



Consumer Advisor Forum

The Current State of, and Improving,
Consumer Engagement in Health

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1.0 Introduction

The Consumer Advisor Forum has been organised by the Community Consumer Collaboration Group (CCCG), a working group of Southern Melbourne Primary Care Partnership (SMPCP). The purpose of this forum is to bring together consumer and community representatives and key personnel with responsibility for supporting consumer engagement drawn from SMPCP Partner Agencies.

The forum held on 24 May 2018, included approximately 40 representatives including consumers and key personnel from health agencies. This included representatives from Star Health, Cabrini Health, Alfred Health, Calvary Care - Bethlehem, Monash Health, Connect Health & Community, Headspace, Monash Partners, Safer Care Victoria, MPN Alliance Australia, Voices of the Valley and the Southern Melbourne Primary Care Partnership. The attendees also included many people with a primary role of representing health care consumers.

The purpose of the day was to review the current state of consumer engagement and develop potential ideas on how to better improve engagement between health care providers and health consumers.

1.1 Objectives

The forum provided an opportunity for consumer 'representatives' and the coordinators with responsibility for consumer participation to learn from one another. The objectives of this forum are to achieve the following;

- Increased consumer participation in the governance, guidance and evaluation of SMPCP Partner Agencies;
- Identify consumer engagement support needs and/or training opportunities that the SMPCP could facilitate along with Partner Agencies; and
- Establish a Consumer Engagement Network to share information and undertake joint activities across SMPCP Partner Agencies.

2.0 Background

2.1 What are Primary Care Partnerships? – Sally Howe, Cabrini Health & Chair of SMPCP Executive Governance Group

The Southern Melbourne Primary Care Partnership is the third largest partnership in the State of Victoria, which has a total of 28 different primary care partnerships. The purpose of these partnerships is to strengthen the primary health sector and improve health and well-being outcomes across the sector. These partnerships commonly involve a mix of hospitals, community health, local government and community service organisations offering a wide range of health and community services. The purpose

of the SMPCP is to help deliver better health outcomes and stronger communities across the municipalities of Bayside, Glen Eira, Kingston, Port Phillip and Stonnington.

Sally Howe highlighted the work undertaken by the SMPCP to develop the Community Health Model of Care which brought together consumers, clinicians and managers from all four Community Health Services in the SMPCP catchment to co-design a model of care that provides care options for clients when they are self-managing and when they need comprehensive assistance and care coordination. It has 'built in' fluidity enabling the client to move through care options dependent on their changing health status. The implementation of the Model of Care has provided consumers with a consistent community health experience across the catchment.

2.2 Safer Care Victoria and the Changing Role of Consumer Engagement - Belinda MacLeod-Smith

Safer Care Victoria (SCV) is a relatively new initiative, which arose to address the failings and gaps in Victoria's Health System. It was key outcome of the "Duckett Report": Targeting zero: putting patient safety first in Victoria. The mission of Safer Care Victoria is to provide outstanding care for all Victorians, always. SCV embeds consumer engagement as a business as usual approach.

SCV consists of 6 core branches of interest, with one of the main branches focusing on Consumers as Partners. This branch drives an increased interest in engaging consumers in the health care system they are experiencing. The branch focuses on improving patient safety culture, communication breakdowns, unwarranted variation in practice and unwarranted variations in patient experience. This includes opportunities for patients and families to take charge of their own health care, particularly regarding avoidable deaths.

2.2.1 Some Key Initiatives of SCV focusing on Consumer Engagement

As consumer engagement is one of the core focuses of SCV they have several initiatives that focus on improving engagement across Victoria. The following outlines some of the core initiatives of SCV:

- Patient Opinion Pilot: A website with someone directly responsible for care responding to patient questions
- The SCV Patient and Family Council: A new committee with 13 members established by SCV to adopt patient engagement and experience.
- Patient reported outcome measures and experience measures (PROMS and PREMS)
- SCV Academy and 'PEER': A systematic approach to aid in high quality RCAs (Root Cause Analysis) if something goes wrong that includes consumer engagement

- Partnering and Healthcare Framework – seeking to evaluate high quality partnering in healthcare. A co-designed framework that has both a consumer lead and a sector lead.

