and some ideas for amplifying the range of activities, which they undertake.

Carolyn Searle said:
I’d like now to start using CAF as a means of encouraging GP’s to have consumer input at the practice level. So they can engage with their patients about how the practice operates and explore issues around communication, the services that the practice makes available to its patients. Maybe the role of the practice nurse, use of recall systems etc. That to me would be the next logical step.

Debra O’Connor pointed out:
I think renewal is important. How do we actually renew the CAF and draw in new members and the broader consumer network. If the Division had $10,000 I’d put that into a project about developing a public constituency around the CAF for the Division.

I think it’s important to mentor new leaders in CAF. In fact everyone is having a go at chairing this year.

There is a need for statewide network of consumers in Divisions, and maybe an opportunity to have a forum every two or three years to share some of that bigger picture stuff, and to showcase what people are doing.

Rose Bushby said:
I think we should probably have another consumer representative on the board. Two heads are better than one.

Sue Hookey stated:
In the future I would certainly hope that we can consolidate what we have done. We see CAF very much as being an important part of the Division’s work and it will continue to be funded.
Case Study 2: ST. GEORGE DIVISION OF GENERAL PRACTICE.

"The St George Division of General Practice (SGDGP) aims to promote General Practice and support General Practitioners in their own right and enhance their ability to provide quality primary healthcare to the community. It also aims to promote and foster strong and productive alliances with local hospitals, health and community services, both public and private, in pursuit of the best possible health outcomes."\(^1\)

The St George district is located along the edge of Botany Bay and bounded by the Cooks River to the North, the Georges River to the south and Salt Pan Creek to the West. At the 1996 Census, there were 197,875 residents in the St George District. \(^1\) There are 200 GP members.

SGDGP’s were nominated by the Alliance of New South Wales Divisions (ANSWD) and the Health Services Development Branch of DHA as being a NSW DGP who actively promote consumer participation strategies as part of their work. This was confirmed by the SDGP Executive Director, Dr Klaus Stelter, who met informally with NRCCPH staff prior to case study selection and who was able to corroborate the Division’s work in this area.

Interviews with 7 representatives of SGDGP consumer participation strategies were held on the 28\(^{th}\) May 2002. They included:

- Vanessa Rivers, Program Coordinator and Mental Health Program Officer;
- Lesley-Ann Pullen, Consumer Liaison and Women’s Health Program Officer;
- Linden Harper, Quality Use of Medicines and Enhanced Primary Care Program Officer;
- Mariam Faraj, Non-English Speaking Background (NESB) Program Officer;
- Ibtisam Hammoud, Al Zahra Muslim Women’s Association;
- Bee Koh, Chinese Australian Services Society Cooperative Ltd. (CASS); and
- Elizabeth Martin, Consumer Representative on SGDGP Management Committee.

History

Consumer participation strategies: an overview

The St George Division of General Practice has the following consumer participation strategies in place:

1. The Consumer and Community Liaison Program: this program has been running for five years and aims to develop and maintain partnerships between the Division, consumers and local health and community services. A Community Liaison Officer was appointed by the Division when the program started in 1996 and a NESBAvisory Committee was established

\(^{10}\) www.stgeorgedgp.asn.au/
\(^{11}\) www.stgeorgedgp.asn.au/
to support the program. The Advisory Committee has been active in developing forums, which meet the needs of the community and provide the Division with a ‘public face’. In the second half of 2002 the Division will undertake a Community Needs Assessment to further inform the program.

2. The NESB Health Program was developed to respond to the primary health needs of the non-English speaking background (NESB) communities in the St George district. The Division, through the NESB Program is involved in collaborative projects including investigating attitudes towards smoking in the Chinese community with SEH Health Promotion Service, and the Maternity Access project in the Lebanese community with SEH Women’s Health Service. The SGDGP also liaises with the St. George Hospital Multicultural Health Committee, the St George Ethnic Interagency, the Young NESB Women’s Action and Access Project (St George Youth Workers Network) and the Al Zahra Muslim Women’s Association.

Other activities include: the cervical screening mini-clinics targeting Arabic speaking women and the development of the Traditional Chinese Medicine (TCM) Resource Kit which is available to assist GPs in managing patients using both western medications and traditional Chinese medicines. The TCM kits, developed by the Division, have received publicity in a number of medical magazines including *Medicine Today* and *Medical Observer*.12

3. At the Management Committee level: the SGDGP have had a consumer representative on their Management Committee since 1995. When the interviews took place, Ms. Elizabeth Martin, the current consumer representative, was very new in her position. She was appointed in February 2002.

**Origins**

The SGDGP Consumer and Community Liaison Program and the NESB Program have been in place for five years.

Lesley-Ann Pullen, the Consumer and Community Liaison Officer at SGDGP explained:

> The Consumer Program was started when the Commonwealth Department of Health called for expressions of interest for funding in the area of Consumer Participation. The Division applied for the funding, and once the funding ran out, made Consumer Liaison part of their core business plan.

> In 1996 the first needs assessment was done... NESB wasn’t actually covered, so a subsequent NESB needs assessment was undertaken in 1997.

The result of that needs assessment was the Division’s appointment of Mariam Faraj to the role of NESB Program Officer. She recalls:

> The NESB Needs Assessment came about on completion of a Community Needs Assessment in 1996. Due to time and financial constraints the initial report did not include the health needs of the non-English speaking residents in the area. As a result the Division sought funding to carry out

12 [www.stgeorgedgp.asn.au/](http://www.stgeorgedgp.asn.au/)
an NESB Community Needs Assessment as the non English-speaking residents made up about 33% of the population back then.

In addition to Mariam Faraj, who did the Arabic needs assessment research, the Division employed other bilingual workers who carried out the needs assessment for the Chinese, Macedonian, Greek and Italian communities. Mariam remembered that their work was part of a larger research project involving other issues such as women’s health and traditional Chinese medicine:

The NESB Needs Assessment involved interviews with GPs and key stakeholders as well as focus groups with consumers in their main community languages. A number of new health programs were developed as a result of the findings. These included the Arabic Women’s Program and as part of that the cervical screening mini-clinics, a broader NESB Health Program was subsequently developed which included the Traditional Chinese Medicine strategies.

Model for consumer participation

The Division undertook research on current models for consumer participation[For a description of models on consumer participation see the National Resource Centre for Consumer Participation library or their website]. The Division also followed the specific requirements that the Commonwealth Department of Health had in place when calling for expressions of interest.

Lesley-Ann Pullen explained:

To set up the Consumer Program the Division investigated how other organisations were involving consumers and how they encouraged participation. The Consumer Health Forum information was consulted, as was the Support and Evaluation Resource Unit [These were academic units set up by the Commonwealth Department of Health to support DGP's with education and evaluation resources].

Vanessa Rivers, the current Programs Coordinator, reviewed the policy statements when she began her position in 1998 and evaluated the documents as positive starting points for the development of the program. Her involvement has meant that participation of consumers has extended from consultation to involvement in all stages of the program. She explained:

We were reasonably well aligned with the policy already, so it seemed to me that the Division was going in the right direction. But, [I thought] that we could possibly have more involvement with consumers in terms of not just the planning of activities and not just consulting them about needs, but actually including them in implementation. A full circle involvement.

The NESB Program implemented a model by which the project workers liaise directly with consumers. These project workers carried out research resulting in the first NESB health needs assessment of the Division. This was based on feedback from a series of focus groups.

Mariam Faraj explained:

Consumers were heavily involved in the NESB Needs Assessment. We held focus groups in the five main community languages, using project workers who spoke the language. Three focus groups were held in each of the community languages.
Consumers are represented in various programs within the Division. For instance, the Diabetes program had a dedicated consumer representative who has enhanced the implementation of this program by the unique perspective he brings. Vanessa Rivers explained:

*Our diabetes consumer has great interest and real commitment to educating people and to helping people with that condition. It’s where new people see a great need or they see that they can make a difference or a change, then that’s really motivating for them [consumers].*

**Initial invitation to consumers**

The SGDGP has developed a variety of methods to invite consumers to participate. Lesley-Ann Pullen explained:

*We advertise for consumers in our consumer newsletter, which is published quarterly. This newsletter is sent to the consumer groups that we have on our database, and also to all GP surgeries. We also have close links with [other] centres in the area and can advertise through their newsletters. We haven’t actually got to the stage of advertising in the local paper, but that would be another strategy we would use if necessary. Sometimes through liaison with our stakeholders we may find a consumer who uses, or is involved with, their services. That way we can find a consumer who has an interest in a particular health issue.*

Mariam Faraj explained how she engaged the community for the research with focus groups:

*I liaised with a number of community groups including the St George Migrant Resource Centre and Multicultural Day Care Centre in an effort to involve consumers in the research project. I went along to these community groups and invited consumers to participate. The one to one approach was effective for recruitment. I also approached small community organisations like the Al Zahra Muslim Women’s’ Association. We also recruited participants by placing fliers in GP surgeries, placing ads in community language newspapers and on local radio.*

Linden Harper, the Quality Use of Medicine and Enhanced Primary Care Program Officer, explained how she develops consumer engagement in projects. She referred specifically to the development of the Traditional Chinese Medicine Resource Kit and to the Enhanced Primary Care Program.

