



cutting through complexity

DEPARTMENT OF HEALTH VICTORIA

Discussion Paper

Evaluation of Doing it with us not for us

August 2014

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The findings in this report have been formed on the above basis.

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Executive summary

This discussion paper is the final component of the evaluation of the *Doing it with us not for us* policy and the *Cultural Responsiveness Framework*. The paper is structured to provide high level recommendations and rationale based on the evaluation activities for the consideration of those developing Victoria's next consumer participation policy.

KPMG was engaged by the Victorian Department of Health (the Department) to undertake a summative evaluation of the impact of the Department's policy, *Doing it with us not for us*, and *Cultural Responsiveness Framework*, to inform the development of a new Victorian public policy on consumer participation. As part of the evaluation KPMG undertook several activities; a literature review to garner a sense of the current state of consumer participation and public policy in Victoria, Australia and internationally; a survey of health service staff; consumers and carers and Department of Health staff; a desktop review of key documents; and a series of consultations across rural, regional and metropolitan Victoria.

Following the evaluation activities, an outcomes summit was held with key stakeholders to validate the evaluation findings and inform the development of the recommendations.

The evaluation found that whilst the policy and framework have been strong influences in public health services, the drivers currently directing consumer participation have changed, in light of developments in public policy and the introduction of national standards across public hospitals, mental health services, community health services and residential aged care facilities.

The evaluation also highlighted that the role of the consumer is changing, with a stronger focus on person and family centred care and shared decision making. Equally, the alignment between diversity, equity and consumer participation needs to be strengthened.

This discussion paper provides a summary of the key findings from the evaluation activities and makes a number of recommendations for consideration in the development of a new policy.

The recommendations summary

The recommendations summary describes the high level recommendations, which have been guided by the literature and the evaluation findings. Further recommendations can be found in the chapters of the discussion paper.

Foundations of a new policy

- 1. A new policy needs to reflect contemporary approaches of person centred care and shared decision making, recognising the diversity of the Victorian population**
- 2. A new policy needs to recognise current legislative and policy drivers**
- 3. The scope of a new policy should consider all funded and regulated health services**

Diversity and equity

- 4. A new policy needs to incorporate cultural responsiveness, diversity and equity**

The consumer, carer and community level

- 5. Future directions need to consider person centred care approaches to strengthen the involvement of the consumer, carer and community in the continuum of care and governance**

The organisational level

- 6. Accountability mechanisms need to be strengthened at an organisational level**
- 7. Consumer feedback methods need to be robust and feed into continuous improvement initiatives and the design of services**
- 8. Organisations need to invest in capability building to support the development of learning cultures**

Government and policy levels

- 9. Mechanisms to enhance consumer and carer partnership in governance are required**
- 10. Reporting requirements need consolidating to reduce the duplication of reporting whilst meeting legislative, regulatory and policy requirements**
- 11. A self-assessment maturity matrix needs to be developed to determine the level of consumer participation in the organisation and as an ongoing measure of progress**
- 12. Consideration should be given to new funding arrangements to incentivise consumer involvement and person centred care approaches**

Principles of a new policy

- 13. A new policy should review with the services and programs, consumer, carers and the community, the principles and values upon which the new policy should be based**

Acknowledgements

The KPMG evaluation team wishes to express its gratitude to all those who generously contributed their time in providing information to inform the evaluation. We are also grateful to the staff of the Department of Health's Consumer Partnerships and Quality Standards Unit and members of the Participation Advisory Committee and the Evaluation Reference Group for their support in the conduct of this evaluation.

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List of acronyms, abbreviations and definitions

Abbreviation	Definition/source
The 'policy'	Doing it with us not for us – Participation in your health service system 2006-09: Victorian consumers, carers and the community working together with their health services and the Department of Human Services
	Doing it with us not for us: Strategic Direction 2010-13
The 'framework'	Cultural responsiveness framework: Guidelines for Victorian health services 2009
The 'Department'	The Victorian Government Department of Health
The 'health workforce'	Staff working in the health system, including staff who participated in the consultation process and the survey evaluation
Acronym	Definition
CAC	Consumer Advisory Committee
CALD	Culturally And Linguistically Diverse
CQUIN	Commissioning for Quality and Innovation
QoCR	Quality of Care report
NSQHS Standards	National Safety and Quality Health Service Standards
VHES	Victorian Healthcare Experience Survey
VAGO	Victorian Auditor-General's Office
CDC	Consumer Directed Care

1 Background

Victoria has been a leader in Australia in the development of consumer participation policy through *Doing it with us not for us*¹ which was launched in 2006, and which sets out the guiding principles for public hospitals, mental health services, community health services, and residential aged care facilities.

This policy was updated in 2009 and 2011 resulting in the current *Doing it with us not for us: Strategic Direction 2010-2013*.² Following a review of cultural and linguistic diversity and cultural competence reporting requirements, minimum standards and benchmarks for Victorian health services, a cultural responsiveness framework was also developed in 2009.³

The development of the policy, strategic direction and cultural responsiveness framework occurred within an existing system of legislation, infrastructure and resources supporting consumer participation. This included funding and service agreements with peak consumer and carer non-government organisations, mental health consumer and carer consultants and programs, the requirement for public health services and registered community health services to provide annual Quality of Care Reports (QoCR), the Victorian Health Policy and Funding Guidelines, the Victorian Patient Satisfaction Monitor survey (superseded by the Victorian Healthcare Experience Survey from April 2014), and the specification of board level Community Advisory Committees in the Victorian *Health Services Act 1988*.

In 2012, the Victorian Auditor-General's Office (VAGO) performance audit report *Consumer Participation in the Health System* made a number of recommendations in relation to consumer participation, including that the Department of Health (the Department):

- evaluate the impact of *Doing it with us not for us: Strategic Direction 2010-2013*
- update its consumer participation policy and guidelines in the context of the new National Safety and Quality Health Service (NSQHS) Standards and the Victorian Health Priorities Framework.⁴

KPMG was engaged by the Department to undertake a summative evaluation of the impact of the Department's policy, "*Doing it with us not for us*" (the policy) and the Cultural responsiveness framework (the 'framework'), to inform the development of a new Victorian public policy on consumer participation.

This discussion paper is the final component of the evaluation and is structured to provide high level recommendations and rationale based on the evaluation activities. This paper is supported by a findings series which capture all the evaluation activities, including:

¹ Victorian Department of Health 2006, *Doing it with us not for us – Participation in your health service system 2006-09: Victorian consumers, carers and the community working together with their health services and the Department of Human Services*, Victorian Government, Melbourne.

² Victorian Department of Health 2011, *Doing it with us not for us: Strategic Direction 2010-13 – Participation in your health service system: Victorian consumers, carers and community working together with their health services and the Department of Health*, Victorian Government, Melbourne.

³ Victorian Department of Health 2009, *Cultural responsiveness framework: Guidelines for Victorian health services*, Victorian Government, Melbourne

⁴ Victorian Auditor-General's Office 2012, *Consumer Participation in the Victorian Health System*, VAGO, Melbourne, p. xi

- a report on the current state of consumer participation and public policy in Victoria, Australia and internationally
- a desktop review of documents and data provided by the Department
- results of a survey of health service staff, consumers and carers and Department staff
- a consultations findings paper which captures data from consultations conducted across metropolitan, rural and regional Victoria.

In addition, an outcomes summit was held with key stakeholders, including members of the Department of Health, representatives from health organisations, consumers and carers, to validate the findings of the evaluation activities and to inform the development of recommendations. This discussion paper incorporates the feedback received at the outcomes summit.

The evaluation findings series are accessible on the Department of Health consumer website: www.health.vic.gov.au/consumer.

1.1 Structure of this discussion paper

	Description
1	Background
2	Foundations of a new policy
3	Equity and diversity
4	Consumer, carer and community participation level findings and recommendations
5	Organisational level findings and recommendations
6	Government and policy level findings and recommendations
7	Strategies and principles for a new policy

2 Foundations of a new policy

Key findings:

- The 'Doing It with Us Not for Us' policy was innovative at the point of inception and is still regarded as beneficial by many public health services
- Over time there has been a shift towards more participatory health systems, and this needs to be reflected in a new policy
- A new policy should incorporate strategies for consumer participation at all levels of the health system in line with international better practice
- Policy makers are increasingly recognising that better outcomes are achieved when consumers are active partners in decision-making

Around the world, policy makers and service providers increasingly recognise that better outcomes are achieved when consumers are active partners in decision-making. Strategies to involve consumers in their own healthcare, local service delivery, and at the system level are an increasing feature of health reform efforts.

