

MI Fellowship Carer and Consumer Participation Framework

Introduction:

Mental Illness Fellowship has a strong commitment and practice to working with individuals who have a mental illness and families, friends and or carers of people who experience mental illness. MI Fellowship values the lived experience of people with mental illness and people who support them.

People are passionate about their experiences and want to make a difference for others within the mental health service system. Participation strengthens accountability and responsibility; builds relationships, empowers individuals; improves quality and effectiveness of services and helps build stronger communities.

'Participation' refers to being part of the process. It is more than observing and commenting; it refers to actual involvement in decisions, the authoring of solutions and development of sustainable frameworks. Queensland Health (2010) *Consumer engagement framework*.

The aim of the Carer and Consumer Participation (CCP) framework is to set the direction for participation at MI Fellowship. The CCP framework will guide MI Fellowship to invite the Carer and Consumer perspective, values the lived experience and support the development of consumer and carer leadership. The CCP Framework sets a benchmark for participation within MI Fellowship but is not an exhaustive list of participation.

Context:

Carers and Consumers are involved in MI Fellowship community recovery and family centred practices which works to include families and friends in partnership with the participant and community in the recovery process. Family and friends' participation in supporting a person can also improve recovery outcomes.

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Mental Illness Fellowship has a strong culture of Carer and Consumer participation that derives from a history as a mutual support and self help organisation. The Vision, Mission and Values of the organisation support a culture that values the lived experience of mental illness and recognises the individual expertise people have in their lives. The development of the CCP Framework ensures implementation of practices where that expertise contributes to the design,

delivery and evaluation of services. The *UN convention on the Rights of Persons with a Disability*, *The Fourth National Mental Health Plan*, *The National Mental Health Standards* and *Consumer participation: An action plan for consumer involvement in Victoria's public mental health services*, set the policy context for the development of this document.

Purpose: A Quality Improvement Framework:

Mental Illness Fellowship carer participation is informed by evidence based peer practice, peer workforce, focus groups, evaluations and a number of collaborative key partnerships with mental health services and universities, key policies, frameworks and acts.

MI Fellowship has a commitment to delivering high quality services and values the input of consumers and carers as integral to planning, development, improvement, review, evaluation and provision of services. The primary purpose of the CCP Framework is to improve systems and service delivery by incorporating feedback, advice and the experiences of consumers and carers. This document will be monitored by regular audits, reviewed and updated regularly within the strategic planning cycle of the organisation.

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Quotes from participants and carers - illustrative statements

“I work to include people in my community...

“ I take part in my community....

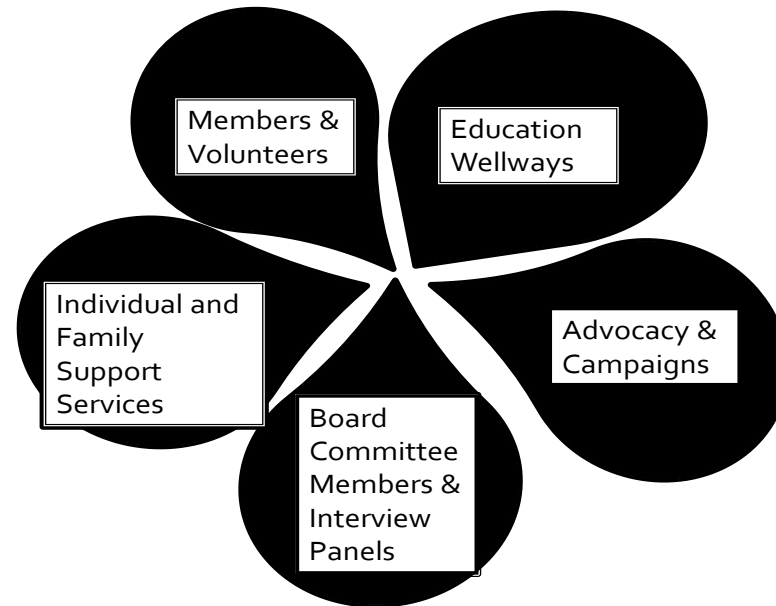
“ I have a voice in my community....