*The Traditional Chinese Medicine Kit had consumer input. I have liaised with community groups and delivered talks to many community areas on the Enhanced Primary Care items.*

**Funding arrangements**

After having used the initial funding given by the Department of Health to promote consumer participation in Divisions, SGDGP incorporated the NESB Program and the consumer participation strategies into their core financial business.

Lesley-Ann Pullen explained:

*After the initial funding from the Department of Health, the Division felt Consumer Liaison was important and added it to their core business plan.*
Vanessa Rivers also explained:

*My understanding was that the Division continued funding because it was recognized as being important. With a 30% demographic of NES, how can you not? It was always seen that we had to represent our member base. It was always seen that we needed to address consumers and NESB issues.*

**PROCESSES**

**Communication strategies**

The Consumer and Community Liaison Officer publishes a quarterly newsletter called *Consumer Focus*. This newsletter is included in the *St George Division Newsletter* and is distributed to all GPs in the Division. The newsletter includes: advertisements for a variety of health promotion programs, offers services such as the *Division’s GP Speaker Program* (talks given by GPs on general medical issues), profiles on community groups and services in the St George Area, and, when needed, invites consumers to be involved in the Division as consumer representatives.

The Division has an *Application for Consumer Representative* form, which is filled in by people interested in becoming members of a representatives committee. SGDGP has developed a *Consumer Participation* information document. This document includes the job description, the terms of reference as well as a list of eligibility requirements, a list of qualities the Division would look for in nominees, the expectations the Division has for consumer representatives, and the commitment the Division has to support consumer representatives.

**Consumer participation in organisational structure**

Since its inception, consumer participation has been part of the organisational structure of the Division. Financial planning and definition of priority programs have included consumer feedback and the Division considers consumer participation as core business. The Division also tries to ensure that consumer representatives have links with either a constituency, or various community groups. This helps to ensure that the perspective provided is wider than simply that of the individual representative and that consumers, the community at large, and specific community groups (eg. NESB) are represented.

Lesley-Anne Pullen explained:

*Initially the Consumer Liaison Program was a program on its own. We have subsequently changed the program structure because we found that wasn’t as effective as it could be. So now we have Consumer Liaison as a strategy within each of the programs. We also try to have consumer representatives on Program sub-committees, so that we can get some sort of feedback from the communities. Usually we like those consumers coming on the sub-committees to have involvement with an outside consumer group, then they can report back to us, about not just what they think but what their groups think as well.*
Vanessa Rivers also explained the structure of the Division in terms of consumer involvement:

We have a board and then we have sub-committees that report to the board. We have an NESB sub-committee that has GPs, consumers and consumer organization representatives, and they organize strategies around the needs within that area of primary health care, which then gets reported back to the board.

We also have a general Consumer Program and that’s related to issues that affect consumers. So we might do a consumer foot care group because it ties in with our diabetes program. For instance, Linden did a talk to the Chinese group on coughs and colds, and antibiotic taking.

Vanessa Rivers also values having, within an organisational structure, a dedicated Program for NESB issues. She explained:

I don’t know whether integrating it across the programs is a [good] strategy, because sometimes it can get lost then, whereas if it’s a stand-alone program with an organizational structure with a committee behind it, then you have an energy to tap into. So I think that having a dedicated program focussed on NESB issues serves a function.

Vanessa Rivers also sees having GPs from NESB communities on the Board of Management, as a strategy for consumer participation.

In line with this understanding, Vanessa Rivers also sees as relevant the involvement of all GPs in the Division in NESB issues. She explained how the work undertaken by the NESB Program Officer meant an inclusion and subsequent acceptance of NESB issues by GP members.

You also need an approach that is not just sending out a letter [saying]: "would you like to come to something?"... She [NESB Program Officer] door knocked and said: "Hello, I'm Mariam, I'm a Program Officer"... and basically established a personal contact. [This] means that now, five or six years down the track, you can send Community Organisations a written invitation and they will respond to it, whereas they wouldn’t respond to the initial one. So you really have to put in your groundwork.

Mariam Faraj sees advantages in having a NESB Program within the Division’s organisational structure in that it benefits both, GPs and consumers. She explained:

We are here to support GPs and as part of that work we also have to enhance the health of their patients, who are the consumers. So there is a role for us to work directly with consumers to enhance general practice.

Ibtisam Hammoud, the Community Services Settlement Officer from the Al Zahra Muslim Women’s’ Association sees advantages in being part of divisional committees that are core business for the Division. Establishing relationships with the staff members and meeting them at different committees help to build rapport.

We’ve had a good relationship with the Division. I mean definitely through the project officer, through the staff, and meeting a lot of them on different committees, we’ve built a rapport with them.
**Champions for consumer participation**

Commitment and understanding of the issues involving NESB communities from all the GPs working in the St George area, coupled with a commitment at the management level, was seen as essential for the implementation of the consumer involvement strategy.

Lesley-Ann Pullen explained:

*We can only assume what consumers are feeling about health issues or about anything, we really can’t know for sure unless we ask them. Thus their input is important and therefore valued by the Division.*

From the point of view of management, Vanessa Rivers explained:

*I believe that you can make a difference for these communities and that you do it in partnership. So it’s about valuing members of the community and about valuing their input. We pick up partnership projects with the Area Health Service to do with the communities, where we can work in with them by giving the GP perspective or looking at how general practice can support. Often it’s health literacy, it’s how can you use what you’ve got to make a difference to them.*

Mariam Faraj explained how historically, management support has been important:

*The director of the Division at the time was aware that we had a high NESB population some of whom were unable to speak English, with unmet health needs. As a result the NESB Needs Assessment Project was developed. From its initiation it was strongly supported by a number of GPs including Dr Ven Tan who was the GP Advisor. The program also gained support from a number of other GPs during different stages and as new programs where developed. Dr Mervat Mohamed was involved as the Arabic Women’s GP Advisor, we also had the support of Dr Mahmoud Hourani particularly with the cervical screening mini-clinics and antenatal shared-care. We also had involvement from Dr Paul Lai and Dr Leonie Yen with our TCM project.*

Ibtisam Hammoud also explained how management support is relevant:

*I think for anything to continue you’ve got to have the management behind it. You’ve got to have people there who have a goal of where they want to go and reach and this will then affect the morale of the staff, and they will strive for it.*

Vanessa Rivers also sees specific individuals working at the management level, essential for consumer participation:

*We have doctors like Dr. Ven Tan who is on the board, and on the NESB committee, who gives real support.*

**Education and support for consumers**

Vanessa Rivers explained how the Division supports its consumers. Formal support at SGDGP includes an orientation and a package of written information, which outlines the role of the Division and its programs. She also pointed out the importance of having program officers who are involved in the affairs of the community.
You orientate consumers, give them an introduction into the Division, outline their role and their expectations around their role and up-skill them in being consumer representatives. The other thing I decided was as well as having them on our committees we should be on their committees. Mariam was the representative on the Al Zahra Women’s Committee. Al Zahra is the local mosque; she has a position in their organization, so therefore gets feedback about what they’re doing and also what issues are relevant to that organization.

Mariam Faraj, referred to the financial remunerations given for their participation and the orientation given to newcomers:

We pay consumers for their expenses about $25 an hour. In some cases we provide childcare as this may be a barrier for participation.

Evaluation

There has been no formal evaluation of the Division’s consumer participation strategies. Informally however, the Division chose to continue funding consumer participation strategies through its infrastructure budget when the Community Liaison funding ceased in 1998. This helps to demonstrate that the Division saw value in the strategies being used.

Lesley-Anne Pullen explained:

All our initiatives in regard to community events are evaluated to see that we are meeting the needs of the participants.

BARRIERS AND ENABLERS FOR CONSUMER PARTICIPATION.

Enablers

Commitment and an interest in the health issue that consumers are asked to be involved with were seen as enablers of consumer participation.

Lesley-Anne Pullen explained:

Having consumers who are interested or involved in some way with the particular health issue we wish to address enables us to plan and implement a consumer strategy.

Vanessa Rivers said that an enabler for consumer participation is the way in which priorities are set in the Division. To have a focus around diseases only does not seem to encourage participation as much as focussing around diseases and population groups. She explained:

This Division chose to prioritise programs around diseases as well as population groups. We have a Diabetes Program and also a Women’s Health Program, which focuses on women’s health issues.

Another enabler is the general attitude that the Division may have towards consumers. Vanessa Rivers explained:

I think it’s about being involved with consumers, being open to partnership with them and advocating for them when they need it.

