



Consumer and Carer Engagement Framework

2022

Contents

Acknowledgements.....	1
From our Chair	3
From our CEO.....	4
Defining our language	5
Purpose of this document	6
About consumer and carer engagement and participation	7
About Marathon Health	8
Our Strategic Priorities	8
Our ICARE values:	8
What is consumer and carer engagement and how we do it?	9
How does engagement and participation align with our strategic plan?	11
Clinical Governance Framework.....	11
Monitoring, Evaluation and Continuous Improvement Framework	11
Peer Workforce Practice Model	11
Diversity and Inclusion	12
Lived experience.....	12
Aboriginal and Torres Strait Islander peoples.....	12
LGBTIQA+	13
Culturally and linguistically diverse people.....	13
Disability	13
Young people.....	13
Older people.....	13
Rural and remote communities	13
The Consumer Journey	14
Appendix A: Relevant frameworks and policies.....	16
Appendix B:	17
Community and organisation consultations	17



Marathon Health pays respect to the traditional custodians of the land we stand upon.

This seal represents our commitment to working with our communities for a better future for all.

Acknowledgements

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Optimal Health

Consumers Health Forum of Australia

headspace Dubbo Youth Reference Group

Marathon Health's Consumer and Carer Consultation session

Marathon Health staff

These parties contributed their lived experience, knowledge and time to the development of the consumer and carer engagement framework.

Thank you.

From our Board

Marathon Health is committed to protecting the wellbeing and human rights of our stakeholders.

At the heart of our consumer and carer engagement is the acknowledgement that Marathon Health is impacted by, and has an impact on, those with whom we interact. We recognise the importance of the knowledge and perspective consumers and carers bring to the health journey and how we can improve our service delivery. The value of engaging with consumers and their carers across a range of Marathon Health services is key to understanding the capacity and relevance of our services in addressing client and community needs.

This document is the framework to guide the activities of Marathon Health; to ensure genuine engagement and participation with our stakeholders, promote collaboration with and learnings from consumers and carers, to enhance supported and sustainable design and delivery of our services.



Annette Crothers

Chair, Marathon Health Board

From our CEO

Marathon Health is committed to developing and delivering quality health and wellbeing services, together with the communities we work in. An important part of this is ensuring consumers and carers have the opportunity to partner in their care.

This framework guides our services, ensuring that the voice of consumers and carers is at the core of all we do. It outlines how we will engage consumers and carers to be involved in decision making relating to the planning, design, delivery, measurement and evaluation of our services – and through this consultation, we will collect and use the feedback and experience to design fit-for-purpose, person-centred recovery journeys.

Backed by an organisational culture that prides itself on collaboration and understanding, we encourage all of our staff to build relationships and partner with consumers – enabling us to be more confident that we are delivering high-quality and responsive services, that meet the needs of the people who use them. This is supported by ongoing training and upskilling opportunities, and is underpinned by a robust governance structure.

I acknowledge the important role consumers, carers and community members have made in developing this framework, and would like to thank everyone who has contributed.



Megan Callinan
CEO, Marathon Health

Defining our language

Engagement refers to methods and actions taken by organisations to involve the public, consumers and carers generally but also allows for decision-making, co-design and co-production processes to be undertaken. (1)

Consumers are people who identify as having a living or lived experience of a health or wellbeing challenge and, irrespective of whether they have a formal diagnosis, have accessed services and/or received treatment. This includes people who describe themselves as a 'peer', 'survivor' and 'expert by experience'.

Carers are people, often family members, who provide, or have provided in the past, ongoing personal care, support, advocacy and/or assistance to a person with health or wellbeing challenge.

Consumer representative is a consumer who is representing other consumers OR who is representative of consumers in some way through their own experience/knowledge. (2)

Carer representative is a carer who is representing other carers OR who is representative of carers in some way through their own experience/knowledge. (2)

Feedback refers to providing a personal experience perspective with the service, both positive and negative, to collect information on consumer/carers experience.

Consultation is seeking input from consumers and carers related to the development of Marathon Health processes, including policies and procedures.

Codesign is creating a plan with consumers and carers that meets the needs and expectations of those accessing the service. (1)

Coproduction includes a codesign element along with consumer and carers as partners in the delivery and evaluation of the service.