2.2.2 Why is Consumer Engagement Important?

There are several reasons why SCV, as well as the industry in general believe that consumer engagement is important for the future of high quality and safe healthcare. The following identify some of the core benefits of consumer engagement in the health industry:

- Big differences in the capacity to promote and enable people to partner in health care
- Not all Victorians participate in their health in an equal way or have their healthcare needs equally well met
- Many Victorians have poor healthcare experiences and poor health outcomes as evidenced by the Victorian Health Experience Survey (VHES)
- VHES also show a big gap in the ability to access interpreters

2.2.3 New Standards for Partnering with Consumers

The National Safety and Quality Health Service Standards (NSQHS), which will start being assessed in January 2019. They describe the expected safe, high quality care and systems needed to deliver it. From 2019 it will be required that providers meet the necessary standards to access funding. SCV has helped to inform the development of these new standards with the aim of closing gaps in meeting the required safe health care and consumer engagement standards.

The new standards have included new areas of interest including patient centred care, and partnering with consumers is embedded across every standard. This has included a move to making partnering with consumers a mandatory aspect of health care rather than a choice. The focus is on actively involving patients in their own care, meeting their information needs and sharing decision making.

3.0 Session 1: Consumer Value and Support for Consumer Engagement

The first break out session, provided an opportunity for consumers and staff with responsibility for supporting consumer engagement to work together on identifying the value of consumer care and the factors in place to support and document consumer engagement. The core questions asked were:

- What value do you see that consumers bring to health services?
- What helps to support your consumer engagement?
- How is that documented?

The responses included ideas on not only what is working well currently, but also areas that could be improved. The following sections, provide a synthesis of the answers to these questions.

3.1 What value do you see that consumers bring to health services?

Participants identified the core areas where consumers add value to the provision of health services. This includes a wide range of responses, including:

- Consumers are vital to the model of care
- Can help with meeting consumer needs
- Provides detail of the patient lived experience
- Different perspectives, needs and wants
- Measure consumer perspectives on value
- Consumers bring passion
- Consumers see what professionals don't see (blind spots)
- Can provide insights not limited by internal expectations
- Health providers can speak to consumer in a common language
- Identify patient goals

3.2 What helps to support your consumer engagement?

Responses identified not only ways consumer engagement is currently supported but also potential avenues for support in the future. For this purpose, no distinction has been made between current and potential future practice. Instead responses have been organised into three key areas, those addressing internal structure and processes, culture and behaviours and information and consumer training. These responses are summarised below:

Structure and Processes

- Board down processes

- National Standards (Framework)
- Dedicated Staff including those that co-ordinate consumer engagement
- Training staff in how to engage consumers
- Structure, framework and support for engagement
- Specific people, clear contact points of engagement and points of contact for consumers
- Time, budget and resources

Culture and Behaviours

- Respecting Individuality
- Valuing consumers – inclusive recognition and welcome
- Bringing staff and consumers together on an equal level
- Meaningful and genuine leadership
- Organisations providing opportunities to engage
- Not one size fits all – individualise approach
- Team approach to consumer engagement
- Patience with staff
- Feeling valued
- Provide information in simple forms
- Co-design projects and construction

Information and Consumer Training

- Information sharing
- Encouraging health literacy for informed decisions
- Contribution respected, valued and acted on. Not tokenistic
- Avenue for having a voice
- Education and training for staff and consumers
- Knowing your voice matters

3.3 How is that (Consumer Engagement and Support for Engagement) documented?

The responses for how consumer engagement and support for engagement is documented have been split into two categories; high level and policy based documentation and that which is done on an operational/ day-to-day level. Similar to section 3.2 these responses provide a mix of current and potential methods for documentation, as follows:

Policy / High Level

- Policy, framework and procedures
- Embedded into internal strategies
- Medical record documentation
- Accreditation – how is consumer participation acted on
- Individual care plans