Mariam Faraj referred to how supporting consumer representatives is a definite way to enable consumer participation:
Providing consumers with some information or training about their role is important. It is also important that you provide payment for consumer participation and alleviate some of the barriers. Things to be aware of are access to the venue, being close to transport or in a familiar location, providing services like childcare is also a good way to encourage participation particularly if you are targeting women.

Ibtisam Hammoud points out that the person who takes the role of Program Officer is relevant for consumer participation:

Mariam being the Program Officer from a Muslim background, knowing the barriers and speaking the language as well, helps to break down a lot of the barriers.

**Tips and recommendations from the Division**

Ibtisam Hammoud (Al Zahra Muslim Women’s Association) and Bee Koh, (Chinese Australian Service Society (CASS), pointed out the relevance of cultural differences within ethnic communities. They see a specific responsibility of the Division to assess the reality of the communities so as to engage with them in a meaningful way.

Ibtisam Hammoud explained:

It is important for Divisions to do their homework, to find out who lives within their community and not lump everybody together in the same basket. Because, for example, I may be talking about Muslim women, and this can be a Muslim woman from the Middle East from Africa, Australia, from any country, it really doesn’t matter. Some things are essentially the same, but there are some cultural [aspects] that may be different. People have to find out from that community what their needs are and how to work with them. We can’t have one blueprint for everyone.

Ibtisam Hammoud also made some practical recommendations that point towards best practice:

Always have written information available. We’ve had sessions where the women take [information] to their family members: they may not be able to read it, but their daughter or granddaughter can. Also work closely with local GPs as that’s where people go for their health needs. Those GPs have a wealth of information as well about the community, about the issues, so working together with them is important.

**Barriers**

Key barriers to participation were identified as lack of training for consumers to develop skills such as note taking, public speaking, knowledge of the health systems and support for consumers such as remuneration or reimbursement for their time, cost of travel and child care. Use of English and technical language and other cultural issues were also considered key barriers to participation.

Vanessa Rivers referred to the need of training to consumers:

Without orientation and support consumers are unsure of their role. Their value is diminished because they never say anything.
Mariam Faraj, Ibtisam Hammoud and Bee Koh were of the opinions that time constraints were a barrier for consumer participation. Bee, who is the General Manager of a large organisation, said that the requests her organisation receives to represent the Chinese community are so many that she has difficulties attending meetings. Lately, she has assigned another staff member to attend the Division meetings as she values the work the Division does in reaching out to the community.

Mariam Faraj explained that although time is a constraint, the greatest barrier is still related to lack of training:

*Their own commitments to family and time and access, location, they’re all big factors and they always play a role, even [for] participation in forums and seminars. Very difficult because of all these barriers, you’re looking at time, childcare, how are they going to get there. But as far as meetings are concerned and having them on board, I think the biggest barrier is the training.*

Lesley-Ann Pullen and Ibtisam Hammoud referred to the use of technical language in meetings and to other cultural factors that act as barriers to participation. Lesley-Ann explained:

*[In] our meetings with consumers we can sometimes be too technical. I think we need to take the time to explain what we’re doing. The idea is to make our services helpful so the consumers will benefit.*

Ibtisam Hammoud explained some of the wider cultural factors that may act as a barrier to participation. These may transcend the use of English and or technical language and refer to cultural attitudes towards expressing opinions and putting forward ideas:

*The language that is used. This is something new to many people. From a lot of countries that these people come from this is a brand new thing to them. They feel a bit intimidated.*

*It could be also that people are not sure what their role might be. They know that a person has a right but how to talk about those rights, or ask. That’s the barrier that we find. Unless they’ve got the English language or even some education, it’s difficult for them to speak up.*

Linden Harper referred to lack of areas of interest for people to participate and the cases in which people would like to participate only to put forward a particular agenda:

*We have had difficulties recruiting people to sit on committees at times. The time factor and a lack of understanding of what we want from them are a barrier. Then I think possibly in some scenarios a consumer who is pushing their own barrow, who can monopolize perhaps and be tunnel visioned with what they’ve come in to the arena to do. I’ve seen that happen. The facilitator needs to incorporate the need of that consumer, in time bring that out into the open, but not focus on that.*

**The future**

Updating the Health Needs Assessment with input from the community that will feed into the Division planning was seen as an important task. Networking and supporting the current consumer representatives was also mentioned as future tasks for the Division.
Lesley-Ann Pullen said:

At the moment we are putting together our recent Community Needs Assessment. We’ve involved consumers from all areas, age groups, different genders, and different nationalities. This Needs Assessment will help drive our next strategic plan, which is due to start towards the end of the year, and be completed by early next year.

Vanessa Rivers explained:

I think that our Needs Assessment, where we actually do consultations with the community at large, which is your focus groups and your questionnaires and your stakeholder interviews, we do that every three years, on an ongoing basis. I would also think that we would possibly look at having meetings with the consumers maybe twice or three times a year to bring them together as a group. Talk to them about what their needs are, and trying to see what training is available.

Mariam Faraj was of the opinion that consumer participation will continue to be core business for the Division:

I think the consumer participation will always be an important part of the Division’s programs. Consumer input is a core part of how the Division operates, and I think that will definitely continue.
Case Study 3: SOUTHERN DIVISION OF GENERAL PRACTICE.

The Southern Division of General Practice's vision is “to be a united voice empowering general practice in the south. Their mission is to “ensure that GPs feel valued and rewarded, that general practice provides systematic and quality services, and consumers are partners in evidence based care”.13

Membership is open to all general practitioners providing primary care in the southern area of Adelaide, South Australia. The southern area is bounded to the north by Cross Roads, Anzac Highway, Fullarton Road and extends south to Victor Harbour and Kangaroo Island. The Division is classified as both urban and rural. Currently, 455 GPs are members of the Division. In 1996 there were 320,590 people in the region covered by SDGP.14

South Australian Divisions Incorporated (SADI) nominated SDGP as the South Australian Division with the most experience in consumer participation. Additionally, organisations such as South Australian Consumer Representatives Network and South Australian Health Consumers of Rural and Remote Australia Inc validated SDGP as a Division who had put ongoing energy and effort into their consumer participation strategies. The Primary Care Research and Information Service (PCHRIS), based at Flinders University were also aware of the work done in this area by Southern Division of General Practice.

Interviews were held between 23 May and 24 May 2002 with five people involved in SDGP’s consumer participation strategies. They included:

- Ian Dobbie, Executive Officer, SDGP;
- Helena Williams, Medical Director, SDGP;
- Samantha Battams, Health Services Coordinator, SDGP. From 1998-May 2002;
- Trevor Parry, Consumer Representative and observer on the SDGP Board of Directors; and
- Tina Griffin, Consumer Representative and observer on the SDGP Board of Directors.

HISTORY

Consumer participation strategies: an overview

1. Consumer Representation on the Division’s Board of Directors: There are thirteen members on the SDGP Board of Directors15. 9 are general practitioners, one is the Division’s Executive Officer, one is the Flinders University Representative and two are Consumer Representatives. The Consumer Representatives attend as observers.

A Position Description: Community Representative – Management Committee, was developed in November 199916. This states: The broad role of the Community Representative will be to represent consumer’s views on matters bought before the management committee and other forums such as strategic and business planning sessions.

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13 www.sdgp.health.on.net
14 1996 ABS Census data.
15 Southern Division of General Practice 200/2001 Annual Report.
16 SDGP Position Description: Community Representative – Management Committee, November 1999.
2. **Consumer Representation on Program Committees:** The Division has four key results areas\(^{17}\): They are:

- GP Services;
- Population Health;
- Corporate Services; and
- Strategic Partnerships/Innovation.

**Origins**

Consumer involvement at SDGP began with the development of a Consumer Reference Group that was funded by the Commonwealth Department of Health and Family Service’s Community Liaison funding scheme for Divisions of General Practice in 1996. When the funding for this project finished in 1998, SDGP examined ways in which consumer participation could continue to inform the work of the Division.

Recommendations for consumer involvement in the SDGP were discussed at the Management Committee meeting held on August 10 1998. The meeting endorsed the following statement:

*The Division supports consumer involvement across a range of Divisional activities, including needs identification and strategic planning, program development, broader policy debate and feedback on quality in general practice.*\(^{18}\)

The SDGP Policy on Consumer Representation, Consultation and Participation was reviewed in December 2000\(^{19}\). This document outlined a range of activities through which consumer participation would be implemented. This included the following approaches:

- Consultation with consumer groups and community organisations by Divisional program coordinators.
- Consumer representative involvement in planning, development and evaluation of programs via the inclusion of two consumers per Program Steering Committee.

Job descriptions for consumer representatives were developed, an orientation process for consumers was devised, and a series of strategies were conceptualised which aimed to include consumer views across the work of the Division.

For the past four years, the method of using consumer representatives on program committees has been in place across the Division.