Outcome – what we achieve by working with consumers and carers

- full citizenship
- people have better health outcomes
- agency over their own lives

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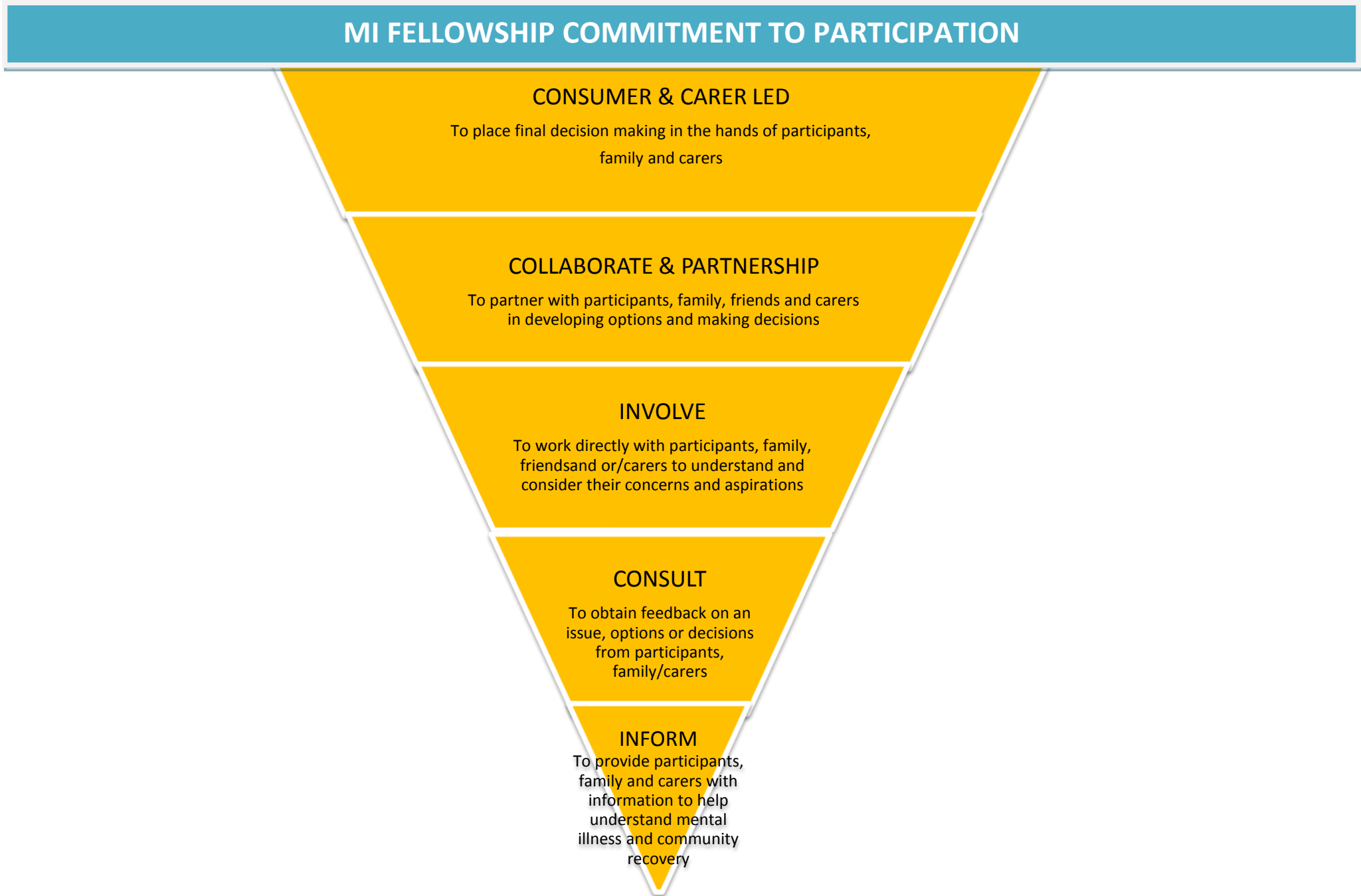
Carer and Consumer Involvement in MI Fellowship



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Type of engagement	INFORM	CONSULT	INVOLVE	COLLABORATE	CONSUMER & CARER LED
Purpose	To provide participants, family and carers with information to help understand mental illness and community recovery	To obtain feedback on an issue, options or decisions from participants, family/carers	To work directly with participants, family/carers to understand and consider their concerns and aspirations	To partner with participants, families and carers in developing options and making decisions	To place final decision making in the hands of participants, family and carers
Examples	Mi Recovery	Advice on practice improvement Consumer and Carer Advisory, Practice Innovation and Excellence (PIE) Committees	Involvement in systems and processes – staff orientation, planning, interviewing and training	Involvement in organisational strategy and governance	Drive personal wellbeing and recovery process
	Well ways	Focus group, surveys	Day Programs	Doorway	Govern, design and deliver services
	Factsheets	Individual participation plan	Peer Workforce	Co-design and Evaluate Programs	Mental Health Advocacy
	Newsletters/resources (oral, electronic, print, web)	Involved in developing and delivering evaluation	PHAMS Employment	Choir, Brainwaves & Speakers Bureau	
		Planned activities	Residential (service support and activities)	Peers on interview panels	
			Respite Services to carers and families	NDIA services, purchased by consumers	
			Home Based Outreach Service	Family Inclusive Practice – family dialogue	
			Helpline	Well ways facilitators	
			Volunteer in Op Shops	Peer workforce	