The shift towards more participatory health systems has occurred over a number of decades and the catalysts for change have been proactive and reactive, both within and external to the health system. These catalysts are illustrated in Figure 1 below and include:

- **Social movements** that have demanded greater citizen involvement, transparency and accountability in the formulation of health and social policies and the design of public services. The health consumer movement is considered reflective of broader rights-based social movements that have emerged since the 1960s.⁵ This has involved community advocacy for greater involvement, transparency and accountability in the formulation of government health and social policies, professional regulation, and the design of preventative health and clinical services.⁶
- **Community-based primary healthcare models** which emphasise holistic and preventative approaches to healthcare over traditional medical-driven models of care. There has been a shift from traditional medical driven models of care to contemporary community-based primary health care models which emphasise person-centred and goal-based approaches to care.⁷
- **The concept of person centred care** which has reframed the relationship between consumers and healthcare practitioners and elevated the consumer experience as a key indicator of healthcare performance and quality. Person centred care has been defined as "health care that is respectful of, and responsive to, the preferences, needs and values of patients and consumers".⁸ The Picker Institute has been at the forefront of defining the principles of person centred care, providing a basis for developing measures of patient experience. In Australia, a

⁵ Coney, S. 2004, *Effective Consumer Voice and Participation for New Zealand: A Systematic Review of the Evidence* New Zealand Guidelines Group, p.8

⁶ *ibid.*

⁷ *ibid.*

⁸ <http://www.safetyandquality.gov.au/our-work/patient-and-consumer-centred-care/>

person centred approach is supported by the Australian Charter of Healthcare Rights, the National Safety and Quality Framework, other national service standards, reports of state-based inquiries, and a range of jurisdictional and private sector initiatives.⁹ It is also being recognised as a key input in health service planning activities.¹⁰ It is noted that dialogue is now transitioning to person and family centred care. This needs to be taken into account in relation to references to person centred care in this discussion paper, which reflects the literature at the time of the evaluation.

- **Inquiries into medical failures** which have put a spotlight on the need for more effective accountability arrangements that take the consumer voice seriously. In Australia, a number of high-profile, state-based inquiries involving patient care and adverse clinical incidents have acted as a catalyst for an increased focus on person centred care.¹¹
- **Rising healthcare costs** and the recognition that a health system that is closely aligned with the needs of its users is more effective and efficient. In recent years, there has been an increased focus on rising health care costs and demand pressures on health systems. Governments have increasingly sought to involve consumers in debates around spending on health, rationing and health care priorities as a tool to increase the legitimacy of budgeting and funding decisions.¹² This is consistent with the view that a health system that is closely aligned with needs of its users and clients can be more effective and efficient.¹³
- **Changing consumer expectations** over the last few decades has seen a shift towards the provision of accessible and high quality health information for the purposes of educating and empowering the community on health matters and decisions regarding their health.¹⁴ This has been facilitated through the creation of authoritative websites and resources on the internet and increased information sharing, particularly through social media.
- **Growing body of evidence of improved clinical outcomes** when consumers are involved in decision-making about their care.¹⁵

⁹ ACSQHC 2011a, p.7

¹⁰ Health Issues Centre (HIC) 2011, 'The latest evidence and future directions in consumer engagement; It's possible and it works!' *Emerging themes from the Health Issues Centre's Consumers Reforming Healthcare Conference, July 2011*, Health Issues Centre, Melbourne.

¹¹ ACSQHC 2011a, *Patient-centred care: Improving quality and safety through partnerships with patients and consumers*, ACSQHC, Darlinghurst, p.37

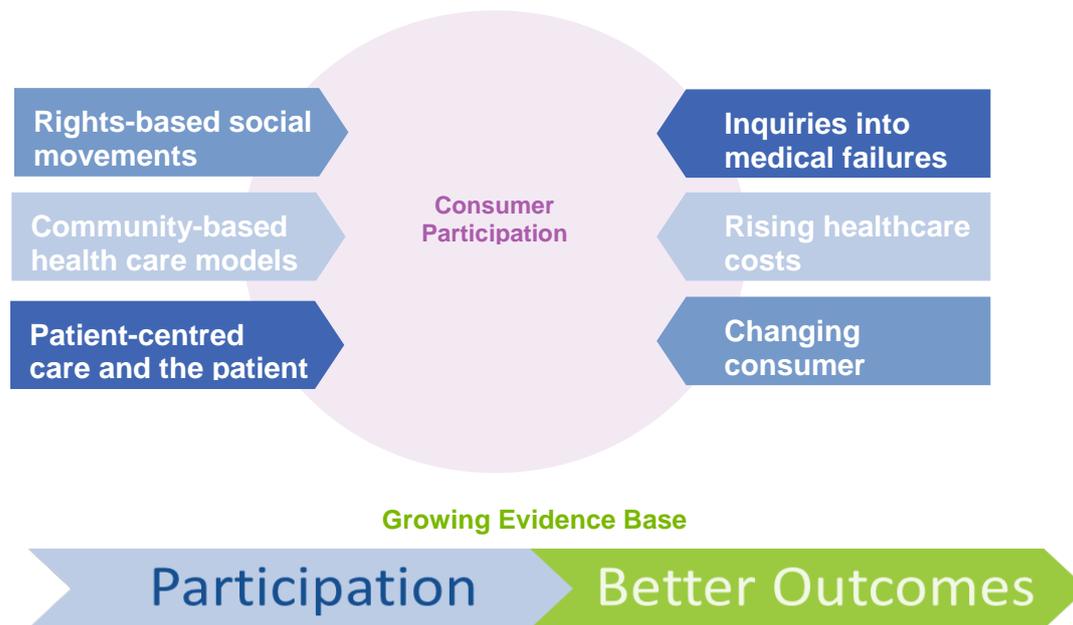
¹² Coney, S. 2004, p.12

¹³ Gregory, J. 2007, 'Conceptualising Consumer Engagement: A review of the literature' *Australian Institute of Health Policy Studies Research Project Working Paper 1 (Revised)*, Australian Institute of Health Policy Studies (AIHPS), Melbourne, p.8

¹⁴ Coney, S. 2004, p.10

¹⁵ Institute for Patient- and Family-centred Care in ACSQHC 2011, p.48

Figure 1: Drivers for consumer participation



Source: KPMG 2014

This gradual shift towards more participatory approaches is reflected in the evaluation findings as many health organisations are driven increasingly by contemporary influences in the design and implementation of consumer participation initiatives. This will be an important consideration in the development of a new policy. A number of health organisations still regard the policy as a point of reference for current practice, however, a new policy will need to be built around contemporary practices and reflect the growth in person centred care approaches.

Furthermore participation is often viewed as a progressive scale of engagement that reflects the level of control that consumers are exercising. At lower levels, participation is about consumers having access to the information they need to understand their situation and decisions that affect them. At higher levels, participation is about placing the final decision making in the hands of consumers.

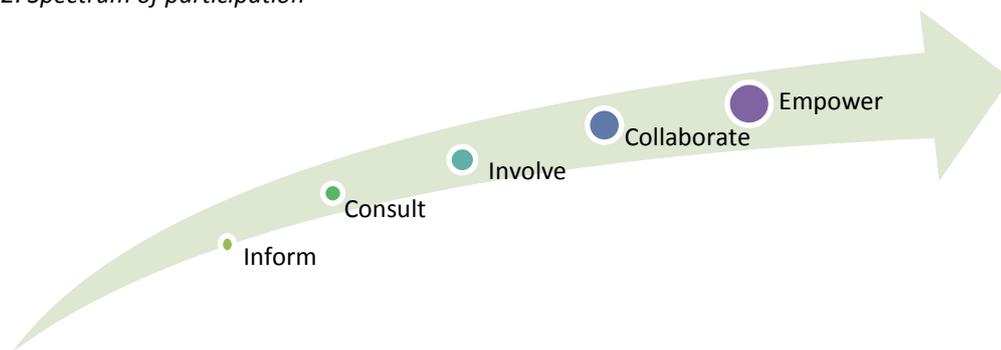
Contemporary approaches to conceptualising the intensity of consumer participation have transitioned from a hierarchical classification to discontinuous interactions, with no single methodology and no shared theoretical base.^{16,17} This model was considered in Victoria, with an adaption of this typology incorporated into the *Doing it with us not for us* policy.

¹⁶ Gregory, J. 2007 p.15

¹⁷ Bishop, P. and Davis, G. 2002 'Mapping public participation in policy choices' *Australian Journal of Public Administration* 61:14-29

An example of this type of framework is the ‘IAP2 Public Participation Spectrum’, developed by the International Association for Public Participation.¹⁸ The spectrum identifies forms of participation with increasing levels of public impact, progressing from the provision of information to empowerment of the public to make final decisions which are then enacted. Figure 2 below illustrates this spectrum of public participation which is being applied in the health setting.

