Consumer Participation in Health and Community Organisations in Melbourne’s West
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Full survey report – January 2017

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Acknowledgement

HealthWest thanks all of our members who completed the consumer participation mapping survey or contributed to the development of the Project and survey questions.

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What is the Consumer Participation Mapping Project about?

The Consumer Participation Mapping Project (the Project) explores how consumer participation is being used by health and community organisations in Melbourne’s west to facilitate consumer input into organisational planning and decision making.

Specifically, we wanted to find out:

1. How consumer participation is being used within organisations
2. How organisations are supporting consumers and staff through this work
3. The changes that organisations are seeing as a result of consumer participation.

What is consumer participation and why is it important?

‘Participation occurs when consumers, carers and community members are meaningfully involved in decision making about health policy and planning, care and treatment, and the wellbeing of themselves and the community. It is about having your say, thinking about why you believe in your view, and listening to the views and ideas of others. In working together, decisions may include a range of perspectives.’ (Doing it with us not for us, p2)¹

By seeking out and including input from consumers and communities, services are better able to meet their needs. Consumer participation can take many different forms and can be described as falling along a spectrum where consumers have increasing impact on decision making. Different types of participation are suited to different situations and meet different needs².

HealthWest Partnership (HealthWest) understands that bringing local communities and organisations together can achieve real improvement in the design and delivery of health and wellbeing services and programs across Melbourne’s west. Consumer participation is a key priority in HealthWest’s strategic plan 2013–17. We are working to build the capacity of our member organisations to partner with consumers. This will lead to consumers being actively involved in organisational decision making, including planning, policy development, priority setting, quality improvement and evaluation.

In this report we use the term consumer to refer to past, current and future service users as well as their carers, families and the broader community.

For an overview and discussion of literature relevant to consumer participation in Victorian health and community organisations, please refer to the report Consumer engagement in Central Victoria: A literature review for health and community services³.

¹ Doing it with us not for us: Strategic direction 2010–13, Victorian Department of Health 2011
² International Association for Public Participation website 2016 https://www.iap2.org.au/About-Us/About-IAP2-Australasia-/Spectrum
Why did we undertake this Project?

The idea for the Project was born out of suggestions made at a HealthWest Partnership Forum, and supported by informal conversations with members involved in consumer participation.

Organisations in the health and community sectors are increasingly recognising the value of consumer participation, as are government, funders and accreditation bodies. Many of HealthWest’s members have prioritised consumer participation and are actively seeking to engage consumers in their decision making processes. However some members have expressed a desire for additional guidance and resources to support the planning and implementation of good practice consumer participation.

There is not a comprehensive understanding of current or planned consumer participation activities in Melbourne’s West, or of the support that organisations might need to conduct these activities. HealthWest has taken on the role of exploring how organisations are working with consumers, through a consumer participation mapping survey. The Project is intended to inform the discussion about consumer participation within organisations in our region.

It is anticipated that Project findings could be used:

- Internally by our member organisations to advocate for and inform consumer participation within their organisation,
- To help build broader understanding of different consumer participation activities being used by organisations, and
- To help build broader understanding of the support required to implement and maintain these processes.

What did we do?

The purpose and format of the Project was proposed by HealthWest and refined through consultation with the Community Engagement in the West Network (now known as the Community Participation Practitioners Network) which is facilitated by HealthWest.

An online survey was developed using the process outlined in figure 1. This work was done by a university student on placement at HealthWest, with the support of the community partnership program manager. A list of survey questions has been included as an appendix to this report.

The survey was designed to collect both qualitative and quantitative information. Qualitative responses have been grouped and analysed by theme. No statistical analysis was carried out on quantitative data due to the small sample size.

It is noted that participation in this Project was entirely voluntary. Organisations who value and are actively involved in consumer participation are more likely to have completed the survey and so their views are more likely represented. Project findings will provide valuable information on consumer participation activities and outcomes in Melbourne’s west, however are not necessarily representative of our broader membership.
Who took part in this Project?

The Project was aimed at HealthWest member organisations that have begun to partner with consumers to incorporate consumer participation into their structure and practice.