- Documentation (pamphlets/info) which are reviewed by consultants
- Identify that you have the patients consent
- Information should remain in a clinical context

Operational and Day to Day

- Surveys: experience, exit, post case,
- Responding to feedback – actions are generated
- Patient stories
- Pockets of excellence shared and highlighted
- Internet, intranet and social media – mission and value statement
- Annual reports
- Monthly reports – how many participated in various activities
- List consumers where they participate
- Focus groups or video focus groups to document feedback post experience

4.0 Session 2: Role Based Discussion Groups

The second session focused on a role based discussion of opportunities. This session divided attendees into three consumer groups and two health care provider groups. Consumer groups were asked to discuss and respond to the following two questions:

- Tell us one strategy that works well in your setting?
- Tell us one thing you would like to do to improve consumer engagement in your setting?

The responses to these questions are summarised in section 4.1

Health service providers were asked to tackle similar questions with a focus on their own unique point of view. These questions were as follows:

- What resources are effective in supporting consumer engagement in your setting?
- Tell us one thing you would like to do to improve consumer engagement in your setting?

The health service provider responses are summarised in section 4.2.

4.1 Consumer Representatives

The following provides a summary of the information provided by consumer groups. Items that were signalled out as of particular importance to the group when discussing in the forum have been highlighted in bold.

4.1.1 *What strategies currently work well?*

- **Working groups that review Patient experience surveys and disseminate information e.g. Alfred Health**
- **Consumer involvement in staff recruitment e.g. interviews and group activities as observers to get the right people for engagement**
- **Active opportunities to train consumers e.g. that done by Star Health**
- **Engage consumers in “pledge” to engage in their own care management**
- Including admin, consumers and volunteers in training and workshop involvement
- Being treated as an equal
- Structured committees that are focused on consumers
- Patient Experience surveys that account for food, environment and service

- Consumer participation refined in operational committees
- Valuing consumer voices
- Having a staff contact – “go to” person
- Allowing consumer advocates to sit on all organisations and actively engaging their input in shaping strategic decisions
- Getting feedback noted, documented and followed up, including helping consumers through feedback and complaint processes

4.1.2 *What could be done to improve consumer engagement?*

- **Use plain and simple language to improve engagement when consumers are involved including a list of acronyms and their meanings**
- **Consumers know their rights and responsibilities so that they know when they are not being treated appropriately and can participate in their own care**
- Access to internal email to encourage inclusion in processes
- Actively seeking partnership relationships between organisations
- Recognition by staff of value of consumer involvement e.g. broad skills
- Make sure consumer reps have used the service they are consulting on to avoid tokenism
- Match the advisory committee with the clients – don’t use new clients
- Consumer surveys with direct feedback to practitioner and department
- Provide training to a consumer advocate that is funded (HIC training) and clarifies advocacy and representation
- Making sure clients on consumer groups develop their own skills and strengths
- Improve and mandate training of consumers that are going to be involved in the committee
- To coordinate, contribute and engage communication to avoid silo meetings
- Upfront in inductions – informed of role and your expectation to perform
- Formal training of staff on consumer engagement
- Comprehensive care/holistic approach – help doctors and professionals to understand each other
- Awareness, training and information communication
- Consistent approach to reimbursing the cost of involvement e.g. parking, meals
- Collect and look for common data in surveys
- Engage people from CALD communities and Aboriginal and Torres Strait Islanders in culturally respectful ways
- To educate consumers around being curious about taking control of their care
- Active communication with all clients
- Get feedback from all consumers

4.2 Consumer Participation Coordinators (last two groups)

4.2.1 What resources are effective in supporting consumer engagement?

- Designated consumer roles
- Using existing mechanisms such as clinical supervision models
- Consumers are equal – meaningful engagement
- Right consumers, right training
- Consumers on working groups/committees
- External organisation drivers: Australian commission, standards, Safer Care Victoria
- Process/mechanisms for hearing the lived experience/ sharing stories (training/ in service/ education)
- Need consumer input for funding projects
- Peer support models
- Recruitment and on-boarding (expectations, roles and responsibilities)
- Patient feedback – satisfaction surveys, compliments/complaints, stories
- Tools and guidelines/policy
- Governance Structure
- Dedicated personal/team
- Reimbursement
- Partnerships/alliances
- Consumer registry
- Diversity of demographics
- Leadership within organisation