Samantha Battams was employed as Community Liaison Coordinator in 1998. (Later her title changed to Health Services Coordinator). She identified the need for a consumer policy and worked to ensure that this was integrated with the business of the Division. She remembers:

\(^{17}\) From The Southern Division of General Practice Strategic Plan, May 2002.

\(^{18}\) From SDGP Policy on Consumer Representation, Consultation and Participation in the Southern Division of General Practice, December 2000.

\(^{19}\) Ibid.
My very first task in the Division was to establish a consumer policy for the organization. This was done because the Consumer Reference Group had been set up separate to the organization, so it was just another project, and the consumers weren’t integrated into the organization.

Ian Dobbie, the Division’s Executive Officer notes that it was important to have a policy for consumer participation to guide practice within the Division. He recalls: The idea was to guide the Division in its involvement with consumers and to work on some specific projects with consumers. It was taken up through the Board as a policy issue and then once that scene was set at the policy level, it then became part of our normal business.

Two consumer representatives, Tina Griffin and Trevor Parry, were appointed to the Board of Directors as observers in 1998 following a review of governance and both have continued in their role since this time. Previous to this, a consumer representative had attended the Board of Management for a twelve-month period.

Model for consumer participation

The SDGP planned to extend the role of consumer observers on the Board of Directors, to having full voting rights. This amendment to the Division’s constitution was put to members vote at the 2001 Annual General Meeting (AGM). Despite support from the Board, the motion was defeated by the membership.

Helena Williams is a general practitioner and has been the Medical Director at SDGP for 3 years. She has a background in consumer participation, having been the Consumer Liaison Officer at Northern Division of General Practice in Adelaide. She was at the AGM:

At our last AGM we put forward a motion to give the consumer representatives on the Board voting rights. Myself and all of the GP’s who actually work in the Division were strongly supportive of the consumers having voting rights. But the average grass roots GPs had some concerns. So that didn’t get up. There probably wasn’t as much debate as I wanted.

All of the people interviewed for this case study believe that voting rights for consumer representatives on the Board will happen with time, and that more ground work to inform general practitioners about the benefits of consumer participation in the Division is the key for making this happen.

Initial invitation to consumers

Consumer representatives were recruited to the Division through a multi-pronged strategy which included raising community awareness about the role of the Division through articles and advertisements in the local newspapers. The Community Liaison Coordinator also attended community meetings and spent time creating links and networking with local consumer organizations. Key individuals from consumer groups were also targeted directly and asked to consider participating. A database of key consumer networks was developed by the Community Liaison Officer, and Divisional Staff were encouraged to use this list and add new resources.
Tina Griffin has been involved in SDGP as a consumer representative on various Divisional Programs and also as a consumer representative observer on the Board. She was recruited the following way:

   They had an advert in the paper asking interested people to attend an evening meeting on diabetes. I was asked to be part of the Consumer Reference Group.

Trevor Parry has been a consumer representative on the Division’s Mental Health Program for more than five years and is also an observer on the Board of Directors. He was approached directly by the Division and asked to participate. He remembers:

   I’ve been involved as a mental health consumer representative activist, and systems activist since 1996. I spoke at a community meeting that Samantha Battens attended in Port Norlunga. I was the only consumer there. I can’t go to a meeting and not say anything from a consumer perspective. Sam approached me afterwards and asked if I would be interested in going on the Division’s Mental Health Steering Committee. So I very willingly became involved. They’re probably one of the best ones in Australia with regards to their mental health program and their involvement with consumers etc.

Links with the Community

Southern Division of General Practice has aimed to recruit consumer representatives who have strong links with their community. For instance in the Position Description for Community Representatives\(^\text{20}\), one of the criteria for selection is that “The person is expected to look beyond their personal health issues to contribute a consumers perspective on issues relevant to general practice and services provided by GPs in the southern region.” An “essential requirement” for the position is to have “strong links to consumer groups and/or community organisations.”

Ian Dobbie explains that this is so that consumer representatives:

   Would go out and have their own links with the community, then they could bring that information back into the Division.

Trevor Parry explains this from his perspective:

   Tina and I were selected as being appropriate consumer reps., because we both have very large networks. It’s great because they need to hear us, they need to hear our opinions.

Samantha Battams discusses the need for links to the community, but also notes that consumer representatives must be supported in their role. She also recognized that consumer representatives on committees work best when they are not simply a lone voice:

   I went to the Board saying, either there needs to be two consumer reps, or none. Because it can’t be token representation. The person needs to have feedback to groups and vice versa.

\(^{20}\) SDGP Position Description: Community Representative – Management Committee, November 1999.
**Funding arrangements**

Community and consumer representatives are paid at the Divisional rate of $25 per hour. Assistance with travel costs and child or respite care is available.21 The Division also funded support for consumer representatives through the Health Service Coordinator’s position.

**PROCESSES**

**Consumer participation in organisational structure**

While most program areas have consumer involvement into the planning and implementation of activities, there are some programs that do not.

Ian Dobbie explains:

> There is very little consumer involvement in any of our IT programs because that’s basically a program that trains GP’s and practice staff to use computers. But by contrast, there’s a lot more involvement in our mental health program, because it’s got a higher focus on consumer education for GP’s. In the diabetes area we have funded three consumers to attend chronic disease self-management courses. The next step to that process will be to utilize those people’s skills as peer educators running programs.

The Division is planning to implement a Chronic Disease Self-management program, based on the Lorig22 model, which is strongly grounded in consumer involvement. The course is taught by both peer leaders and health professionals, and structured so that any part of the course can be taught by any of the leaders.

Helena Williams has concerns that there is the potential for consumer input and feedback into program development may be lost due to competing influences. She tells:

> It’s probably fair to say that the consumer input into those program steering committees may get diluted by the time it gets to the Board. But feedback from the program teams is that everyone there is an equal partner, and there have been significant changes made to our programs because of involvement from the consumer reps on the committee.

Trevor Parry, when asked whether he was able to put issues on the agenda and have them changed, commented:

> It’s one of those hard things, the Division is a GP’s organization and forum. I can voice an opinion but it’s up to the organization as to whether they change the way GPs think. Now this is just from my side of things. However I strongly believe that it is a GP organization for the benefit of GPs, it isn’t a GP organization that has to change itself because of consumers.

Samantha Battams has a unique perspective on this, as her role was to enhance and support the integration of consumer involvement across the Division. Her

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21 SDGP Position Description: Community Representative – Management Committee, November 1999.

advice to others planning consumer participation activities would be to ensure that this is a core value and part of all staff’s job description not simply one staff member. She saw staff become more accepting of involving consumers in planning and implementation of Division programs as they were exposed to the perspectives consumers bring, but needed to work hard to convince some staff of its value. She notes:

I had an integration role and it was written into my job description, and I had the perspective that I wanted to develop, and continue consumer participation in health. But everyone else had very specific roles, immunization, diabetes, continuing medical education, and I had to push it constantly from my position saying, have you got consumer reps involved. It was up to me because I believed that it should happen. I think it’s also important to have consumer participation activities in the job descriptions of all staff. This is perhaps what the organization will look at in the future.

Champions for consumer participation

Champions for consumer participation are those people within the Division who actively advocate for consumer involvement. Ian Dobbie notes that an environment in which consumer participation strategies could flourish was set by Dr David Tye. He was the chair of the SDGP Board five years ago and he spoke at a number of Divisional events and conferences about why it is necessary to involve consumers in the affairs of the Division. The current chair, Dr Rob Wight and the Medical Director, interviewed for this report have also voiced strong support for consumer participation activities.

The consumer representatives, the Medical Director and people from other organisations such as PHCRIS, SA Consumers Network and SADI all nominated Samantha Battams as a champion for consumer participation and noted that her grassroots approach had helped to build and sustain a core network of consumers involved in Divisional activities. As Trevor Parry noted:

Samantha has always been a very, very strong advocate for consumer involvement. I think she’s had a considerable influence on the Southern Division’s practice.

This appears to indicate, that in the case of SDGP, the support from the Board for consumer representation is necessary, and this needs to be followed through and put into practice by a Divisional staff member at ground level.

Culture clash.

The consumer representatives noted that the clash of cultures between the worldviews of consumers and general practitioners could be an issue. Both have overcome this with time and note that mutual respect occurs through ongoing contact and exposure to each other’s perspectives.

Tina Griffin networks with other consumer representatives and hears their ‘war stories’:

Some people say that they go on committees and they think they’re just a token and nobody ever listens to them. They just say: “very well dear”, and pat them on the head. But Trevor and I have always been listened to, and what we’ve suggested has been accepted. I’ve always been treated as
an equal, which I think in the medical world is rather remarkable. I think this Division may be rather exceptional.