Out of 45 member organisations, 13 chose to take part. HealthWest received 12 completed surveys and one partially answered survey. Responses came from a wide range of member organisations. Organisations ranged from small (0-20 staff) to large (400+ staff) and represented different sectors including:

- Hospitals
- Community and women’s health
- Mental health
- Community organisations
- Local government
- Peak bodies.
Results section 1: What are organisations doing in consumer participation?

This section examines how organisations are working with consumers. This includes what activities consumers are involved in and how well this is done in the organisation.

13 organisations completed this section (n=13).

1.1 Prioritising consumer participation

Out of 13 responding organisations 11 formally recognise consumer participation as a priority. This is most commonly done via a strategic plan (n=5) or a community engagement framework or plan (n=3), but is also recognised through plans and policies relating to clinical governance, accreditation and operations.

1.2 Key drivers of consumer participation

Organisations identified the key drivers for consumer participation as:

- Executive leadership (n=10)
- Compliance with relevant accreditation standards or the Local Government Act 1989, which require consumer or community input in planning (n=9)
- Staff members responsible for driving consumer participation (n=8)

It is interesting to note that few organisations nominated funding requirements (n=3) as a key driver, as this is often framed as a method to drive change. One organisation also commented that consumers themselves are key drivers for their own participation.

1.3 Communicating with consumers

All organisations (n=13) regularly update consumers on important organisational issues and news.

Organisations relied more heavily on written communication to do this, using organisational websites (n=4), newsletters (n=9; both email and hardcopy), social media platforms (n=6), print media (n=2) and their annual report (n=2).

This approach was often used in combination with in-person communication including through consumer committees (n=3), community events (n=5) such as info sessions, consultations and launches and directly through service staff (n=2).

1.4 Consumer participation activities

Participants were asked to nominate specific activities that their organisations has conducted over the past 12 months, and how well they feel these activities have gone.

As can be seen in Figure 2, organisations have worked with consumers in many different ways over the past 12 months.
Organisations are more likely to include consumers and to do so successfully in:

- once-off input (consultations, surveys or feedback)
- areas related to service or project level input (evaluation, service design)
- committee participation (consumer advisory groups, as members of internal committees).

Organisations are less likely to include consumer input in high-level or structured decision making, doing so:

- less often (governance, infrastructure planning and critical incident review processes), and
- less successfully (policy input, priority setting).

It is encouraging that organisations are successfully working with consumers in many different ways. However it would be desirable to see consumers having meaningful input into high-level decision making in more organisations. Limiting consumer input in these areas is likely to limit the overall impact that consumer participation can have within organisations in our region and therefore should be addressed.

Despite mixed uptake and success in different activities, it is worth noting one or more organisations said that they work ‘well’ or ‘very well’ with consumers in each activity listed. This suggests that there is expertise and experience in all of these activities within our region, including in high-level decision making.
Organisations should be able to improve their performance in all activities if they can share and learn from each other.

1.5 What are organisations planning to do in the next 12 months?

Organisations indicated they are planning a lot of work in consumer participation over the next 12 months. Some key areas of focus are:

- **Develop and embed a consistent framework or approach to consumer participation across all parts of the organisation** (n=6). This might be in the form of a community engagement or consumer participation framework or policy.

- **Work with consumers on committees** (n=6). This was also popular and included working with consumer groups and committees, including consumers on existing organisational committees and including consumers on steering and working groups for new projects.

- **Strengthen connections with community** (n=5). Organisations are intending to improve communication with consumers and community, hold events and consultations and create community spaces where community voices can be heard.

- **Train staff in consumer participation** (n=2).

- **Develop new ways of working** that will empower consumer and community engagement and participation (n=2).

Comparing these areas of focus with the work conducted over the past 12 months we notice that looking ahead:

- Committees continue to be a common way of accessing consumer input.

- There is an increasing focus on establishing structures to enable organisation-wide consumer participation.

- There is a need for greater focus on consumer participation in high level decision making within organisations.
Results section 2: How are organisations supporting consumer participation?

This section looks at how organisations are supporting consumer participation. It also explores what other support and resources organisations feel that they need to work effectively with consumers.

12 organisations completed this section (n=12).