4.2.2 What could be done to improve consumer engagement?

- Choosing the right person for a consumer facing role (needs passion)
- Co-design in service improvement and infrastructure planning
- Health literacy including checks of understanding
- Empower the consumer – training?
- Bring into undergraduate/ training curriculums
- Moving from advice to true partnership
- Incentives/reimbursement (could be a barrier)
- Utilising feedback data to improve
- Seeing outcomes from feedback
- Training with staff on working with consumers (facilitation of meetings)
- Can't rely on individual people need systems to support
- Online platforms/forums
- Diversity of consumer engagement

- Collaborative training – set up networks with information sharing between all parties

5.0 Panel Session: Advocacy – Resourcing – Recruiting

A presentation session around advocacy, resourcing and recruiting was a central focus of the forum. This session included three speakers with different experiences and approaches to consumer advocacy. The panel members included:

- Ron Ipsen: Voices of the Valley
 - Mobilising the community to improv health support following the Latrobe Valley mine fires
- Nathalie Cook: MPN Alliance Australia
 - Advocated for myeloproliferative neoplasm (MPN) patients to access PEGylated interferon. First consumer led drug listing with Pharmaceutical Benefits Advisory Committee (PBAC)
- Jacqui Gibson
 - Carer and consumer representative

These presentations were three very different takes on the change that can be affected by individuals and small groups, and the invaluable help that can be given by those in the health care industry. At the conclusion of the session, Ron Ipsen was asked if there was anything he would have done differently as an advocate for his community and in response answered “I would have believed that it was possible to achieve something earlier”. This provides a valuable piece of inspiration for all advocates moving forward, that affecting change is possible even in the smallest groups and with limited resources.

6.0 Session 3: Short and Long Term Goals for Consumer Engagement

Working in Service Provider groups, participants were asked to work with consumers to identify short term and long term organisational goals. These simple and implementable goals were recorded for documentation and ongoing reference. Providers that were willing to share these goals have had them recorded in the following sections as a key outcome of the forum.

6.1 Calvary Health Care Bethlehem

Short Term Goals

- To get consumer representatives together on a regular basis (quarterly?) as a group
- Include consumer representatives on transition committee over-seeing the moving of the hospital
- Communicate with customers about moving the hospital to a new location

Long Term Goals

- Maintain a caring culture through multiple hospital transitions over the next five years with consumer integration

6.2 SMPCP Community Consumer Collaboration Group (CCCG)

Short Term Goals

- Develop Networks with consumer groups in other Vic regions
- Better transparency from Local Health Department about food standards and hygiene of other businesses (e.g. hairdressers)

Long Term Goals

- Greater transparency by Local Government Health Departments on local compliance

6.3 Monash Health

Short Term Goals

- Chair training – consistent committee support person for each committee
- Peer support – discussion forum, complete the loop ensuring outcome feedback

Long Term Goals

- Sitting fees

6.4 Alfred Health

Short Term Goals

- Training and support of consumers and staff – meaningful engagement for all
- Audit of consumer involvement

Long term Goals

- Establish consumer portal to share projects, wins, resources and outcomes

6.5 Star Health

Short Term Goals

- Gather consumer reps together to share their ideas and provide support
- Induction training to include how to have an effective voice

Long term Goals

- Develop pathways for consumers
 - Create opportunities through volunteering to build skills and support into workforce

6.6 Cabrini Health

Short Term Goals

- training and support of staff and consumers

Long term Goals

- Incorporate the voice of the consumer in training of staff and strategy

7.0 Next Steps and Conclusion

Based on the wealth of knowledge and ideas that arose from this forum, one of the key outcomes is the recording of attendees and their interests to help build valuable partnership networks moving forward. This information has been compiled and shared in section 7.1.