Figure 2: Spectrum of participation



Source: Adapted from IAP2 Public Participation Spectrum, developed by the Internal Association for Public Participation

In addition to recognising the development of person centred care approaches, a new policy will also need to reflect the intensity of consumer participation required at different levels of the health organisation and the supports required to achieve this. It is important to remember that ‘consumers’ are not a homogenous group and not all types of participation are equal. The skills and capabilities that consumers, the health workforce and policy makers require will vary depending on the level (or ‘intensity’) of consumer involvement and the role that the consumer is expected to play, as will the organisational supports necessary to sustain effective participation. These requirements are described in the findings and built into the recommendations.

2.1 Frameworks for participation

The term ‘consumer participation’ encompasses a range of activities, which can occur at different levels of the health system and vary in the extent to which they achieve active consumer level involvement. This is an important consideration as different types of participation serve different purposes and achieve different outcomes. It is helpful, therefore, to keep in mind the different ‘lenses’ through which to view participation, in relation to the findings and recommendations in this discussion paper.

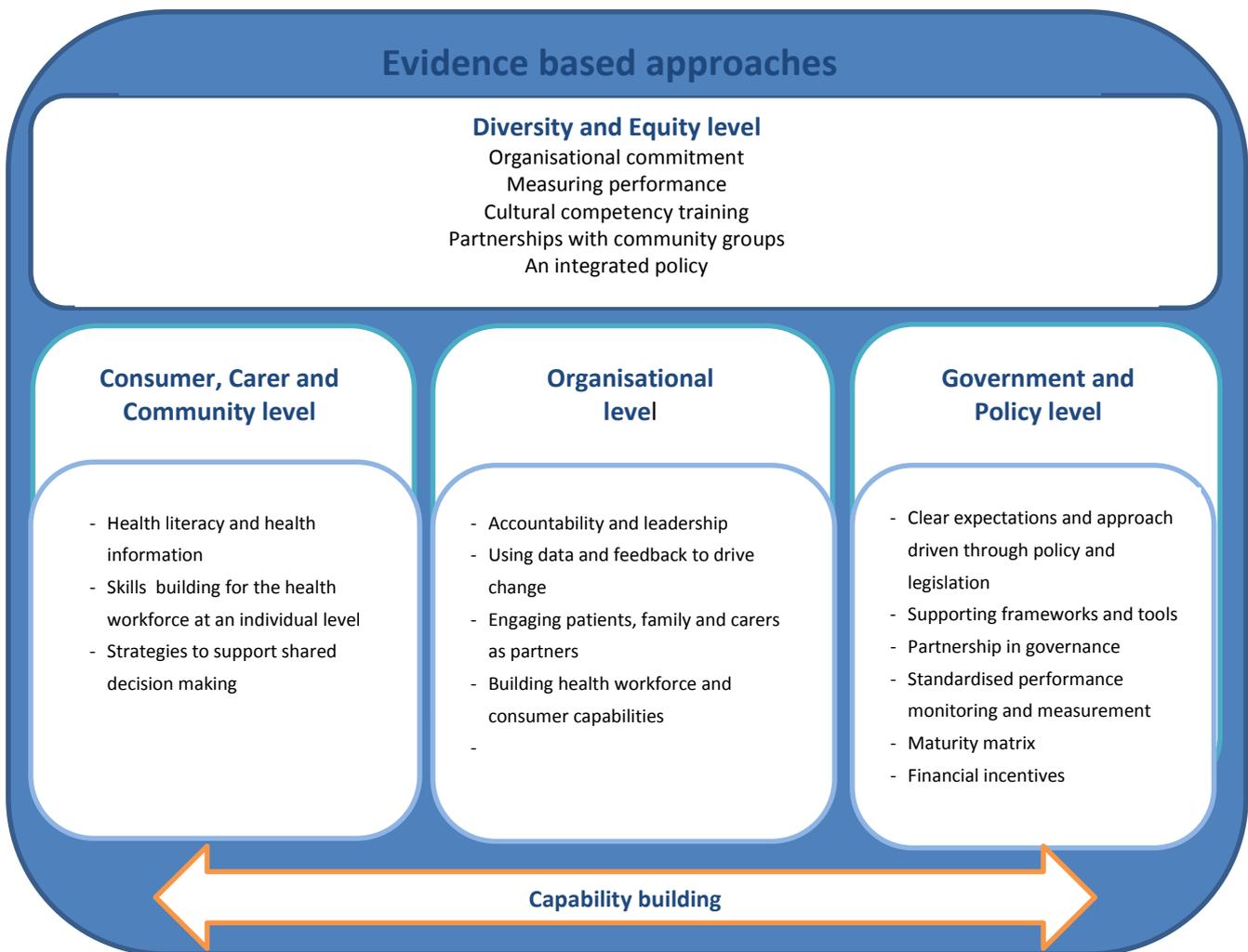
The policy described four key levels of the health system, incorporating actions to demonstrate consumer participation. These were; the individual level, program or department level, health service level and the Department of Health level. In keeping with this approach and with reference to contemporary literature, this discussion paper describes three levels:

¹⁸ International Association for Public Participation (IAP2) 2004, *IAP2 Public Participation Spectrum*, IAP2 website, Retrieved from <https://www.iap2.org.au/sitebuilder/resources/knowledge/asset/files/36/iap2spectrum.pdf> on 3 March 2014.

- The consumer, carer and community level, which relates to improving processes to enable person centred care at the individual level
- The organisational level, which relates to funded and regulated health services
- The government and policy level.

In addition diversity and equity is described as a fourth level and is aligned across the three levels of participation. This reflects the evaluation findings which highlighted the important role diversity and equity plays across all levels of participation. Figure 3 below describes the recommended levels of participation which inform the structure of this paper and includes proposed areas of focus which have been guided by the literature and through the evaluation findings. Capability building has been identified both as an enabler across the health system and at the different levels of participation.

Figure 3: Levels of participation (Source KPMG 2014)



Whilst the existing policy has been regarded as influential across Victoria and Australia, changes in consumer expectations are resulting in a need to more strongly recognise person centred care approaches and intensity of consumer involvement, where individuals wish to be more involved in decision making about their health care. A new policy should be designed to reflect this changing face of consumer participation.

Recommendation:

- 1 A new policy needs to reflect contemporary approaches of person centred care and shared decision making, recognising the diversity of the Victorian population**
- 2 A new policy needs to recognise current legislative and policy drivers**
- 3 The scope of a new policy should consider including all funded and regulated health services**

3 Diversity and Equity

Key findings:

In considering diversity and equity, key elements of participation should include:

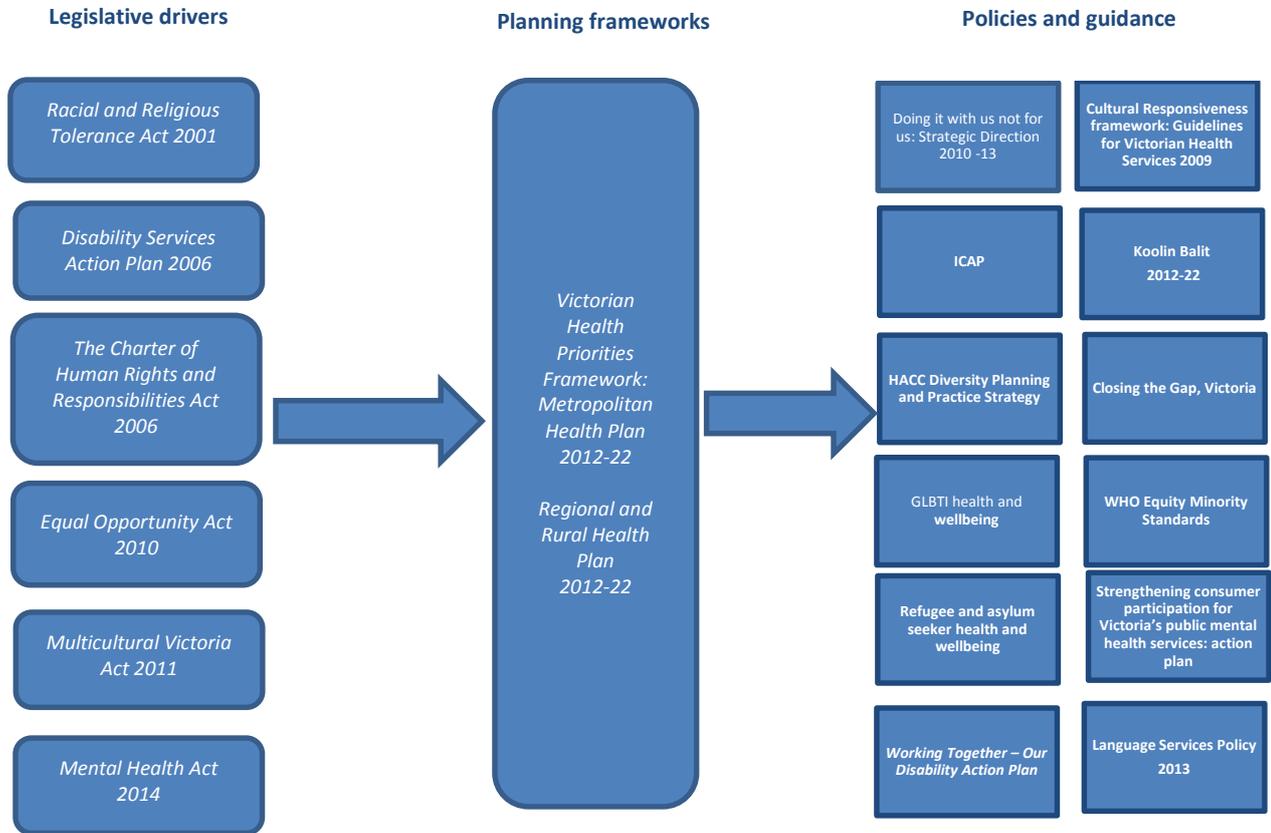
- Organisational commitment
- Measuring performance
- Cultural competency training
- Partnerships with community groups
- An integrated policy