2.1 Supporting consumers to work with organisations

Organisations support their consumer participants in many different ways (see Figure 3), most commonly:

- Preparation and training (orientation n=7, other training opportunities n=10)
- Monetary benefit (sitting fees, honorariums or vouchers n=8)
- Support to enable participation by diverse consumers (interpreters and translated materials n=7)
- Practical support to attend (provide transport or reimburse travel costs n=10, childcare n=2 and meals n=2).

Regular supervision for consumer participation was not provided often (n=4). This could be because there is not enough staff capacity to do so, or ongoing supervision is not required for most consumer roles.

Where payments are made to consumer participants there is wide variation between organisations.

- The amount paid ranged from $30 for a half day to $60/hour. Amounts also varied within some organisations for different types of activities.
- Some organisations chose to make payments for all participation activities, others only did so for specific activities (large time commitments, specific projects, high level committees).

One organisation noted that recognition of consumer participants is important. It is possible that payments are valued by consumer participants as a form of recognition, in addition to the monetary value.
2.2. Supporting staff to work with consumers

Organisations are using a variety of methods to support staff to partner effectively with consumers. As can be seen in Figure 4, organisations are supporting staff using a combination of methods. One respondent commented on the importance of having a combination of dedicated and well-trained staff members that are also supported by clear policies and guidelines.

![Figure 4: How are organisations supporting staff to work with consumers?](image)

While almost all organisations have staff with a dedicated consumer participation roles (10 out of 12), there was large variation in the number of positions and portfolios with this responsibility. Total staff time ranged from 0.6 to 10 equivalent full time (EFT) positions, with half of the responses indicating between 1.0 and 2.0 EFT organisation wide. Some organisations noted that consumer participation or community engagement is built into the roles of particular teams (youth participation, health promotion) or simply expected of all staff across the organisation.

The funding to support consumer participation comes from internally-allocated funds at all organisations, with around half of organisations (n=7) saying they also receive funds from an external source to support their consumer participation work.
2.3 Staff competencies

A range of competencies are required for staff to work effectively with consumers (see figure 5).

![Figure 5: When working with consumers, how often do staff at your organisation demonstrate:](image)

Among responding organisations, staff are most likely to display a positive attitude to consumer participation with most organisations (n=8) saying that staff demonstrate a value for it ‘often’ or ‘almost always. It is worth noting that staff are most likely to lack confidence when working with consumers, with less than half organisations (n=5) stating that staff ‘often’ or ‘almost always’ demonstrate confidence.

This suggests that staff training in consumer participation should have a greater focus on building the confidence of staff to do this work, in addition to developing knowledge and skills.

2.4 Community and peer workers

This report has so far discussed staff and consumer participants as distinct roles. However in reality this divide is not so distinct with over half of responding organisations (n=7) employing consumers or peer workers as paid staff members. Again, the number of community or peer workers employed varies widely, ranging from 2 to 45, with them often being employed on a part-time or temporary basis.

The role that community or peer workers play can also vary, including:

- Providing direct education or support to communities and community members (peer educators, peer support workers).
- Informing and educating staff members who are working with community (community advisors, staff training).
- Acting as a point of contact between community and organisations to facilitate communication and access for the broad community (concierge) or particular community groups (Aboriginal support workers, settlement service users).
2.5 Further support and resources for organisations

Organisations were asked what support or resources could be provided by external organisations to support them to work more effectively with consumers.

Training was a key area mentioned by organisations, including:

- training on key topics such as co-design
- training for staff in key roles that affect consumers and community members
- training for consumers and community members to build their ability to participate effectively.

Partnership and networking was another key area mentioned:

- access to networks and other meetings relevant to consumer participation
- assistance linking with other organisations and people who can help them connect with hard-to-reach community groups.

Funding was nominated by very few organisations as a key area of need. Where it was mentioned (n=2), it was in relation to a very specific activity or project rather than a general need for increased consumer participation funding.

Respondents suggested that HealthWest could play a key role in two key areas:

- Provide networking and partnership opportunities between organisations and connection into community groups (as discussed above).
- Provide practical support in aspects of consumer participation such as development of consumer participation frameworks, consumer databases or training that better meets the needs of our varied members.
Results section 3: Outcomes of consumer participation

This section focused on the outcomes of consumer participation activities in organisations.

12 member organisations responded to this section (n=12).