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Appendix i Check List for participation

Accessible information and support: develop accessible information and support for people affected by mental illness.

Benchmarking and linkages: develop performance measures that assist in measuring the effectiveness of carer engagement and facilitate benchmarking opportunities for quality improvement. Leaders develop linkages to help build sustainability and facilitate involvement of communities whose outcomes are poorer.

Champions: Key leaders with experience in involvement advocate to improve the level of understanding among peers.

Clear objectives: involvement is informed by clear objectives in Terms of Reference documents, policies and procedures to assist carers and health professionals, researchers, policy makers and service planners to understand the role requirements and the context within which they participate.

Combined professional development: encouraged to undertake professional development together with professionals to learn from each other's knowledge and experience.

Communication: communicate with professionals in a way that builds knowledge, understanding and mutual respect.

Cultural engagement: actively involve people with respect to their cultural needs and work with those whose outcomes are poorer e.g. Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse communities and rural, remote and regional communities.

Delivery of quality services and best practice: work together for the delivery of safe and quality mental health services based on best practice.

Equality: considered equal members of the group or team.

Education and training: training and development opportunities are made available to assist in their participation role. Organisations provide shared development opportunities for professionals that strengthen their understanding of the benefits of participation.

Facilitation: actively facilitate and coordinate involvement activities and enable feedback and participation in organisational business strategies, aiming for improved outcomes.

Governance: governance structures, including boards and committees, policies and procedures, incorporate the principles, values and elements for effective participation.

Mutual respect: respected and valued for their contribution; views being actively sought, listened to and considered.

Policy development: participate in policy development for improved mental health outcomes.

Research, data and evaluation: organisations monitor involvement activities and research and evaluate involvement strategies to help build continuous quality improvement and benchmarking.

Resources and support: explicit resource and appropriate support to enable people to be effectively engaged, including sitting fees and out-of-pocket expenses, travel and accommodation, where appropriate.

Support and networks: support to perform representative role through involvement in the organisation, networks, support groups etc.

Adapted from Cancer Australia and Cancer Voices Australia, 2011. *National Framework for Consumer Involvement in Cancer Control*. Cancer Australia, Canberra, ACT.

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Appendix ii References

A Contributing Life: the 2013 National Report Card on Mental Health and Suicide Prevention

National Mental Health Commission. <http://www.mentalhealthcommission.gov.au/our-report-card.aspx>

Caring together: an action plan for carer involvement in Victorian public mental health services

Mental Health Branch, Department of Human Services, Victoria 2004

<http://www.health.vic.gov.au/mentalhealth/carer/carer-involve.pdf>

Carer and Consumer Participation Policy: a framework for the mental health sector.

Mental Health Council of Australia. National Carer and Consumer Forum 2004.

<http://nmhccf.org.au/documents/ConsumerandCarerParticipationPolicy.pdf>

Family and Carer Participation and Involvement in Victorian public mental health services

Department of Health 2013 progress report on *Caring together* and the implementation of mental health service carer participation plans.

<http://docs.health.vic.gov.au/docs/doc/Family-and-carer-participation-and-involvement-in-Victorian-public-mental-health-services--progress-report>

National Mental Health Commission's Participation and Engagement Framework

September 2013 sets out principles to guide the way the Commission and its stakeholders engage and work together. It describes a spectrum of participation with an increasing level of involvement, and sets out what the Commission will do to ensure participation efforts will be fulfilled.