The broader policy context for cultural diversity is primarily informed by the principles contained in the following legislation:

- *Equal Opportunity Act (2010)*
- *Racial and Religious Tolerance Act (2001)*
- *The Charter of Human Rights and Responsibilities Act (2006)*
- *Disability Services Act (2006)*
- *Multicultural Victoria Act (2011)*
- *Mental Health Act (2014)*

This legislation focusses on addressing and preventing discrimination, and improving access to services for diverse groups including people from multicultural backgrounds and people with a disability. At a state level, the Department of Health has developed planning frameworks, policies and guidance designed to support health services in being responsive to Culturally and Linguistically Diverse (CALD) communities and these, together with the legislative drivers, are shown in Figure 4 below:

Figure 4: Legislative drivers, policies and guidance in Victoria



Victorian Health Priorities Framework 2012-22

At a strategic level, the *Victorian Health Priorities Framework 2012-22: Metropolitan Health Plan* describes the development and planning priorities for Victoria’s Health services, demonstrating a commitment to building the capacity of health services to respond to CALD communities and with a specific focus on health literacy and access to information on which to make choices about individual care. This Framework also forms the basis of the Rural and Regional Health Plan 2012-2022.

A range of policies, guidance and actions have been developed to provide further support for public health services and the key initiatives in relation to diversity and equity are highlighted below:

Cultural responsiveness framework: Guidelines for Victorian health services

Following a review of cultural and linguistic diversity and cultural competence reporting requirements, minimum standards and benchmarks for Victorian health services were incorporated into the framework in 2009. This framework is designed to improve Victorian health services’ cultural responsiveness at strategic and organisational levels.

Doing it with us not for us: Strategic direction 2010-13

The policy set out priority actions for consumer participation across four levels of the public health service system; the individual care level, program or department level, health service organisation level and the Department of Health. In doing so, the policy highlighted the need to respect the diverse backgrounds of people in the community.

Promoting the participation of Aboriginal and Torres Strait Islander peoples

The Victorian Government's commitment to enabling the participation of Aboriginal and Torres Strait Islander peoples is expressed in the Victorian-funded Closing the Gap programs and the expansion of the Improving Care for Aboriginal and Torres Strait Islander Patients (ICAP) program.

In 2012, the Victorian Government launched *Koolin Balit: The Victorian Government's strategic directions for Aboriginal Health 2012-2022*. The document provides a 10-year strategy setting clear directions for improving the health of Aboriginal and Torres Strait Islander people in partnership with the Indigenous community. A key focus is improving the continuum of care which is consistent with the principles of person centred care.

Home and Community Care Diversity Planning and Practice Strategy

The Victorian Home and Community Care (HACC) Program has implemented the HACC Diversity Planning and Practice strategy to improve access to HACC services for special needs groups, including people from CALD backgrounds.

Language Services Policy

The Language Services policy 2013 outlines requirements needed to enable people who cannot speak English or speak only limited English, to access professional interpreting and translating services.

Refugee and asylum seeker health and wellbeing

The development of an action plan to define the long term strategic vision for how the health system can best meet the health and wellbeing needs of people from refugee backgrounds and asylum seekers is currently underway in collaboration with the Victorian Refugee Health Network.¹⁹

Gay, Lesbian, Bisexual, Transgender and Intersex (GLBTI) Health and Wellbeing

The GLBTI Health and Wellbeing Ministerial Advisory Committee has established five working groups, which reflect priority issues identified by the committee. The work produced by the group has led to recommendations for consideration by both the Victorian Minister for Health and the Victorian Minister for Mental Health in supporting priority health issues identified by the committee.²⁰

WHO Minority Standards in Health – Second Stage Pilot

The Department is currently working with the WHO Health Promoting Hospitals Task Force on the Migrant Friendly and Culturally Competent Health Care's Equity Standards Project. At an

¹⁹ Refugee and asylum seeker health, Victorian Department of Health website, Available at <http://www.health.vic.gov.au/diversity/refugee.htm>, Accessed 5 March 2014.

²⁰ Gay, Lesbian, Bisexual, Transgender and Intersex (GLBTI) Health and Wellbeing Ministerial Advisory Committee, Victorian Department of Health website, Available at <http://www.health.vic.gov.au/diversity/glbtime.htm>, Accessed 5 March 2014.

international level the project aims to develop specific measurable standards to promote equity in healthcare, in particular relating to accessibility, utilisation and quality of health care for ethnic minorities and migrants.

Working Together – Our Disability Action Plan

The Department of Health Action Plan, Working Together – Our Disability Action Plan, commits to the inclusion and engagement of people with a disability in the workplace and the community.

3.1 Findings and recommendations

Diversity and equity need to be considered across all levels of the health system; consumer, carer and community, organisational, government and policy. Research in Australia has identified links between culture, language and patient safety outcomes and the barriers that CALD consumers face when engaging with health services. VAGO findings^{21, 22, 23} have highlighted challenges, consistent with the findings of this evaluation (See Table 1 below).

Table 1: Challenges to CALD participation in health services

Level	Challenges
Consumer, carer and community	Lack of familiarity with the local health system, the services available and how to access them ²⁴ Language and cultural barriers to understanding information, developing trusting relationships with health professionals, and providing informed consent ²⁵ Different concepts of health and illness which may affect understanding of treatment and impact compliance ²⁶
Organisational	Lack of effective collaboration and coordination in planning and service delivery ²⁷ Unclear cultural competency training and reporting requirements for departments and service providers ²⁸ Weaknesses in complete and reliable data and measures ²⁹
Government and policy	Scope for greater community consultation relating to engaging Aboriginal community members at all stages of program development, implementation and evaluation. ³⁰

²¹ VAGO 2013, Accessibility of Mainstream Services for Aboriginal Victorian
²² VAGO 2013, Access to Services for Migrants, Refugees and Asylum Seekers
²³ VAGO 2012, Consumer Participation in the Health System
²⁴ Ibid
²⁵ Ibid
²⁶ Ibid
²⁷ VAGO above n22
²⁸ VAGO above n23
²⁹ VAGO above n22,23
³⁰ VAGO above n22

The evaluation highlighted a number of challenges in relation to diversity and equity, which correlate with the findings of the evaluation of the consumer participation policy. This section outlines the challenges and related recommendations. However, it is noted that a number of recommendations are common across diversity, equity and consumer participation; in this instance these recommendations have been highlighted in subsequent sections of the discussion paper, which describe the findings by level.

Organisational commitment

Overall the evaluation findings found that whilst cultural responsiveness was demonstrated at a government level, there were opportunities to further engage with people from Aboriginal and CALD backgrounds and tailor approaches to meet the needs of people from diverse communities. Similarly opportunities exist at organisational and consumer, carer and community levels, with a need for stronger engagement of diverse populations; examples range from engaging and training community health champions to influence their families and community groups to an increased use of interviews, diaries and stories to supplement standard methods of engagement.