7.1 Contact Details and Interests

The following table includes the names and interests of attendees to the forums for future collaboration and ongoing development of the key themes that arose on the day. Attendees that have indicated that they are willing to share their contact details will have their details provided as an appendix to this report.

Name	Contact? (Y/N)	Interests
<i>Jill Linklater</i>	Y	Consumer Health Literacy and Advocacy Consumer Training in their role on committees Helping consumers become involved and have a voice and use their voice in communicating their quality of life needs and goals to their doctor
<i>Veronika Plinte</i>	Y	Education Training Course for First aid Research on treatments available Improving written communication/brochures/website Research study/reports on actual outcomes and changes because of meetings
<i>Amy Lewis</i>	Y	Evidence of consumer input <ul style="list-style-type: none"> - What evidence to collect - How to collect it - How to demonstrate outcomes of input Network with another consumer participation staff Training for staff <ul style="list-style-type: none"> - How to partner with consumers - How to co-design - How to collect evidence - Training for chairs Training for consumer <ul style="list-style-type: none"> - Governance - National standards - How to be an effective advocate - How to operate on a committee - Communication to influence - Quality and safety data Health Literacy
	-	Diversity and Inclusion Policy and Procedure

Name	Contact? (Y/N)	Interests
		Developing and establishing pathways for consumers and volunteers
<i>Sandy Scherer Toula Saltas</i>	Y	Networks for Knowledge sharing Common surveys <ul style="list-style-type: none"> - Gathering common data across organisations Health Literacy course Training specs for chairs/ consumers on committees
<i>Lauri Unkovich</i>	Y	Network of consumer coordinators Training <ul style="list-style-type: none"> - Chairs of committees - Consumers for committee engagement - Staff dealing with consumers - Health literacy for consumers
<i>Mark Heenan</i>	Y	Training all aspects How to engage consumers in meaningful ways How to record consumer engagement for evidence for accreditation
<i>Coral Iceben</i>	Y	Consumer advocate Health care in the home Rehabilitation Food safety
<i>Fiona</i>	Y	Health literacy Consumer training Staff training Staff CP networks across CMPCP Promotion of consumer/community engagement/orgs
<i>Lauren</i>	Y	Research Health Promotion Improved Data Collection
<i>Jacqui Gibson</i>	Y	Training Networks Joint training with clinical staff <ul style="list-style-type: none"> - Consumer engagement - Co-design - Quality issues - Risk management
<i>Micaela Drieberg</i>	Y	Different methods of engaging with a broad range of people
	N	Pain Management Patient Experience Survey
<i>Irene Havryluk- Davies</i>	Y	Patient info Discharge to home Community care/care in the home Nutrition Palliative Care
	N	Patient Ethics
<i>Ash Thornton</i>	Y	Consumer training

Name	Contact? (Y/N)	Interests
		Community engagement Health networks Mental health (staff and consumers) Technology in services Feedback Patient centred care
<i>Claud Bennie</i>	Y	Health Literacy
<i>Phil Williamson</i>	Y	Staff training Consumer peer education
<i>Dave Godden</i>	Y	Co-design <ul style="list-style-type: none"> - Moving from advice/consultation to partnership/co-design/co-production - How can we build capacity of all staff to work more collaboratively with consumers? - Effective feedback mechanisms
<i>Elizabeth Eadie</i>	Y	Consumer training to enable effective participation as a representative at different levels in an organisation Patient/client advocacy
<i>David Brown</i>	Y	Providing good info to consumers when their journey crosses organisational boundaries
<i>Sasha</i>	Y	Training for consumer roles Information on services available Training for first aid
<i>Rebecca Banks</i>	Y	Health Literacy
<i>Lynda Condon</i>	Y	Co-labs for consumers in SMPCP <ul style="list-style-type: none"> - Training and education Health literacy/sentinel events/ root cause analysis Co design strategy
<i>Betty Wilderman</i>	Y	Training for consumer reps related to large health organisation End of life as it fits into hospital care
<i>Katrina Lewis</i>	Y	Training of consumers and staff Frameworks to support co-design Consumer registers Sharing of resources working on shared projects