Trevor Parry notes:
There’s a definite clash of cultures. I suppose in some way that might be a bit of a challenge to me. I don’t try to intimidate professionals. I just treat them as equals, and if they don’t see me as an equal, well that’s tough. There are just a couple of GPs that I’ve come into contact with that quite obviously feel superior to everyone else, and quite possibly don’t see the benefit of having consumer or carer involvement. Whereas I do it passionately – they actually haven’t said that to me, I just have that impression.

Samantha Battams was at the coalface of culture clashes between consumers and the Division. She remembers:
Sometimes it was causing conflict because I wasn’t in the management role, and I was trying to do it by persuasion and telling people that it was a good idea. When we got the new medical director who was supportive of consumers, that also changed, the culture and the attitudes.

**Education and support for consumers**

SDGP have had strong informal support structures in place for their consumer representatives though the Community Liaison Coordinator/Health Services Coordinator who oriented them to Divisional activities and priorities. This included linking consumer representatives with organisations that could provide consumer-to-consumer support and advice such as the South Australian Consumer Representatives Network.

The consumer representative observers on the Board have been involved in the same corporate governance training and professional development opportunities that are offered to all Board members.

Samantha Battams also organised quarterly consumer representative meetings. She tells:
I met with the Division’s consumer representatives three or four times a year just on an informal basis. If there was anything that was a new initiative, that was the opportunity I used.

Trevor Parry has some good ideas about how to support new consumer representatives. When asked about training opportunities he commented:
I think a buddy type system might be an excellent way of training new people. Because, it can be very daunting the first time you participate on a committee. My first committee had 12 mental health workers who I’m very aware all had degrees, and I don’t have one. There was myself and another consumer. There was a bit of trepidation but I soon overcame that. Some consumers would actually need training in committee procedure. Through buddying I would actually try and encourage them to speak. Because I’ve seen so many consumers who are eager and keen to go on committees, but are terrified to say anything.
Evaluation

There has been no formal evaluation which looks specifically at the consumer participation activities in SDGP.

BARRIERS AND ENABLERS

Enablers

When the people interviewed were asked about the elements in their Division that have made consumer participation work and the characteristics of success, their perspectives varied.

For Helena Williams, having consumers involved in planning GP education topics and inviting consumers to attend and tell GPs about their experiences has been very powerful, to the point of sometimes changing the way that GPs practice. She tells this anecdote:

One area that has really taken off is the input of consumers into our Continuing Professional Development program. For instance: last week we did a prostate health education in our rural region, and we invited a consumer who’d had prostate cancer and surgery, who was able to articulate the impact on his life of having prostate surgery. He spoke about sensitive topics such as impotence, incontinence, those kinds of things and a number of our GP’s came afterwards and said,” having that consumer there has completely changed the way I think about screening for prostate cancer”. That moved a lot of our GPs and the feedback we got about that education session was that the most powerful part of it was having a consumer talking about the impact of prostate surgery on his life.

However for Helena Williams, the Division will not have succeeded in good consumer participation practice until all Board members have equal status: She notes:

Until our consumers are able to vote on the Board, then we haven’t been successful from my perspective.

From Ian Dobbie’s perspective, the elements in a Division that make consumer participation work are closely aligned with the strategic support of the Board. He says:

The starting point is to have the support of the Board, and the Board starts that process of recognizing the contribution, developing policies on how to involve consumers in the affairs of the Division. We also need to work to ensure that this filters out, to demonstrate to our membership that there is a benefit in involving their patients.

For Tina Griffin, an enabler is credibility. To follow is her list of the things consumer representatives might want to consider:

As a consumer you’ve got to be totally unbiased and not bring any of our own barrows to push along. Anything you say has got to be backed up by something. Do a lot of homework, read all the vast material that you are presented with, and do not take the job lightly. You’ve got to be in it for the long haul.
This is backed up by Trevor Parry, who notes:

*We bring a different experience perspective and once we’re accepted as part of that committee, then the service providers or the GPs will actually see the benefit of having consumers there.*

Samantha Battams picks up the theme that people are enablers, and found that having a supportive GP as well as herself as a Divisional staff member was useful to strengthen relationships with outside organizations.

*The GP I worked with on the Mental Health Program was a real enabler. He came along to the Schizophrenic Fellowship, the consumer reference group and other public forums to talk about the Division. He was really supportive.*

**Barriers**

People’s perspective on barriers encountered also varied according to their role and experiences.

For Ian Dobbie, there have been no real barriers to implementing consumer participation strategies:

*I really don’t see that we’ve had any barriers apart from the voting issue. Generally speaking there have been no barriers that anyone has put up to consumer involvement in this Division.*

For Helena Williams an issue that needs to be considered is the personal cost of ongoing participation for consumers who become known for their work and are then co-opted onto more and more committees potentially creating burnout. This also raises the issue of finding other consumers to participate in activities and providing ongoing support. She notes:

*I think one of the little traps is that you get a core group of people who put their hands up for everything and then they either get completely burnt out or overworked or stressed. People start to develop a profile of participation in any number of activities and then other organisations hear of them then contact them. For Trevor and Tina, their workload has gone up and then they’ve developed state and national profiles. So we’ve got to support them to be peer leaders and then to empower others to come through as well.*

This is backed up by Tina Griffin who jokes: *Don’t be too good at it because you’ll be hauled onto something else.*

As noted earlier, another barrier was that although the SDGP Policy on Consumer Participation was approved by the Board, it was sometimes difficult to implement because it was not seen as a shared role across the Division. It was left to the Health Services Officer to implement alone. Having all staff responsible for some way in implementing consumer focused activities, via including this in all organizational job descriptions, is a way of broadening and sharing this role and rolling it into core Divisional business.
Tips and recommendations from the Division

To follow is a list of important tips and recommendations that Southern Division of General Practice have developed though their experiences in consumer participation activities:

- Getting support for consumer involvement has to start strategically by garnering the support of the Board of Directors.
- Recognise that it takes time. As Helena Williams said: *One step at a time, you’ve got to gently encourage change, and expose GPs to working with consumers. Help them to discover that in fact it’s a positive thing, not a daunting thing.*
- Recruit consumers who have networks to the wider community.
- Ensure that someone within the organisation can guide and support consumers. As Trevor Parry said: *The organisation needs to have an advocate for consumer involvement who is able to guide consumers if they’re having some sort of difficulty.*
- Have structures within the Division that support consumer participation, such as job descriptions and consumer friendly management practices.
- Do the groundwork by understanding who the local grassroots organizations are and tap into existing resources. As Samantha Battams said: *Know who the consumer agencies are and use existing resources. Divisions need to have really good links with agencies like community health centres, who have got consumer reference groups, collaboration projects which have got consumer reference groups, council of the aging network etc.*
- Commonwealth funding for consumer involvement in Divisions.
- Involve consumers from the start of projects or programs. As Samantha Battams notes: *When it comes to consumer representation, the only experts are consumers.*

THE FUTURE

Ian Dobbie recognises the need to provide a more structured approach to training and professional development for consumer representatives. He also notes that South Australia is in the process of setting up a peak consumer organisation, and this could impact on consumer participation opportunities within the Division. He said:

*One of the things we’d like to do is to provide some further training opportunities for our consumer representatives, particularly those on our Board with their own professional development. Also - if there’s some sort of state organization of consumers is created, we may find it worthwhile talking to that organization to see what they can offer.*

Helena Williams would like to expand the influence of consumers in the SDGP and would like to develop new models for health care built with ongoing consumer involvement. She says:

*There’s a need for the consumer voice in developing models of care, quality assurance and clinical governance in general practice. I have ideas about things like Medical Advisory Committees in nursing homes with either carers or consumers who aren’t quite at the nursing home level, but are able to see themselves there in 10 or 20 years and would like to have input as to how that might work, around quality and audits.*
Tina Griffin believes that consumer participation will continue to be part of the culture at SDGP and that over time, consumers will expect to have a strong voice in the health care debate. She notes:

*I think it will continue, because the average consumer wants to have a bigger say in their own health. The days are gone when people just said:” yes doctor I’ll take it or I won’t take it”.*

Samantha Battams would like to see consumer participation funded directly by the Commonwealth and the implementation of strategies monitored. She also notes that feedback to the community needs to be a two way process, and that this is something that could be explored by the SDGP in the future. She says:

*With consumer involvement in Divisions the Commonwealth should tie part of the infrastructure funding to consumer representation and monitor it. There also needs to be the links back to the community, that is, have a two way communication process.*
DISCUSSION.

Common Elements.

The three Divisions of General Practice examined for this case study have implemented a range of strategies to involve consumers in their work. These strategies were:

- Consumer Representation on the DGP Board of Directors/Management Committee;
- Consumer Representation on the DGP Program Committees;
- A Consumer Committee formed to advise the DGP on matters and issues from a consumer/community perspective; and
- A Consumer Committee formed to consider the needs of a specific sector of the community; in this case Non-English Speaking Background consumers.

A common thread was that all three had at least one consumer representative on their Board of Directors/Management Committee, though their role varied from observer status through to full membership.