3.1 Has consumer participation contributed to better outcomes for your organisation?

Organisations were asked to respond to this question using a 5-point rating scale where 1=no, 3=somewhat and 5=yes. All organisations (n=12) responded positively by selecting ‘somewhat’ or above, with half of respondents (n=6) selecting ‘yes’.

This is unsurprising, as organisations who volunteered to participate in this Project are more likely to value consumer participation and its outcomes. This section instead aims to look more deeply into how organisations measure consumer participation outcomes, and what changes they are seeing as a result of their activities.

3.2 Measuring outcomes

This survey shows wide variety in how organisations measure outcomes of their consumer participation work, with many identifying it as an area for improvement.

- Most organisations nominated only one or two ways in which they measure outcomes of consumer participation work (n=9).
- Only a few organisations used a broader mixed-methods approach (n=3).
- Two organisations said they measure outcomes based on a broader consumer participation plan (n=2).
- Three organisations stated that they do not measure outcomes from consumer participation activities, or do so poorly (n=3).

Outcome measures that were nominated include:

- Consumer feedback (eg consumer satisfaction surveys, feedback forms and interviews) (n=6)
- Feedback from staff (n=1)
- Evaluation of individual activities (eg workshops) (n=1)
- Effective implementation of consumer participation or program plans (n=2)
- Accreditation results (n=2)

From these results, it appears that organisations in Melbourne's west would benefit from good-practice examples of different approaches to measuring outcomes. HealthWest could play a role by facilitating networking, sharing and coordination, as well as through continued projects such as this Consumer Participation Mapping Project.

3.3 Most noticeable changes

Organisations were asked to state the three most noticeable changes that have resulted from consumer participation in the last 12 months. Respondents mentioned a wide variety of changes across different areas of their organisation. Organisations fell along a spectrum that ranged from taking their first steps on the
consumer participation journey by recognising the importance of consumer input, through to visible and meaningful consumer involvement in a broad range of activities.

Emerging themes include:

- Increasing **awareness and prioritisation of consumer participation** was mentioned by half of respondents (n=6). This includes making consumer participation a formal priority for the organisations, as well as increasing awareness of the value of consumer participation and how consumer input can be meaningfully incorporated into the organisations.

- Development of **policy and guidelines** for staff and consumers to follow was another noticeable change (n=5). The development of clear and consistent processes was considered a very positive change to support staff and consumers in their practice.

- A number of respondents noted **increasing staff capacity** to partner with consumers (n=4). This includes the establishment of dedicated consumer participation positions as well as increased awareness and training on consumer participation principles and practice among the broader staff body.

- Over half of respondents said that the most noticeable change had been **consumers actively and meaningfully participating within the organisation** (n=7). This includes consumer representation on organisational committees and project working groups, input into consumer information and publications, involvement in staff training and active participation in project design and implementation.

- Some organisations mentioned that consumer participation had led to better relationships with their community leading to **increased community engagement and service use** (n=2) among the broad community and specific community groups.

### 3.4 Challenges of consumer participation

Respondents were also asked to reflect on the three biggest challenges their organisation had faced while doing consumer participation work. Again, challenges encompassed many themes depending on the type of organisation and consumer participation work they were doing.

- Over half of respondents noted challenges **resourcing consumer participation work** (n=7). They noted limited budget to fund dedicated consumer participant roles, provide training for staff and consumers and support consumer participation in project work. This is made more difficult by many competing priorities.

- Organisations found it challenging to **incorporate diverse representation** of their consumers (n=4). The large size and diversity of many organisations’ catchments meant that some groups were very difficult to reach and include, while others were over-represented.

- Organisations had difficulty **ensuring that consumer participation is meaningful and purpose-driven** (n=4). Organisations found it challenging to ensure consumer participants had the skills and ability to enable them to have meaningful input and to use appropriate modes and methods of participation to maximise meaningful input from different people with different desires and needs. Once they had input from consumers they noted difficulties managing the information they had received, demonstrating how the information was being used and reporting back to communities.
• Organisations found it difficult to **embed consumer participation** as standard practice (n=3). This includes keeping it on staff radars over time, ensuring that different programs and disciplines remain engaged and ensuring that consumer participation remains a part of improvement and planning processes.