As the healthcare system moves from volume to added value, involving people more strongly in designing services and highlighting priorities for change will ultimately result in greater efficiency.³¹

Measuring performance

In keeping with the VAGO findings above, the evaluation identified the need for meaningful measures at an organisational level. The WHO minority standards, which are currently being piloted by the Department with health services, may provide a mechanism for measuring performance which could be integrated with measures of consumer participation more broadly. These are:

- Equity in policy – development of policy, governance and performance monitoring systems to measure equity
- Equitable access and utilisation – ensuring access to available care and utilisation, including elimination of barriers relating to communication
- Equitable quality of care – high quality care available to everyone, through provision of person centred care
- Community involvement – organisations proactively engaging with the community, enabling community groups to be active participants in health service delivery and improvement.
- Promoting equity – through education, research, advocacy and capability building.

It is recommended therefore that the pilot of the WHO minority standards be evaluated and leveraged across the system and used as an ongoing measure of diversity and equity.

Cultural competency training

Moving towards a person centred care model will require a system wide understanding and capability in consumer engagement and the impact of poor consumer engagement on CALD populations. The underpinning organisational culture was cited as an impenetrable culture within a number of health services which is frequently at odds with the notion of consumer participation.

³¹ KPMG 2014, *Creating new value with patients, carers and communities*

Equally the evaluation showed differing perceptions in relation to organisational ability to cater for the needs of people from Aboriginal and diverse backgrounds.

Provision of cultural competency training for the health workforce, supported by accessible language services and health information, will be necessary to support a shift in culture and meet the needs of people to better understand and participate in shared decision making. In line with this, the Department, through a Cochrane Systematic Review, has reviewed the effects of cultural competence education for health professionals. The protocol and the review can be found in the Cochrane Library³². This review can form a good foundation on which to develop an approach to cultural competence training and education.

Partnerships with community groups

The evaluation found that whilst the majority of the health workforce perceived their organisation to be committed to involving consumers in decision making about their health and treatment some organisations struggled to find consumers willing to participate, for example, aged care and people from culturally and linguistically diverse backgrounds. Exploring different avenues for participation will be important going forward and initiatives from other jurisdictions such as the Northern Territory should be considered (see examples below);

Strengthening participation examples

Aboriginal community workers in remote communities in the Northern Territories are employed to improve communication between consumers, carers and health professionals

Refugee 'walk arounds' to gain feedback and support the provision of care that is responsive to community needs

At a consumer, carer and community level, there was some evidence of health services going out into communities to educate refugee and newly arrived migrant communities on health services available. In addition, Aboriginal and Torres Strait Islander communities were in some instances given opportunities to connect informally with health services and meet and connect with the health workforce. These initiatives were designed to educate communities and help to alleviate some of the anxiety consumers may feel when interacting with health services for the first time. In most instances these initiatives, together with those developed in mental health organisations, were seen as very effective and health services valued more opportunities to share successful innovations in this area.

An integrated policy

Through evaluation activities it became evident that, in general, health services needed to focus more strongly on improving engagement for diverse populations. The health services that had introduced initiatives reported that they were generally not influenced to do this by the framework. For certain diverse groups, the legislative and policy drivers encouraging or mandating participation were regarded as more influential for health service consumer participation initiatives than the framework.

³² Horvat, L., Horey, D., Romios, P. and Kis-Rigo, J. 2011, cultural competence education for health professionals, Available at <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD009405/abstract>, Accessed 5 March 2014.

The evaluation findings also demonstrated that community requirements were a strong driver and that diversity and equity should be integrated within an overarching consumer responsiveness policy, which could be tailored to the different community groups.

Recommendation:

- 4. A new policy needs to incorporate cultural responsiveness, diversity and equity**

4 Consumer, Carer and Community participation findings and recommendations

Key findings:

At the consumer, carer and community level, key elements of a person centred approach include:

- A focus on health literacy, including well-written health information, the use of web-based information sources, virtual support, and tailored information for groups with low levels of health literacy
- Training for the health workforce in person centred consultation styles and communication, for example, armchair technology
- Strategies to support shared decision-making and self-management, including the use of technology

Participation at the consumer, carer and community level focuses on ability to play an active role in managing their health, choosing appropriate treatment for episodes of ill health, and managing chronic disease.³³ Health literacy, capacity for shared decision-making and capacity for self-management of chronic conditions are key aspects of participation at this level. Strategies, initiatives and programs shown to be effective in these areas are described below.

4.1 Health literacy

Health literacy is fundamental to service user involvement. Unless people can access, understand, evaluate and use basic health information, they will not be able to make appropriate decisions about their health and health care.

Ensuring individuals have the necessary skills and capacity to engage with health organisations as equal partners is critical to effective engagement. The provision of access to orientation and training for consumers, carers and the community can be an effective means to support meaningful engagement.

Training programs run independently of health services also exist to provide consumers with the skills needed to engage with health organisations and advocate for greater consumer involvement, for example, training run by the Health Issues Centre in consumer leadership.

Health literacy was highlighted as a concern across a number of health organisations. The Cochrane Consumers and Communication Review Group has supported the Department in reviewing health literacy, to help reduce barriers and to improve the health outcomes of consumers who experience health inequalities. To better meet the needs of the consumer, carer and community, health organisations will need to have a stronger focus on health literacy; to support this the health

³³ Coulter, A., Parsons, S. and Askham, J. 2008 'Where are the patients in decision-making about their own care' Policy Brief for the WHO European Ministerial Conference on Health Systems: Health Systems. Health and wealth, Tallinn, Estonia, 25-27 June 2008, WHO Regional Office for Europe, Copenhagen, Denmark

workforce will require practical advice that they can implement to improve health literacy and consumer involvement.

4.2 Communication skills

Consumers increasingly expect information and involvement in decision making related to their healthcare.³⁴ As consumer expectations change, there is a need to ensure the health workforce receives training in the principles and practice of consumer participation and person centred care and are equally confident in communicating with people from diverse backgrounds.

While a partnership approach to consumer participation is becoming more prominent on the agenda in medical education, a study found that skills gaps, a general lack of awareness of needs and few examples of good practice exist.³⁵ Extending the role of consumers in clinical education has been identified as an important strategy to build the skills of healthcare professionals in this area.³⁶

4.3 Technology and self-management

Personalised computer-based information and virtual supports are increasingly being used to increase access to health information. 'Armchair involvement' is a term used to describe the use of technology to improve engagement, which encompasses information, feedback and participation.³⁷ The NHS Institute has discussed the relative benefits of a range of engagement tools including apps on mobile phones, booking services through digital TVs, podcasts and websites, consumer generated online content and electronic patient records.³⁸

4.4 Strategies to support shared decision making

In response to a shift towards person centred care, community-based primary healthcare has emphasised holistic and preventative approaches to healthcare over traditional medical-driven models of care. Similarly, the concept of person centred care has reframed the relationship between consumers and the health workforce and elevated the patient experience as a key indicator of healthcare performance and quality. Consumers are increasingly well informed and engaged about their treatment options and care pathways and expect to interact with the health workforce in similar ways to other service industries.

Consumer Directed Care (CDC) is one such approach which offers consumers more choice than is provided through traditional approaches to care.^{39, 40} CDC is not one model of care, but a continuum of care with the consumer able to direct their level of involvement. Person centred approaches are

³⁴ ACSQHC 2011, p.54

³⁵ Hasman, A., Coulter, A., Askham, J. 2006, *Education for Partnership: Developments in Medical Education*, Picker Institute Europe, London.

³⁶ *ibid.*

³⁷ NHS Institute for Innovation and Improvement 2007, *Armchair involvement: practical technology for improving engagement*, NHS Institute for Innovation and Improvement.

³⁸ *ibid.*

³⁹ Tilly, J. & Rees, G. 2007 *Consumer Directed Care: A way to empower consumers?* Alzheimer's Australia, Paper 11

⁴⁰ Aged and Community Services Australia (ACSA) 2010, *Guiding principles for consumer directed care*. ACSA

a key feature of successful consumer directed models and a move to a person centred care approach was recognised in a number of health services.

This should be integrated at a policy level, to provide a more robust approach to consumer participation at an individual level. In addition, a regular opportunity to reconsider and potentially refresh the policy would enable the policy to keep pace with contemporary thinking.

Recommendation:

5. Future directions need to consider person centred care approaches to strengthen the involvement of the consumer, carer and community in the continuum of care and governance

- 5.1 Mechanisms to improve health literacy and health information should continue to be developed, based on state wide, national and international developments*
- 5.2 Capability building is required to support staff in developing person centred care approaches*

5 Organisational level findings and recommendations

Key findings:

There are a number of characteristics common to health organisations that are considered to have successfully adopted a person centred approach. These include:

- committed senior leadership
- using data and feedback to drive change
- engaging consumers, family and carers as partners
- building health workforce capacity and a supportive work environment
- accountability at all levels
- a learning culture.⁴¹

Most importantly, a systematic approach to implementation, that integrates consumer participation strategies and actions across the organisation is critical to embed participation approaches and person centred care as 'business as usual'.