Consumer representation in the decision-making and governance structure of the organisation was identified as an important mechanism for ensuring that ‘consumer friendly’ practices were employed in the design and implementation of projects and programs across these Divisions.

Another theme identified was that the DGPs in this study have all implemented strategies through which consumer representatives are used to inform the direction of programs. This usually implied that a consumer was a member of the committee running or overseeing a particular program. However, the level of consumer consultation varied according to the kinds of programs being implemented.

Each of the Divisions also attempted to ensure that the consumer representatives engaged in their various roles had a constituency. That is, that they represent and are accountable to an external consumer or community organisation and refer information back to their group. This was done either by recruiting consumer representatives through consumer and community organisations and/or by including this as a requirement in their job description. This strategy aims to ensure that participants had a real representation role from their community, thus avoiding individual or particular agendas.

Levels of Participation

In Improving Health Services through Consumer Participation: a Resource Guide for Organisations\(^\text{23}\), different modes of participation are sometimes represented as a continuum. Brager and Specht (1973) have developed a ladder of participation that ranges from no participation through minimal levels where consumers receive information, but little say, through to joint planning and ultimately to consumer or community control (Figure 1).

Figure 1. The ladder of participation

<table>
<thead>
<tr>
<th>Degree</th>
<th>Participants’ action</th>
<th>Illustrative mode</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>Have control</td>
<td>Organisation asks community to identify the problems and to make all the key</td>
</tr>
<tr>
<td></td>
<td></td>
<td>decisions on goals and means. Willing to help community at each step to</td>
</tr>
<tr>
<td></td>
<td></td>
<td>accomplish goals.</td>
</tr>
<tr>
<td></td>
<td>Have delegated</td>
<td>Organisation identifies and presents a problem to the community, defines the</td>
</tr>
<tr>
<td></td>
<td></td>
<td>limits and asks community to make a series of decisions, which can be</td>
</tr>
<tr>
<td></td>
<td></td>
<td>embodied in a plan it can accept.</td>
</tr>
<tr>
<td></td>
<td>Plan jointly</td>
<td>Organisation presents tentative plan subject to change and open to change</td>
</tr>
<tr>
<td></td>
<td></td>
<td>from those affected. Expects to change plan at least slightly and perhaps more</td>
</tr>
<tr>
<td></td>
<td></td>
<td>subsequently.</td>
</tr>
<tr>
<td></td>
<td>Advise</td>
<td>Organisation presents a plan and invites questions. Prepared to modify plan only</td>
</tr>
<tr>
<td></td>
<td></td>
<td>if absolutely necessary.</td>
</tr>
<tr>
<td>Low</td>
<td>Are consulted</td>
<td>Organisation tries to promote a plan. Seeks to develop support to facilitate</td>
</tr>
<tr>
<td></td>
<td></td>
<td>acceptance or give sufficient sanction to plan so administrative compliance can be</td>
</tr>
<tr>
<td></td>
<td></td>
<td>expected.</td>
</tr>
<tr>
<td></td>
<td>Receive information</td>
<td>Organisation makes a plan and announces it. Community is convened for</td>
</tr>
<tr>
<td></td>
<td></td>
<td>informational purposes. Compliance is expected.</td>
</tr>
<tr>
<td></td>
<td>None</td>
<td>Community not involved.</td>
</tr>
</tbody>
</table>

The consumer participation strategies identified in this study varied across this continuum. Most appear to be at the level of participation whereby consumers are ‘consulted’ and are asked to ‘advise’ on the work of the Division. NWMDGP’s Community Action Forum was an example of ‘joint planning’ although opportunities exist within this group to identify issues and set priorities for Divisional work.

Emerging Issues.

A series of emerging issues were identified through the process of interviewing key individuals involved in the consumer participation activities at the DGP studied.

1. *Links between consumer participation at different levels in the Division’s structural organisation.*

As part of the interview process, staff and consumers at SGDGP were asked to identify the existing links and communication pathways between the various levels of the organisation; from the Board of Directors through to management and the various Divisional programs. At the SGDGP there was no formal link between the consumer representative on the Board of
Management and the consumer representatives on other programs. The involvement of the SGDGP staff in this study opened the possibility that connections, networking and communication between consumer representatives across each element of the Division be developed in the future thus facilitating the integration of consumer representation at all levels in the Division.

2. Evaluation.

Although none of the DGP's in the study formally evaluated their consumer participation strategies following the completion of their Community Liaison Projects, each DGP clearly saw value in continuing to involve consumers in ongoing work. When questioned about this, each DGP was able to articulate the elements that enabled consumer participation to continue and grow.

These Divisions found that determining the appropriateness of chosen strategies for participation is useful to inform future practice. For example: The Evaluation of NWMDGP's Community Action Forum (CAF) by the Health Issues Centre in 1997, resulted in a number of recommendations which were acted upon. Key to this was the establishment of stronger links between the CAF and the Division’s Board of Directors.

We recommend that DGP's consider formally evaluating their consumer participation activities in ways that fit with principles of partnership.

3. GP participation in the Division’s structural organisation as ‘cultural representation’.

GPs from various ethnic communities can represent his/her community, thus bringing a cultural perspective to Divisional Programs. In the case of SGDGP the NESB communities are represented not only by consumer and community representatives, but also by GPs from these communities who understand the language and cultural sensitivities.

4. ‘Professional’ consumer representatives vs. consumer representatives.

It is a common experience amongst consumer representatives to become involved in several committees and act as consumer representatives in more than one organisation. People who have experience in the health system are often called upon to be involved on other committees and further representation work. This brings a high cost to individual representatives in terms of their time and energy, with a potential for burnout.

Managers of community organisations are similarly called upon by health organisations to represent their constituencies. These high profile people also face problems of time management and energy to represent their communities in more than one organisation. DGPs should consult with consumers about the commitments that representatives may already have and facilitate the consumer’s role in the Division. Divisions should also consider strategies to recruit new consumers to participate in activities and provide them with ongoing support.
5. *Information delivery as consumer participation.*

Some confusion exists about the provision of information: This is a method of communicating to, but not with consumers and the community, as there is no inbuilt mechanism for feedback. On the Ladder of Participation (Figure 1), the delivery of information is at the lowest point on the participation continuum. DGP should be aware that programs that focus on health education and information delivery have a value in themselves, but are not consumer participation unless consumers have been involved in developing the information.

**Questions to Consider.**

Based on the information gleaned from these case studies, other Divisions of General Practice contemplating consumer participation strategies may want to consider the following questions:

- What is the level of commitment within the DGP to support consumer participation?
- What is the general view of the GP membership towards consumer participation in the Division?
- Have there been any attempts to implement consumer participation activities in the past?
- Are there members/staff with knowledge about consumer participation?
- What structures are in place for supporting consumers?
- Are the timelines long enough to allow consumer participation to develop?
- What level of participation does the DGP want?

By answering these questions, Divisions can start to work through the issues for their own organisation and can start to determine which methods and models are most appropriate for their own circumstances.

**Elements of Success.**

The three DGPs interviewed for this case study report have all had consumer participation strategies in place over a number of years. Each began their work in consumer participation with a Commonwealth Department of Health and Family Services’ Community Liaison funding scheme for Divisions of General Practice in 1996 but chose to continue and/or evolve their strategies when the funding from this original grant finished.

The following list is synthesized from their ideas, and represent a checklist that other DGPs might want to consider when planning and implementing their own consumer participation strategies:

- Ensure that the organisation’s management structures support consumer participation.
- Allocate resources to enable a staff member to carry out preliminary research, develop a plan and implement consumer participation in the Division.
- Research the existing experiences, attitudes, opinions of members towards consumer participation
- Work towards developing a positive attitude and a general culture favourable to consumer participation in the Division
- Work towards educating, informing and breaking myths about consumer participation among the members of the Division.
- Implement a policy statement on consumer participation so that staff and people external to the organisation are aware of the DGP’s commitment in this area.
- Nurture a GP ‘champion’: an individual who is part of the culture of the DGP and who supports, enables and actively promotes consumer participation activities both within and without the organisation.
- Promote the work the Division does and encourage involvement and feedback from the community the Division serves.
- Establish links with community and consumer organisations that exist locally. These could include support groups, ethnic organisations and community health centres.
- Make resources available: time and money. Establish a sitting fee for representatives and/or reimbursing participants for costs incurred. This could include assistance with transport costs, childcare or respite care. The best approach is to ask consumers what they need.
- Orientation for consumer representatives. This includes an outline of Divisional structures and the system in which they are participating. This may include an introduction to the Division, terms of reference for participating and clear lines of accountability. Ideally, consumers should be involved in developing these terms of reference.
- Offer initial and ongoing training and support to consumers to help them to give their best.
- Give it time. The strategies used by the DGPs in the study represent a medium to long-term investment by the organisation. Divisions need time to become familiar with the kinds of input consumer representatives can provide, and the consumer participants need time to come to terms with their role and scope in Divisional activities.
Where can DGPs begin?