<http://www.mentalhealthcommission.gov.au/media/79498/FINAL%20PEF%20-%2011%20September%202013.pdf>

National Framework for Consumer Involvement in Cancer Control Cancer Australia 2011 This Framework offers principles to govern consumer engagement and elements and guidance which can be adapted to local circumstances. The evidence is that where consumers are viewed as equal and integral members of health services, cancer research groups and policy development, there will be improved outcomes and experiences for those affected by cancer.

http://canceraustralia.gov.au/sites/default/files/publications/national_consumer_framework_web_504af020f2184.pdf

National Standards of Mental Health, Commonwealth of Australia. National Mental Health Strategy 2010

<https://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-n-servst10>

Mental Health Professional Online Development (MHPD) website. <http://www.mhpod.gov.au/>

Mental Health Act vii Section 120A family and carers in an ongoing care relationship are entitled to information that is reasonably required to carry out the carer role. In order to provide information to carers in a reasonable and timely manner services must develop and implement policy and processes that are inclusive of carers. http://www.austlii.edu.au/au/legis/vic/consol_act/mha1986128/s120a.html

Mental health statement of rights and responsibilities Report of the Mental Health Consumer Outcomes Taskforce, Department of Health and Family Services, Canberra. 1991

<https://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-m-rights>

Partnerships online, UK, Wilcox D 2004 <http://partnerships.org.uk/guide/frame.htm>

Partners in Respite Psychiatric Disability Services of Victoria Inc (VICSERV) 2010. The Building Capacity in Community Mental Health Family Support and Carer Respite Project, funded by the Australian Government under the Mental Health Respite Program, provided a structure to bring

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people and organisations together to develop new and innovative support and services for families and carers of people with a mental illness.

http://www.vicserv.org.au/uploads/documents/VICSERV%20publications/VicservPartnersPubFA_web_ready.pdf

PDRSS Standards 2004

3.1 The PDRSS has policies and procedures related to participant, community and carer participation which are used to maximise their roles and involvement in the PDRSS

3.2 The PDRSS undertakes and facilitates a range of activities that maximise participant, community and carer involvement in the service.

3.3 The PDRSS assists with training and support for participants, carers and staff, which maximises their involvement in the service. http://health.vic.gov.au/mentalhealth/pdrss/pdrss_standards.pdf

Prahran Mission Carer Involvement and Participation Strategy 2012-2014 This report was commissioned with a view to meeting current National and State Standards for carer participation and involvement in mental health service delivery.

Recognition and Respect Mental Health Carers Report 2012 produced by the Mental Health Council of Australia, a report based on a survey of 508 mental health carers and describes their perspectives on the services available to them and the people they care for.

<http://mhca.org.au/publication/recognition-and-respect-mental-health-carers-report-2012>

Strengthening Consumer Participation in Victoria's Public Mental Health Services. An Action Plan. Department of Health 2009

<http://www.health.vic.gov.au/mentalhealth/publications/cons-part.pdf>

The Essential U&I, Victorian Health Promotion Foundation, Melbourne. Wadsworth, Y and Epstein M, 2001 <http://www.ourcommunity.com.au/files/OCP/TheUnderstanding.pdf>

The National Carer Recognition Framework comprises two pillars. The first of these is the *Carer Recognition Act 2010* (the Act) which commenced on 18 November 2010. The Act acknowledges the significant role of carers and the importance of ensuring that the needs of carers are considered in the development, implementation and evaluation of policies, programs and services that directly affect them or the care recipient(s). The second element of the Framework is the National Carer Strategy.

<https://ndoch.govspace.gov.au/resources/national-carer-recognition-framework>

The National Standards for Mental Health Services 2010viii, Standard 3 requires that "Consumers and carers are actively involved in the development, planning, delivery and evaluation of services". Standard 7 recognises respects, values and supports the importance of carers to the wellbeing, treatment and recovery of people with a mental illness.

[https://www.health.gov.au/internet/main/publishing.nsf/Content/CFA833CB8C1AA178CA257BF0001E7520/\\$File/serv7.pdf](https://www.health.gov.au/internet/main/publishing.nsf/Content/CFA833CB8C1AA178CA257BF0001E7520/$File/serv7.pdf)

The Triangle of Care. Carers Included: A Guide to Best Practice in Mental Health Care in England Second Edition Carers Trust 2013 identify the six key elements (standards) required to achieve better collaboration and partnership with carers in the service user and carer's journey through mental health services.

<http://static.carers.org/files/caretriangle-web-5250.pdf>

Working Together with Families and Carers: Chief Psychiatrist's Guidelines 2005xviii outlines work with families and carers in a manner that recognises respects and supports them as partners in the provision of mental health care. These guidelines recommend that 'families and carers be engaged as early as possible in the episode of treatment and care'.

<http://www.health.vic.gov.au/mentalhealth/cpg/families.pdf>