Representative OF:

- May be appointed by an organisation on the basis of their lived experience knowledge base, and the expertise they bring
- No expectations of consulting with or feeding back to consumers/carers about the representation they undertake but may do this casually
- Would be expected to stay up to date in their knowledge through reading, attending events etc
- More likely to draw from their own perspectives.

Representative FOR:

- May have been elected or nominated by consumers/carers
- Will consult with consumers/carers in some direct way
- Will feed back to committee, focus group, working group or alike, the perspectives of the consumers/carers they consulted with
- They then feedback to consumers/carers about any outcomes or responses as a consequence of the representation



Purpose of this document

The purpose of this document is to guide and inform the development and ongoing strategy for consumer and carer participation within Marathon Health. This framework guides the engagement of consumers and their carers at a program, organisational, and systemic level to continue the delivery of quality client focused services in line with our ICARE values.

This document intends to:

- Support the continued and enhanced engagement and participation of consumers and carers within Marathon Health
- Ensure Marathon Health provides a safe space for consumers and carers to give feedback and receive appropriate response
- Guide Marathon Health in building meaningful consumer and carer engagement and participation in individual, program based and organisation wide contexts with the opportunity for codesign and coproduction.
- Provide structure for reviewing progress of consumer and carer inclusion and adapting services to maintain development and best practice over time.
- Create an environment that encourages and values the voice, perspective, and participation of the consumer – ensuring shared decision making.

About consumer and carer engagement and participation

Engagement and participation are important in creating genuine partnerships between workers and consumers and carers in health and mental health sectors. True engagement and participation is deeper than theoretical principles, and creates better outcomes at an individual, program and organisational level.

Historically, the nature of our health systems has had traumatic impacts on consumers and carers. The right to self-determination, meaning without interference to economic, social, or cultural development (3), is critical for mental health and wellbeing, and therefore addressing the structure of our health system became a matter of human rights. Consumer and carer's understanding and application of lived experience knowledge-base when providing support combined with a recovery-focused and person-centred approach, healing can begin to happen. Creating communities of wellbeing gives the skills and resources back to the consumers and carers and grows resilience and opportunity for shared learning. (4)

Engagement and participation ensures that diversity and inclusion are considered within service design and implementation. This is important as research shows that access to appropriate health care, especially in the space of mental health, is greatly reduced for marginalised populations. Barriers to health care can include prohibitive costs of the service, stigma, lengthy delays for services, location and cultural inappropriateness. (5) Ensuring the incorporation of diversity and inclusion principles when providing health and well-being services, allows us to better engage marginalised groups in a manner that can inform how to adjust or modify services to meet the specific needs of this high-risk group (6).

In addition to improved outcomes for consumers and carers, meaningful engagement and participation supports benefits for other stakeholders including staff, policy makers and funders. Without the engagement and participation of consumers and carers, the ability to measure the success towards fulfilling aims and outcomes is significantly impacted.



About Marathon Health

Marathon Health is a not-for-profit, registered charity with a vision of enabling communities to thrive through improved health and wellbeing. We're one of the few health organisations largely based in country Australia with the core purpose to develop and deliver health and wellbeing services in partnership with communities. We're passionate advocates for equal access to quality health services for people wherever they choose to live.



Our Vision

Enabling communities to thrive through improved health and wellbeing.



Our Mission

To develop and deliver quality health and wellbeing services together with our communities.

Our Strategic Priorities



QUALITY WORKFORCE

Grow a skilled health and wellbeing workforce within our communities.



QUALITY KNOWLEDGE

All services measure their impact and continuously build knowledge to improve the health and wellbeing of our communities.



QUALITY SERVICES

Advocate for, and collaborate with, communities to grow investment in health and wellbeing services.

Our ICARE values:



Integrity and Trust
Be real



Collaboration and Innovation
Make connections



Achievement and Excellence
Be proud



Respect and Empowerment
Demonstrate equality



Empathy and Understanding
Open compassion

What is consumer and carer engagement and how we do it?