The evaluation found that health organisations have implemented a range of initiatives to improve and sustain consumer participation in the delivery of services. However, the extent to which health organisations have implemented the detail of the policy and the framework is variable and this variability was not attributed to geographical location or type of service.

The evaluation found that there is variability also in how the policy is perceived; some health organisations still use it as a point of reference to underpin their consumer participation activities, whilst other health organisations are referring to contemporary literature and approaches to inform their consumer participation activities.

As different health organisations are at different stages of implementation of the policy and the framework, there is an opportunity through a new policy to address the variable needs of health organisations, in line with their stages of development in both consumer participation and cultural responsiveness.

⁴¹ Shaller, D. 2007 *Patient-centred care: What does it take?* Picker Institute and the Commonwealth Fund.

5.1 Accountability and leadership

The literature suggests that professional and cultural barriers are an impediment to consumer participation in health organisations.^{42,43,44,45} These barriers are related to both real and perceived time and resource pressures and the cultural shift toward recognising consumers as “actively engaged health care participants”⁴⁶, as opposed to passive recipients of health care. This is consistent with VAGO findings in relation to consumer participation in the Victorian health system, whereby “audited public health services reported that a major cultural shift, particularly among frontline clinical staff, is required to put consumer participation at the forefront of healthcare”.⁴⁷

The evaluation found that whilst the majority of the health workforce perceived their organisation to be committed to involving consumers in decision making about their health and treatment, some organisations struggled with an impenetrable culture which was at odds with the notion of consumer participation.

Leadership has a critical role to play in setting priorities and communicating the need for change across all levels of health organisations.^{48,49} Designating a senior manager or executive with responsibility for implementing consumer participation policy and strategy and designating champions (clinical and executive) who model person centred behaviours are important strategies to support organisational change.⁵⁰ Current research from the US suggests that visible support ‘from the top’ has been the most common driver of success in patient experience efforts in American hospitals.⁵¹

The importance of focused and committed executive-level leadership is reflected in the increasing number of healthcare organisations with dedicated patient leadership roles as their primary resource for addressing patient experience. While committees remain the most popular structure for delivering improved patient experience, an increasing number of organisations are investing in dedicated patient experience roles.⁵² An increasing proportion of these roles have ‘patient experience’ in their title, for example, Chief Experience Officers or Patient Experience Leaders.

Leadership is needed not only at the executive level; clinical champions who model patient-centred practice and consumer engagement can stimulate change at the front line. Across all the evaluation

⁴² Dunn, N. 2004 ‘Practical Issues around putting the patient at the centre of care’, *Journal of the Royal Society of Medicine*, 96(7):325-327

⁴³ West, E, Barron, D.N. and Reeves, R. 2005, ‘Overcoming the barriers to person centred care’, *Journal of Clinical Nursing*, 14:435-443

⁴⁴ Shepherd 2001 in Ridley, J. and Jones, L. 2002, p.39

⁴⁵ Cole 2000 in Ridley, J. and Jones, L. 2002, p.39

⁴⁶ VAGO 2012, p.1

⁴⁷ *ibid*, p.ix

⁴⁸ Schall, M., Sevin, C., and Wasson, J.H. 2009 ‘Making high-quality, patient-centred care a reality’ *The Journal of Ambulatory Care Management* 32(1):3-7

⁴⁹ Luxford, K., Safran, D., Delbanco, T., 2011 ‘Promoting patient-centred care: a qualitative study of facilitators and barriers in healthcare organisations with a reputation for improving patient experience’ *International Journal for Quality in Health Care*

⁵⁰ ACSQHC 2011, p.51

⁵¹ Wolf, J. 2013, *The state of patient experience in American Hospitals 2013: Positive trends and opportunities for the future*, The Beryl Institute, Washington DC, p.21

⁵² *ibid*, p.14

activities the impact senior leadership had on setting a person centred culture was a key factor in reflecting commitment to consumer participation. When members of the executive and health organisation boards were committed to consumer participation, it flowed down throughout the organisation. The evaluation found that currently without many formal structures in place to encourage health service leaders to engage with consumer participation initiatives, the extent to which health service executives' leadership and role modelling impacted across organisations varied.

Equally, at a state-wide level, training for Board members and health organisation executives was commonly cited as crucial to the success of consumer participation initiatives and at present it was perceived that there were few opportunities for this.

Research has shown that organisations that have a culture of consumer participation establish clear lines of accountability for the health workforce. In developing an organisational level culture committed to consumer participation health organisation executives need guidance on the right accountability mechanisms to put in place and the most effective ways to strengthen the vision for and commitment to consumer participation and diversity. Organisations that successfully engage consumers and integrate person centred care approaches establish clear lines of accountability for the health workforce at all levels.⁵³ Strategies to support this include:

- incorporating responsibility for improving patient care experience in job descriptions
- considering patient feedback during performance reviews, including sharing patient stories
- including performance metrics and providing performance incentives for the demonstration of person centred practice at both the health workforce and governance levels
- incorporating consumer participation and patient experience metrics into unit, department and organisational performance monitoring and reporting
- ensuring agendas for board or governance committee meetings include a strong emphasis on quality issues, including patient experience.^{54,55}

In particular, stakeholders recognised that greater accountability is needed at unit and/or clinician levels, where the primary drivers may be different and more strongly linked to best practice and research.

⁵³Luxford, K., Safran, D., Delbanco, T., 2011 'Promoting patient-centred care: a qualitative study of facilitators and barriers in healthcare organisations with a reputation for improving patient experience' *International Journal for Quality in Health Care*

⁵⁴ *ibid.*

⁵⁵ Rave, N., Geyer, M., Reeder, B., Ernst, J., Goldberg, L., Barnard, C. 2003 'Radical systems change: innovative strategies to improve patient satisfaction' *Journal of Ambulatory Care Management* 26(2):159-174

Recommendation:

6. Accountability mechanism needs to be strengthened at an organisational level

- 6.1 *Executive leaders within organisations should build consumer participation into position descriptions and consumer feedback into performance reviews*
- 6.2 *Executive leaders should consider appointing clinical and executive champions to initiate and enhance consumer participation and organisational change*
- 6.3 *The provision of training and/or guidance for Board members and health organisation executives is necessary to strengthen the vision for and commitment to consumer participation*

5.2 Measuring patient experience and using data to drive change

Internationally, few health organisations have robust systems for coordinating patient experience data collection, assessing its quality, or learning from and acting on the results in a systematic way.⁵⁶ The use of patient surveys and complaints data to reveal large scale trends is an important tool to assist with service planning and governance.⁵⁷ To monitor the performance of health organisations' departments and wards, more detailed information about specific aspects of patients' experiences is likely to be useful.⁵⁸ To this end, using patients' personal stories have been shown to have a direct impact on those responsible for care.⁵⁹

The evaluation found that feedback mechanisms existed across most health organisations; however the degree to which the outputs were acted upon was variable. In addition, a number of health organisations are implementing person centred approaches to care, whilst other health organisations are reliant on feedback through surveys, complaints and compliments. In many health organisations there is a lot of activity directed towards improving consumer participation. In other health organisations challenges were cited in obtaining feedback from people from diverse backgrounds. Without effective collection and monitoring of patient experience data, however, it can be difficult to measure the impact of patient experience and determine what strategies are working.

A blended approach to measuring the impact of consumer participation across all levels is required and strategies to act on the information collated; examples of different approaches for consideration are described below.

In moving to a measure of *experience* rather than *satisfaction*, the Victorian Healthcare Experience Survey (VHES) shifts the focus to what actually happened, as opposed to consumers' evaluation of

⁵⁶ Goodrich, J. 2009 'Exploring the wide range of terminology used to describe care that is patient-centred' *Nursing Times* 105(20):14-17 in ACSQHC 2011, p.52

⁵⁷ *ibid.*

⁵⁸ Luxford, K., Safran, D., Delbanco, T., 2011

⁵⁹ ACSQHC 2011, p.51

what occurred, which can be prone to bias or a lack of specificity.⁶⁰ This shift will provide a richer picture of consumer, carer and community experience, for example, by not only focussing on whether the health workforce communication was to the patient's satisfaction, but also the level of information, the method (telephone or face-to-face), language and timing. Consumer experience data also provides health organisations with greater ability to interpret and respond to feedback.