• Finally, two organisations noted they had found it difficult to keep up with the evolving **practical aspects of ongoing consumer participation** work including recruiting consumer participants and using online participation methods (n=2)

### 3.5 Acting on consumer input

When asked if consumer input is reflected in high-level decisions within the organisations, only a third of respondents agreed that it ‘often’ (n=3) or ‘almost always’ (n=1) was. Respondents were more likely to say that consumer input is only ‘sometimes’ (n=7) or ‘not really’ (n=1) reflected in high level decision (see figure 6).

This supports findings discussed in section one that consumer participation in high-level or structured decisions is done less often and less successfully. To delve into this finding further, participants were asked to give an example of a time when their organisations found it difficult to act on consumer input.

Responses reiterated the challenges discussed above. Additionally, they reflected on the need for organisations to have clear plans for consumer participation activities, and for using the input provided.

“Sometimes we aren’t ready for consumer input as we aren’t sorted ourselves. I think it’s important to get the feedback at the right time so it is acted upon – and for this to happen you need to be very clear about what input you need.” (Respondent)
Key Project findings

This Consumer Participation Mapping Project provided information about consumer participation activities of organisations in Melbourne’s west. This led to a series of four key findings and two recommendations.

Key finding #1 – High level decisions

Consumer Participation is being increasingly valued and prioritised by organisations and staff members. However this prioritising is not always reflected in high level decision making within organisations. Organisations are not effectively incorporating consumer input into high level decision making, nor are they planning to focus on this in the next 12 months.

There is a need for guidance and support to encourage organisations to incorporate consumer participation into high level decision making.

Key finding #2 – Sharing expertise

Collectively organisations in Melbourne’s west possess a wide range of consumer participation knowledge and expertise. Once-off consultations and surveys, service and project level input and committee participation are all conducted regularly across the region. Other less-common consumer participation activities are also carried out effectively by individual organisations in the region. Sharing this expertise and experience between organisations can build the capacity of the region as a whole.

Developing mechanisms to enable organisations to share and learn from each other will allow organisations to tap into a high degree of expertise and build their capacity in all aspects of consumer participation.

Key finding #3 – Building staff capacity

It is important that all staff seek and include consumer input into their work. However many staff lack the knowledge and skills required to do so effectively. This is compounded by a lack of confidence in their own abilities to partner with consumers.

Organisations can build the capacity of their staff to partner with consumers by providing:

- Training that focuses on developing staff confidence in their knowledge, skills and practice.
- Organisational policy and procedure that provides guidance and support to staff.
- Leadership that encourages and supports consumer participation practice.

Key finding #4 – Measuring outcomes

Measuring outcomes of consumer participation is important to allow evaluation and improvement of consumer participation activities. Demonstrating benefits will also lead to consumer participation being further valued and prioritised. Many organisations in Melbourne’s west do not measure consumer participation outcomes well.
There is strong need to build the capacity of organisations in Melbourne’s west to measure consumer participation outcomes. Organisations will benefit from a broader knowledge of different approaches to measuring outcomes, and how to put these into practice.

Recommendations for HealthWest Partnership:
Organisations in Melbourne’s west are engaging in consumer participation work in a wide variety of ways. Many organisations would benefit from support and guidance in this area. HealthWest can play a key role in supporting consumer participation in organisations in Melbourne’s west by providing:

- Networking and partnership opportunities for organisations and community groups, to facilitate sharing of knowledge and expertise.
- Practical support through assistance in the development of policies and frameworks, training and other resources.
- Continued projects to build our understanding of consumer participation in Melbourne’s west and contribute to the evidence base around activities and outcomes.

Recommendations for systems change:
The role of government and funding bodies in driving consumer participation has been an area of interest among HealthWest’s members. Project findings relating to funding are complicated. Few organisations suggested that funding requirements were a key driver for consumer participation within their organisation. In fact, when organisations were asked about support and resources very few said they needed additional funding, instead suggesting access to training and networking opportunities. Yet when asked about key challenges, over half of organisations said they had difficulties finding the budget to resource their work. It was suggested that many other priorities are competing for resources within their organisations.