The National Resource Centre for Consumer Participation in Health is an organisation that can assist DGPs who are considering consumer participation strategies, or who want to strengthen the processes they currently have in place.

The NRCCPH was set up by the Commonwealth Department of Health and Ageing to help consumer organisations, providers and policymakers to learn about consumer participation research and practice. We provide a free telephone and email advice service and have a series of resources which have been funded through the Consumer Focus Strategy.
Freecall: 1800 625 619
Website: www.participateinhealth.org.au
APPENDIX 1.

Consumer Participation in Australian Divisions of General Practice: Lessons from the Literature.

The History of the Establishment of Australian Divisions of General Practice

Divisions of General Practice were first established in Australia following a 1992/93 federal budget announcement that $17 million dollars had been allocated to begin establish a network of divisions of general practice. The aim of this was to better integrate general practice with the rest of the health system. Ten demonstration divisions were funded in this initial round. In 1993/94, an amount of $50 million dollars was allocated to the divisions and Projects Grants Program for infrastructure funding and funding of individual projects. The goal of the Program was "to improve health outcomes for patients by encouraging GPs to work together and form links with other health professionals to upgrade the quality of health service delivery at the local level" (Todd & Sibthorp, 1995, p. 8). In order to achieve this goal, Divisions were expected to undertake a variety of roles, including providing "a mechanism for GPs to work more closely with health professionals/workers in hospitals, area health services, community health services, health unions, consumers, community groups" and liaising with other areas of the health sector (p. 8).

From 1992 onwards, the Consumers' Health Forum (CHF) was funded by the Commonwealth to carry out consultations with consumers and Divisions of General Practice about the reforms to general practice. In one of its first documents on general practice, the CHF reported that the proposals for Divisions of General Practice received qualified support from consumers because of concerns that Divisions would be controlled by the medical profession without addressing consumers' issues. On the other hand, consumers were enthusiastic about the potential of Divisions to meet their need for more information about general practice into the local community service sector. The CHF reported that Divisions should display the following characteristics if they were to meet consumers' needs:

- Accepting accountability to the community for the funds they receive and the activities they undertake;
- Initiating an outward looking approach which seeks and values participation from those outside the profession, notably consumers;
- Consulting with consumer groups to determine the most appropriate form of consumer representation at the local level;
- Providing basic information about general practice services in the area/region;
- Acting as a point of contact between GPs, consumers and community organisations and area/regional health committees;
- Involving consumers and others in developing regionally appropriate clinical guidelines of care; and
Inviting participation by consumers in continuing education and quality assurance for general practitioners. (CHF, 1993, pp. 46-48)

In 1994, the Health Issues Centre carried out a study exploring the potential for Divisions of General Practice to enhance linkages and communication between consumers and GPs. Following a series of interviews with GPs and consumers, the study found that overall, GP informants could be characterised as displaying some apprehension about the possibility of a consumer "takeover" of Divisions, although they believed that there was a (relatively limited) role for consumers in developing the work of Divisions in relation to community needs. Consumer informants, on the other hand, were very interested in and saw great potential for Divisions as a means of developing better quality general practice. However, GP attitudes were perceived as a serious barrier to full-scale participation by consumers in the work of Divisions. The study concluded that:

"... Divisions do provide significant potential for the enhancement of consumer participation in the development of better quality General Practice, and that GPs associated with Divisions are amenable to a range of measures which may bring this about." (Health Issues Centre, 1994, p. 6)

In 1996, the Consumers' Health Forum produced a guide for Divisions of General Practice on working with consumers (Consumers' Health Forum, 1996). According to the foreword, the idea for the Manual arose from Divisions themselves requesting such a handbook.

Following the election of a Coalition Government in 1996, the RACGP and the AMA wrote to the new Minister for Health and Family Services, Dr Michael Wooldridge, asking that the General Practice Strategy be reviewed. In its report to the Minister, the General Practice Strategy Review Group concluded that despite controversy and disagreements resulting from the Strategy, the overall effect of the changes that had occurred had been profound. With respect to consumer and community expectations, the report stated that:

"Consumers and the community have a vital interest in the future of general practice. ... Too often the inclusion of consumers on committees is 'tokenistic'. It is time to acknowledge that consumers have a role, that their views are important, and that they want to contribute and be treated equally." (General Practice Strategy Review Group, 1998, p. 67).

By the time of the Review, there were 120 Divisions of General Practice in Australia, and funding was being shifted away from individual infrastructure and project grant arrangements to formal block contacts to provide an agreed program of activities over a three-year time period with performance being measured against agreed objectives. The Review reported support and enthusiasm for Divisions by many GPs, non-medical health workers, and consumer and community groups. On the other hand, it observed a great deal of variation between Divisions in a number of areas, including their collaboration with community and other health providers. The Review saw consumer liaison (including the provision of remuneration for consumer participation as appropriate) as one of a number of core roles for Divisions of General Practice (p. 288).
MODELS OF CONSUMER PARTICIPATION: DIVISIONS OF GENERAL PRACTICE

Despite the growing diversity of the primary care sector, general practitioners are still the primary care professionals with whom members of the public most frequently interact. General practice is also one of the oldest and most traditional components of the primary care platform. Although many reforms have been introduced over recent years, the model on which general practice is based (which combines "small business" and a hierarchical relationship between doctor and patient) still does not lend itself easily to direct community and consumer participation, even when this is conceived of in quite modest terms as the introduction of "a contemporary customer service and quality ethic" (Consumers' Health Forum and Commonwealth Department of Human Services and Health, 1996, p.7).

One of the most important of these reforms has been the establishment and funding of the Divisions of General Practice. A major driver of the establishment of Divisions was the need to create a structure through which GPs could interact with other players in the primary care system, and the very strong emphasis placed on partnerships with government, consumers and others in the reform of general practice (General Practice Strategy Review Group, 1998), one would expect strong patterns of consumer and community collaboration to have emerged.

Partnerships and Consultation

On the basis of their official statistics, there does appear to be a high level of consumer and community involvement in Divisions of General Practice. According to the 1999/2000 Annual Survey of the Divisions (Modra, Kalucy & McIntyre, 2001), 106 (86 per cent) of the 123 Divisions had one or more formal mechanisms for involving consumers. However, this represented a slight decline from 90 per cent in 1997/98. In particular, the proportion of Divisions with a formal consumer advisory or reference group had declined from 61 per cent to 53 percent over the two-year period, with an even more marked decline, from 55 per cent to 31 per cent, in the proportion of Divisions employing a Consumer Liaison Officer. According to the Report, this reduction was likely to be due to the shift to Outcomes Based Funding for Divisions. Prior to the introduction of Outcomes Based Funding, Divisions received specific funding for Consumer Liaison Officer positions. While Divisions no longer receive this earmarked funding, they can negotiate with the Department of Health and Aged Care to include provision for a Consumer Liaison Officer in their Business Plans. The level of consumer representation on Division management or decision-making bodies for 1999/2000 was 43 per cent, and did not appear to have changed substantively over the period since 1997/98. The use of "Other" types of consumer involvement had increased from 30 per cent to 42 per cent. "Other" included consumer representation in individual programs and groups, consumer networks, steering committees and consumer forums.

Ninety-one Divisions (74 per cent) reported formal mechanisms for involving community groups in 1999/00, an increase from 67 per cent in 1998/99. Of these, 30 Divisions had community group representation on Division management or decision-making bodies. Other formal mechanisms reported included Community Liaison Officers, representation on project and program
committees and advisory/reference groups, liaison with community groups, community reference groups, and partnership agreements.

A similar proportion of Divisions (76 per cent) reported being involved in conducting programs to improve GP collaboration with community groups. Again, this was an increase since 1998/99. Specific education programs for community groups were the most common types of programs, followed by GP involvement in patient support groups and patients support group involvement in GP Continuing Medical Education.

More than three-quarters of Divisions with outreach programs for the homeless, Aboriginal and Torres Strait Islanders, migrants and young people had involved consumers in program planning in 1999/00, and over half had involved consumers in implementation of programs. Between one-third and two-thirds of Divisions involved in activities to improve access to GP services reported consumer involvement in planning these activities in 1999/000. Consumers were most likely to have been involved in planning activities aimed at alternative or expanded location of GP services, and in the implementation of activities around immunisation provision. Almost all Divisions had at least one shared-care program with hospitals or community health services. Of these, programs in the fields of aged care, mental health, HIV/AIDS and diabetes had the highest proportion of Divisions involving consumers in planning and implementation, with up to 70 per cent of some program types involving consumers in planning, and up to 50 per cent involving them in implementation. The Annual Survey also includes statistical information on consumer involvement in programs designed to improve collaboration with hospitals and community health centres, and in health promotion and disease prevention programs. Overall, consumers were more likely to have been involved in the planning than the implementation of Division programs.