Different methods of data collection are suited for different purposes and a new policy should provide advice regarding appropriate data collection methods. For example, the use of patient surveys and complaints data is important to identify large-scale trends and assist with service planning and governance.⁶¹ At the ward or service department level, more detailed information about specific aspects of patients' experiences is likely to be useful.⁶² For example, surveys might be complemented by interviews with consumers and the health workforce and observations of clinical encounters.⁶³

Capturing feedback in real-time is important if data is to be used to inform continuous improvement and making use of the latest technology can help health organisations capture feedback in a way that is timely and non-intrusive. In addition the institution of consumer feedback standards would be useful to guide health organisations in the effective management of and use of consumer initiated feedback.

In addition to the approaches described above, there is an increasing focus in Australia and internationally on strategies to ensure the contribution of consumers, carers and the community in service design and practice improvement. Co-design (or Experience-based design) is based on a set of principles which include; a partnership approach; an emphasis on experience over attitudes or opinions; the use of storytelling; emphasis on co-designing services and an integrated systematic evaluation of improvements and benefits.

An example of this is the Mental Health Experience Co-design, in Victoria, which brings together consumers, carers and service providers to co-design mental health services. MC ECO applies the most recent theory and practice of Experience-Based Design in health service quality improvement.⁶⁴

This approach has been shown to benefit both consumers and the health workforce and should be considered to supplement and strengthen the role of consumer participation.

⁶⁰ Aharony, L. and Strasser, S. (1993), 'Patient satisfaction: what we know about and what we still need to explore', *Medical Care Review* 50(1), pp.49-79, Carr-Hill, R (1992), 'The measurement of patient satisfaction', *Journal of Public Health Medicine* 14(3), pp. 236-49.

⁶¹ *ibid.*

⁶² Luxford, K., Safran, D., Delbanco, T., 2011

⁶³ *ibid.*, p.2

⁶⁴ NHS Institute for Innovation and Improvement 2009

Recommendation:

- 7. Consumer feedback methods need to be robust and feed into continuous improvement initiatives and the design of services**
- 7.1 *Guidance is required to support more effective management of and use of consumer initiated feedback at a health organisation level*
 - 7.2 *Co-design of services and practice improvement should be a key feature of consumer, carer and community participation*
 - 7.3 *Different approaches to consumer feedback should be considered in order to engage with diverse populations. This may include using different forms of technology or greater engagement with community groups and leaders.*

5.3 Building health workforce and consumer capability system wide

Health workforce capability

Organisations that have strong consumer participation and person centred care practices have a culture of learning and strongly supporting change and improvement.⁶⁵ These organisations have systems, mechanisms and processes in place that are used to continually improve the capability of those who work with it or for it. In addition, they are adaptive to external forces, able to promote individual and collective learning, and use these lessons to improve outcomes.⁶⁶

There was substantial variation in the breadth and depth of consumer participation initiatives between health organisations, both within and across types of health organisations and geographical locations. The evaluation found that in order to strengthen a broader commitment to consumer participation, the provision of targeted capability building and guidance at all levels throughout health organisations is necessary.

The evaluation found that training and support available to health organisations varied and rural and regional health organisations reported difficulties in accessing training from resourcing and geographic perspectives. Funding and time to release the health workforce were frequently cited as constraints for health organisations accessing training; this was particularly pertinent for health organisations outside of the metropolitan area.

The training provided to date was considered central to health organisations in their early stages of developing consumer participation programs, however; it was less meaningful for the more advanced organisations. A new policy would need to address the support requirements of health organisations in the very early stages of implementing consumer participation initiatives and those more sophisticated in their current practice. Health organisations reported the need for greater training opportunities for regional and rural services through the Health Issues Centre and more frequent opportunities to share best practice throughout. More frequent conferences where best practice can be shared and celebrated and targeted feedback from the Department were both raised as strategies to improve supports for health organisations.

⁶⁵ Luxford, K., Safran, D., Delbanco, T., 2011

⁶⁶ Senge, P. 1990 *The Fifth Discipline – The Art and Practice of the Learning Organisation* Random House, London in ACSQHC 2011, p.55

At the consumer, carer and community level, the way health organisations are structured, how health organisations communicate and the way health information is presented play a critical role in consumers' ability to interact with, make sense of and respond to health related information. The capacity of health organisations and the health workforce to communicate often complex health information in a way that is accessible, clear and meaningful is therefore critical.

Person centred organisations focus on increasing their health workforce's skills to support person centred care delivery.⁶⁷ Strategies to support this include training in communication skills and techniques, including for patients with specific communication needs; training in person centred values; integrating discussion of person centred values into staff orientation sessions; and ensuring consumer involvement in staff education and training.⁶⁸

Recognising the link between the health workforce experience and patient experience is also important.⁶⁹ Exemplary person centred health organisations achieve this by:

- visibly celebrating the successes of the health workforce in improving patient experience
- using health workforce feedback, for example through surveys, in the work environment to improve work culture and processes.⁷⁰

Education and training for health practitioners was often cited as needing strengthening. Throughout university training and within the health organisations it is important that greater emphasis is placed on teaching practitioners about consumer participation and what it looks like to different groups. Similarly, at an organisational level there will be a need to provide adequate education, training and tools to health practitioners and consumer representatives to support them in embedding person-centred approaches within health organisations.

Consumer capability

Across evaluation activities, it was found there was a need to invigorate CACs and their place and purpose within public health services in line with broader consumer participation changes. Similarly, CAC membership in general was in need of an injection of 'new blood' to bring consumers with recent experience to the fore.

CACs would benefit from a stronger focus on the revision of appointment terms which could include fixed term appointments to ensure membership is regularly refreshed to reflect recent experiences. Further, this needs to be supplemented by a structured program to support and develop the skills of consumers who sit on committees and contribute to organisational activities, for example, through peer level mentoring, alumni groups and consumer leadership programs.

⁶⁷ Luxford, K., Safran, D., Delbanco, T., 2011

⁶⁸ ACSQHC 2011, p.54

⁶⁹ Coulter, A. 2009 'Patients' expectations' in Carter, Y., Jackson, N. (eds) putting Patients First: Designing and Practicing Patient Centred Care Jossey Bass 163-190 in ACSQHC 2011, p.52

⁷⁰ Luxford, K., Safran, D., Delbanco, T., 2011

Recommendation:

8. Organisations need to invest in capability building to support the development of learning cultures

- 8.1 Targeted health workforce training is needed and should be flexible and adaptable to local requirements, to facilitate engagement of consumers from diverse backgrounds*
- 8.2 Improved access to training and support for staff, in consumer participation, is required in rural areas*
- 8.3 It is important that greater emphasis is placed on teaching health practitioners about consumer participation at the undergraduate level, from professional colleges and at the post graduate level*
- 8.4 Clinicians need to be provided with tools to guide them in how to engage and share decision making with consumers and carers*
- 8.5 Health organisations and practitioners would benefit from more resources to translate policy into action*
- 8.6 Forums to encourage the sharing of initiatives and better practice and support health organisations in developing innovative consumer participation strategies*
- 8.7 Revisit the structures and supports to refresh CAC memberships and build capabilities for new and existing consumer representatives.*

6 Government and policy level findings and recommendations

Key findings:

Features considered important at the system level for a person centred approach include:

- Clear expectations and approach driven through policy and legislation
- Supporting frameworks and tools
- Partnership in governance
- Standardised performance monitoring and measurement
- Maturity matrix
- Financial incentives

6.1 Clear expectations and approach driven through policy and legislation

Public policy plays a foundational role in defining the decisions, plans and actions required to achieve health goals within a society. In doing so it can define a vision for the future, outline key priorities and the expected roles of different groups and build consensus. In keeping with this the evaluation showed that the policy had successfully set the scene for consumer participation at its onset, however, in the current environment different drivers had taken priority. In particular the evaluation showed that the standards relating to acute, mental health, community and residential aged care services were the current primary drivers of consumer participation.

The evaluation was undertaken in the context of the policy, which is applicable only to public health services. Findings have suggested that the principles of consumer participation are applicable across the continuum of care and therefore a future policy should look towards expanding its scope to include all funded and regulated health services. In addition, the policy needs to be supplemented by appropriate governance arrangements, measurement frameworks to measure the impact of consumer participation and associated financial incentives. The following section of the discussion paper reflects the evaluation findings and opportunities in relation to these supports.

6.2 Partnership in governance

The establishment of the Consumer Advisory Committees (CACs) has reportedly impacted positively in many public health services, in terms of how the policy has translated into practice. Some CACs were considered as active and influential with members attending staff orientation, sitting on interview panels and providing input to service improvement projects. However, similar to the policy, the influence of CACs varied across public health services.