Government and funding bodies may wish to consider the following points when seeking to build consumer participation among the organisations and activities they support:

- Prioritise consumer participation when funding projects and activities. Making consumer participation a required component in project plans would place greater importance on effective consumer participation planning and evaluation practices. Ensuring that sufficient resources are allocated in project budgets will support meaningful consumer participation.
- Support consumer participation by increasing access to training and networking opportunities for staff and consumers of health and community organisations.
Appendix: Survey questions

The following questions were distributed to participants via survey monkey.

A few questions to start...

1. Does consumer participation occur at your organisation? (Yes/No)

2. What type of organisation do you work for?
   - Hospitals
   - Community health organisation
   - Community organisation
   - Mental health
   - Ethno-specific organisation
   - Peak body
   - Local government
   - Other (please specify)

Section 1: What are you doing?

This section will focus on how your organisation is currently working with consumers. This includes what activities consumers are involved in and how well this is happening in your organisation.

3. Is consumer participation formally recognised as a priority at your organisation? (e.g. mission statement, strategic plan) (Yes/No)

   If yes, where is it identified as a priority?

4. What are the key drivers of consumer participation at your organisation? (Choose all that apply)
   - Accreditation standards
   - Funding requirements
   - Executive leadership
   - Staff member/s responsible for driving consumer participation
   - Other (please specify)

5. Are consumers being regularly updated about important issues within your organisation? (Yes/No)

6. How do you communicate this information?

7. Has your organisation worked with consumers in the following ways in the last 12 months? If so, how well?
   - Participate in service design
   - Participate in research
   - Input into policy planning and development
   - Setting priorities for your organisation
   - Evaluation of services or projects
   - Consumer advisory groups
8. What is your organisation planning to do in the next 12 months to improve consumer participation?

**Section 2: Supporting consumer participation**

This section will focus on how your organisation is supporting consumer participation. It will also explore what other external support your organisation needs to effectively work with consumers.

9. How does your organisation support consumers to participate within the organisation?
   - Consumer orientation
   - Training opportunities for consumers
   - Regular supervision for consumer participants
   - Access to interpreters and translated materials
   - Sitting fees/honorariums
   - Reimbursing travel costs (myki, taxi, parking)
   - Other support (meals, childcare; please specify)

10. If you pay sitting fees or honorariums, how much do you pay?

11. How does your organisation support staff to work with consumers?
   - Consumer participation policy or framework
   - Training for staff to work with consumers
   - Staff member(s) with a dedicated role for consumer participation
   - Consumer participation included in staff orientation
   - Partnering with community/consumer organisations.
   - Other (please specify)

12. When working with consumers, do staff at your organisation demonstrate: (Not really/Occasionally/Moderately/Often/Almost always)
   - Knowledge about consumer participation?
   - Value for consumer participation?
   - A high level of confidence to work with consumers?
   - Good practice and skills?

13. How much staff time is allocated to consumer participation in your organisation? (e.g. 1.0 EFT)

14. Does your organisation employ community/peer workers as staff? (Yes/No)

15. Approximately how many community/peer workers do you employ?

16. Tell us more about the roles community/peer workers are employed in.
17. How does your organisation fund consumer participation?  
   - Internally  
   - Externally  
   - Both internally and externally  
   - Other (please specify):  

18. How can HealthWest support your organisation to work more effectively with consumers?  

19. What other resources or external support would help your organisation work more effectively with consumers? Please try to be specific.  

**Section 3: Outcomes**  
*This section will focus on the outcomes of consumer participation in your organisation*  

20. Has consumer participation contributed to better outcomes for your organisation? (  

21. How does your organisation measure outcomes related to consumer participation?  

22. What are the 3 most noticeable changes you have seen in your organisation, as a result of consumer participation in the last 12 months?  

23. What are the 3 biggest challenges your organisation has experienced when doing consumer participation? How have you managed these challenges?  

24. In your opinion, is consumer input reflected in high level decisions in your organisation? (Not really/Sometimes/Often/AImsost always  

25. Give an example of when your organisation has had difficulty acting upon consumer input.  

**A few last questions...**  

26. How many staff are in your organisation?  
   - 0-20  
   - 20-50  
   - 50-200  
   - 200-400  
   - 400+  

27. What is your role in your organisation?  

28. We are interested in conducting some case studies of consumer participation at individual organisations. Can we contact you to discuss participating in a case study?