An optimistic interpretation of the information contained in the 1999/2000 Annual Survey would be that despite the shift away from formal consumer bodies and the employment of Consumer Liaison Officers in Divisions of General Practice, the use of a greater variety of consumer participation methods and the increased involvement of community groups represents an overall development in collaboration between Divisions and consumers and community groups. On the other hand, it may be that in the absence of a specific financial incentive to employ Consumer Liaison Officers, consumer participation in Divisions has ceased to develop or has even declined. This interpretation is supported by Rogers and Veale's (1999) analysis of changes in Divisional priorities and activities associated with the change to outcome based funding. They found important changes in patterns of expenditure, with increases on spending of GP issues, information technology and immunisation and decreases in expenditure on needs assessment, all national health priority areas except immunisation, aged care, and community access and liaison. This apparent trend may have been exacerbated by the defunding in 1999 of the Consumers' Health Forum's General Practice project, which had previously made it possible for the CHF to provide advice and support to Divisions on consumer involvement (General Practice Partnership Advisory Council, 2000).

Unfortunately, there is almost no evaluative or case specific literature available that might provide further insight into these issues, including the effectiveness of consumer and community involvement in Divisional activities, and the perceptions of consumer and community participants. This is despite a growing
body of literature on Divisional partnerships with other health care players, especially community health centres, hospitals, community care providers and allied health professionals, and may indicate that consumer and community collaboration is seen as of less critical importance to the process of primary care reform by Divisions, GPs, funders and/or evaluators.

Walker, Adam and Lewis (1997) examined the experiences of GPs and staff in Divisions and those with whom they collaborated in 20 Commonwealth funded projects undertaken by Divisions between 1994 and 1996. The projects covered a wide range of health care topics, with only one being primarily focused on consumer issues. The other projects covered: mental health (3), Aboriginal health (2), pre/post-acute care (2), youth health (2), aged care (2), palliative care (1), post-natal care (1), childhood asthma (1), sun safety (1), domestic violence (1), farm injuries (1), diabetes (1) and health of the homeless (1) (p. 25).

An examination of the organisational roles played by different participants in these projects showed that consumers were most likely to be involved in formal advisory/decision-making structures. Thirteen of the projects had such structures, and five of them involved consumers. Three other projects had consumer-only committees. Consumers were also involved in providing informal advice/input to four projects. However, there was only one case each of consumer involvement in the management of specific project activities, networking, and promotion/recruitment, and no cases of consumers being actively involved in project oversight, management of inter-organisational relationships, establishing communication systems, establishing protocols, day-to-day communication or service provision (p.40). The picture which emerges from this study is consistent with that provided by the Annual Survey statistics, of a certain level of consumer representation on Divisional projects, but an uncertain impact on processes and outcomes, and adds to the need for further evaluation and research focused on the effectiveness of consumer and community involvement.

A single case evaluation carried out by the Health Issues Centre in 1997 provides a rare insight into the issues which are likely to emerge when a Division begins to engage with consumer and community representatives. The evaluation assesses the effectiveness of a Community Action Forum (CAF) established by the North West Melbourne Division of General Practice as part of a larger Community Liaison Project. The Community Action Forum had eight consumer members, most of whom were involved in specific community or consumer organisations, such as the Consumers' Health Forum, the Council on the Ageing, and the Islamic Women's Welfare Council of Victoria. Meetings were held monthly, and were also attended by the Community Liaison Project team, the Division Executive Director, and other GP Board members (on a rotating basis), supervisors and project officers. Consumer members were paid $25 per hour to attend the meetings. Major issues which emerged from the evaluation were:

- **Roles** — The perceived roles of the Community Action Forum differed somewhat between the various players, with the project team and the Division Board members emphasising the provision of consumer input into Division projects, especially the Community Liaison Project, and the CAF members seeing their role more broadly as a ways of bridging the gap between GPs and consumers within their community.
• **Recruitment** – The Community Liaison Project team had asked community groups identified from the Division's needs analysis report to nominate a list of consumers from which the team could choose suitable members. However, in reality, the project team found that they had to actively "sell" the concept of the Community Action Forum to the groups and that only one nomination per group was put forward, so that in the end the project team had no choice in the selection process. This was seen as a disadvantage by the project team, although not necessarily by the evaluators.

• **Definitions of a consumer** – The evaluation revealed much discussion between CAF consumer members and board members about whether consumer representatives should be "true" consumers (direct users of health care services) or "professional" consumers, with experience in consumer representation within formal organisational structures.

• **Training of consumers** – Although some consumer members were able to use their parent organisation for assistance and support, this was not an option available to them all. These consumers members felt that they would have benefited from the provision of training by the Division.

• **Levels of involvement** – Consumer representatives varied from feeling that their level of involvement was satisfactory to wanting a higher level of involvement, particularly in undertaking preparatory work prior to decisions about projects being made, and in the early developmental stages of projects.

Members of the Division's Board who were interviewed for the evaluation openly expressed a sense of initial apprehension about consumer involvement within the Division and general practice more generally. Those who had attended CAF meetings reported that it had reassured them about the benefits of consumer involvements, as well as allaying any concerns about professional consumer agitators taking control of the Division. There were, however, still considerable differences of opinion among Board members about the extent to which consumers should become involved in the Division's activities. The evaluation concluded found that although the CAF held a peripheral position in relation to the Board and the Division, it had been successful in laying the foundation for further consumer involvement and participation, and had provided acknowledged benefits to all participants.

One interesting finding was that several of the GP Board members interviewed reported being able to translate their increased awareness of consumer issues into their own clinical practices:

"These general practitioners spoke of having new perspectives on cultural difficulties, of involving consumers in decision-making in managing their illness and of developing innovative clinical practices to improve clinical care for consumers." (p. 18)

This raises the question of whether and how reforms to general practice, and in this case particularly the establishment and funding of Divisions of General Practice, have contributed to any change in the nature of the relationship between individual consumers and GPs. Certainly, the General Practice reform strategy has generated and funded considerable research into consumer attitudes to and expectations of GPs (General Practice Strategy Review Group, 1998, pp.67-74). Some Divisions have also carried out their own consultations
around these issues (Hider & Sullivan, 1997). While there is some indication of consumers looking for a more egalitarian relationship with GPs, the strongest themes which emerge relate to access and quality of care issues (including technical competence, GP's interpersonal skills and qualities, a holistic attitude by GPs, the provision of information by GPs, and an adequate length of time being devoted to the consultation). On this basis, it seems that changes to the relationship are likely to be evolutionary rather than revolutionary, and that general practice is unlikely to adopt the model of individual empowerment which exists, at least in theory, in the community health sector.

**Conclusion**

In conclusion, it appears that the establishment of Divisions of General Practice in Australia did generate formal models of consumer and community involvement in general practice based on partnership and/or consultation. However, it is not yet clear how effective these models have been in changing the nature of general practice. Nor is it clear to what extent they will be sustained or reconfigured in the absence of specific funding to Divisions and consumer health organisations.

It is also important to recognise that Divisions of General Practice are engaged in many other types of partnerships and programs which do not have as their primary purpose increased consumer or community involvement in general practice, but which may nevertheless have this effect. The Coordinated Care Trials and the Chronic Disease Self-Management Programs, discussed below, are two examples of program initiatives which have actively involved at least some Divisions of General Practice.

The factors which have enabled the development of community and consumer involvement appear to have been:

- the establishment of the Divisional structure itself;
- specific funding for Consumer Liaison Officers;
- the provision of strategic support to Divisions by consumer organisations;
- resourcing of national and state level consumer groups to support consumer involvement;
- a positive attitude towards Divisions and their potential on the part of consumer and community groups;
- a willingness by many Divisions to enter into collaborative projects with community health services and community groups.

Factors which seem to have operated as challenges or barriers to participation have included:

- a very cautious attitude towards consumer groups and consumer involvement in Divisions on the part of many general practitioners;
- the removal of specific consumer liaison funding from Divisions;
- the tendency of Divisions to prioritise their functions as "associations" of and for general practitioners above their structural function as a potential partner and collaborator within the broader health system;
- lack of training for consumers to allow them to participate effectively in Divisional activities.

Lessons which can be learned from the experiences of consumers and community groups to date include the following:
• Different types and levels of consumer and community participation are mutually reinforcing. In particular, in the case of Divisions, the existence of community health services and community groups with strong consumer involvement will multiply the opportunities for consumer participation in Division activities.

• The level and type of resource incentives provided will influence the willingness of Divisions to establish formal structures for consumer and community involvement.

• As in the case of government administrative regions, Divisional regions are an arbitrary construct which are not likely to align with the levels at which consumer and community groups are organised.

• Consumers and consumer representatives may require considerable support and training to be able (and willing) to effectively manage the difficulties inherent in working with Divisions of General Practice.
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