Evaluation activities also found that approaches to remuneration or reimbursement of consumer varied across public health service types and that there was a need to streamline approaches. Similarly a standardised approach to the role of consumers and carers would be beneficial, as it was found that there is a need to professionalise the role of consumers and carers and more effectively

recognise the contribution of consumers and carers through remuneration and capacity building opportunities.

Recommendation:

9. Mechanisms to enhance consumer and carer partnership in governance are required

- 9.1 *The role of consumer and carer representatives and peer support workers should be expanded building on lessons learned in mental health*
- 9.2 *Expand the role of CAC members and consumers to include mentoring and consumer leadership roles*
- 9.3 *The development of a single set of guidelines around remuneration and reimbursement for consumer participants would be beneficial in order to more strongly recognise the value of consumer and carer participation.*

6.3 Standardised performance monitoring and measurement

The measurement of processes and outcomes associated with the quality, safety and experience of care helps to embed person centred care in the healthcare system.⁷¹ Linking funding and accreditation to consumer, carer and community experience measurements; accountability through public reporting; and the development of standardised measures to facilitate comparison and benchmarking are important strategies to ensure measurement and monitoring activity is used to drive improvement.⁷²

All Australian states are increasing their activity in measuring healthcare quality, especially related to consumer, carer and community experience. Most jurisdictions collect a variety of feedback, including national and local survey data, complaints data and web-based feedback.⁷³

Evaluation activities revealed that the reporting requirements of the policy standards and indicators of the policy were not always well met by many health organisations. This was often due to the view that reporting was duplicative, there was a lack of resources to meet the requirements, reporting was not seen as useful to the health organisations or in some case there were not initiatives and activities to report on. There is an opportunity, therefore, to consolidate the reporting requirements in a new policy and develop a more effective accountability mechanism than Quality of Care reports.

The standards across acute health, mental health, community services and residential aged care are regarded as the key drivers of consumer participation and could be considered a key reporting mechanisms. It was noted, however, that cultural diversity is not well reflected in the NSQHS

⁷¹ Institute for Patient- and Family-centred Care in ACSQHC 2011, p.48

⁷² *ibid.*

⁷³ ACSQHC 2011, p.48

⁷³ *ibid.*

Standards, therefore, consideration should be given to using the WHO Minority Standards as a measure of diversity.

Given that accreditation occurs infrequently, however, local measurement approaches should be developed to enable more frequent reporting. Measurement in Victoria, to date, has been achieved through the introduction of the Victorian Patient Satisfaction Monitor's Consumer Participation Indicator and the overall core index in the Victorian Health Service Performance Monitoring Framework. With the change to the VHES, new measures and targets are currently under consideration by the Department.

Stakeholders from a large number of health organisations outlined that they were more likely to report on indicators that they felt were relevant and easily accessible. It may also be more effective to combine reporting on consumer participation through existing reporting and accountability processes, for example, annual reporting.

Recommendation:

10. Reporting requirements need consolidating to reduce the duplication of reporting whilst meeting legislative, regulatory and policy accountability requirements.

- 10.1 The national standards across acute health, mental health, community services and residential aged care and the WHO minority standards should be considered as an accountability and reporting mechanism for consumer participation.*
- 10.2 Reporting of consumer participation initiatives should be updated and reinforced through existing reporting and accountability processes for Victorian public health services*

6.3.1 Maturity matrix

A maturity matrix would provide health organisations with a means to undertake a self-assessment to determine the level of consumer participation in their organisations and opportunities for improvement. This could also act as a measure of consumer participation at both organisational and government levels.

The evaluation found that health organisations are at different stages of maturity in how they approach consumer participation. In general acute and mental health services were the most evolved, however, variability was also evident between health organisations of the same type.

Moving to an approach which offers the patient greater involvement in their own healthcare, will require health organisations to understand their current position and identify how they can transform their health systems across a number of dimensions.

A maturity matrix would provide policy makers and health organisations with a means to assess the level of consumer participation, system wide, and identify opportunities for growth. In addition a maturity matrix could act as an additional measure of consumer participation at both government and organisational levels. A sample maturity matrix can be found in Appendix 1.

Recommendation:

- 11. A self-assessment maturity matrix needs to be developed to determine the level of consumer participation in the organisation and as an ongoing measure of progress**

6.3.2 Funding incentives

Experience from the UK and the US suggests that funding arrangements can provide an effective mechanism for incentivising consumer involvement and person centred approaches. In these jurisdictions, defining consumer, carer and community experience as a key outcome metric has enabled the use of financial incentives to drive improvements in person centred care.⁷⁴ In the UK, the Commissioning for Quality and Innovation (CQUIN) framework was introduced in 2009. Under the framework, providers who agree to a CQUIN scheme with their funding body have a small proportion of their income made conditional in relation to an agreed package of goals and indicators relating to quality, safety, innovation and patient experience.⁷⁵ Since 2011/12, providers who fail to meet agreed patient experience goals may have a proportion of their contract payment withheld.⁷⁶

In the US, financial incentives are used to promote consumer, carer and community feedback. This includes direct financial incentives to doctors and hospitals that submit data on quality measures (including patient experience).⁷⁷

In light of this shift internationally, consideration may be given to the introduction of financial incentives at a state-wide level and performance incentives to support increased accountability at an organisational level.

Recommendation:

- 12. Consideration should be given to new funding arrangements to incentivise consumer involvement and person centred care approaches.**

⁷⁴ ACSQHC 2011, p.15

⁷⁵ ACSQHC 2011, p.15

⁷⁶ ACSQHC 2011, pp.16

⁷⁷ *ibid.*

7 Strategies and principles for a new policy

The evolution of consumer participation in health care, together with a shift in the policy context of consumer participation in Victoria, will require a re-shape of consumer participation in the future.

The key findings from the evaluation activities and recommendations, which draw upon examples of better practice internationally, will assist the Department in defining the strategies required to transform the health system, to enable consumers to become equal partners in decisions about policy development, service design and their own health care and treatment.

The evaluation found that in light of developments in public policy and the introduction of national standards across public hospitals, mental health services, community health services and residential aged care facilities, the drivers currently directing consumer participation have changed. At the same time the expectations of the consumer is changing, resulting in a need for the government and health services to proactively revise their consumer, carer and community participation strategies. There is also a need to better align and strengthen diversity and equity with consumer participation across the health system.

Health literacy, capacity for shared decision-making and capacity for self-management of chronic conditions are key aspects of participation at the consumer, carer and community level. At an organisational level, the evaluation found that different health organisations are at different stages of implementation of consumer participation initiatives and there is an opportunity through a new policy to address the variable needs of health organisations, in line with their stages of development in both consumer participation and cultural responsiveness. Key strategies for better consumer participation at this level include executive and clinical leadership, the use of data to drive change, active engagement of consumers, their families and capacity building for consumers and the health workforce in health organisations. Furthermore, exploring different avenues for participation, such as co-design and shared decision making, will be important for increased engagement of consumers, carers and the community. At the government and policy level, it will be important for a new policy to outline key priorities and the expected roles of different groups and build consensus around this.

Evaluation activities indicated that, in general, health services needed to focus more strongly on improving engagement for diverse populations. While cultural responsiveness was demonstrated at a government level, there are opportunities to further engage with people from Aboriginal, CALD and other diverse backgrounds and tailor approaches to meet the needs of people from diverse communities. Provision of cultural competency, diversity and equity training for the health workforce, supported by accessible language services and health information, will be necessary to support a shift in culture.

Recommendation:

13. A new policy should review with the services and programs, consumer, carers and the community, the principles and values upon which the new policy should be based

Appendix 1

Figure 5 Sample Maturity Matrix (KPMG 2014)

	0	1	2	3	4	5
1. Is work underway to create a new person centred culture?	No focus on the consumer experience	Recognition that a narrative is required about consumer experience	A strong narrative about consumer experience	Key principles of consumer engagement are visible	Some focus on consumer involvement and experience	Absolute focus on consumer involvement and experience
2. Is there consumer, carer and community input into service design?	No consumer, carer and community input in service design	Recognition that input is required	Some pilots of consumer involvement in service design	Consumers and carers beginning to be involved routinely in service design	Consumers involved in service design	Sophisticated methods for understanding the consumer experience are integrated
3. Are there measurement systems in place to support ongoing improvement?	No consumer experience or outcome data collected	Recognition that measurement systems and data are important	Data systematically reported to the Board	Real time data collected and used at the front line	Consumer experience is embedded in performance management	Consumer experience in embedded in all performance management and governance