Consumer and carer engagement is about involving consumers and carers in decision-making. This may be decisions at an individual or an organisational level – The individual level includes decision making regarding a person's own health, treatments, and illness-management (consumer-centred care) The organisational level includes decision making regarding policy development, service design, delivery, and evaluation. (7)

Six key best practice principles for engagement and participation were identified in the course of developing the National Mental Health Commission's (NMHC) consumer and carer engagement guide. (1). Marathon Health has adopted and adapted these principles, as they align with our ICARE values; embedding best practice into policy and procedure, and having resources and knowledge to put meaningful engagement and participation into practice.

1. Conceptualising participation and engagement as routine practice

This means having guiding documents for how consumer and carer participation will be implemented throughout the organisation. This involves an intentional and purposeful shift of focus and power from doing *to and for*, to doing *together with* consumers and carers. Beliefs, assumptions, and attitudes are critical here and can foster or undermine participation and engagement. Genuine respect for consumers and carers and the value that they offer is essential. Where challenges exist, they need to be recognised, addressed, and mitigated by the organisation.

2. Skills and knowledge are recognised and developed

Supporting stakeholders, including organisation leaders, all staff, consumers, and carers to share their voice, and to support the development of skills needed to share their voice where appropriate. This competency goes to the learning of lived experienced, other skills consumers and carers have, as well as the ability to be involved in codesigning services and making informed decisions about service modelling.

3. Leadership culture

Fostering a supportive environment for engagement from inclusive leadership, that thereby influences an organisational culture of inclusion and engagement. Leadership needs to be recognised and opportunities need to be offered for development with staff members, consumers, and carers. Leadership is a core requirement of recovery on a personal level and becomes a source of inspiration and hope at the communal level.

4. Dedicated resourcing

This means ensuring dedicated staff and budget towards consumer and carer engagement activities, to sustain meaningful participation. Genuine co-production is generally more time-consuming than top-down decision-making and requires careful strategic planning, including human resource management. There also needs to be enough time for everyone to think about and discuss issues. Participation often becomes tokenistic when timeline pressures take priority over time required to consider questions and issues deeply. Relational expertise is honoured in the coproduction and codesign process.

5. Respect, safety, and support

Respect, safety and support is fundamental in ensuring a safe environment throughout the organisation for people to share their health and wellbeing experiences, in a supported and inclusive way that promotes respect and empowerment. It is important to remember that safety is about the environment in which the activities occur and the issues under focus. It is not about targeting specific individuals or creating processes that apply only to health and wellbeing consumers and carers. The supports needed to do so may differ, and in some cases consumers and carers may have greater resilience due to their previous experiences. This includes the consideration of diversity and inclusion, where adjustments should be made to facilitate varied needs and capacities of engagement and participation. Similarly, it includes culturally appropriate pathways that require a holistic approach incorporating connections to Country, culture, and community.

6. Evaluation and quality improvement

Engagement and participation is embedded in quality improvement through listening, responding and actioning feedback and consultation in design, development, and delivery methods. Evaluation is itself an opportunity for engagement and participation. Not only can consumers and carers participate in evaluating programs and services as users, they can also participate in objective evaluation of those programs and services. This includes evaluation design and methods, collecting and interpreting feedback and planning how to use it.

The following table demonstrates different levels and types of consumers and carer engagement across the organisation, including feedback and consultation participation.

	A. Individual	B. Service or program	C. Organisation	D. Policy or system
1. Design	Shared decision-making in treatment and care planning	Co-design of services and programs (as appropriate)	<ul style="list-style-type: none"> Steering committee Advisory groups Representatives in working groups 	Co-design of policies and strategies (as appropriate)
2. Governance		<ul style="list-style-type: none"> Reference groups Steering committees 	<ul style="list-style-type: none"> Representatives on committees Consumer/carers-led committees, equal representation in decision making bodies 	
3. Delivery	Self-help programs and tools	<ul style="list-style-type: none"> Peer workers Peer-led programs 	Consumer-led and carers-led training for staff	Regular reviews of policy and its implementation by consumer and carer representatives
4. Evaluation	Experience surveys	<ul style="list-style-type: none"> Consumer and carer feedback Co-evaluation 	<ul style="list-style-type: none"> Interviews with consumer and carer representatives Regular audit of engagement activities 	

Figure 1. Matrix of engagement and participation activities (CMHC practical guide) (1)

How engagement and participation align with our organisational values

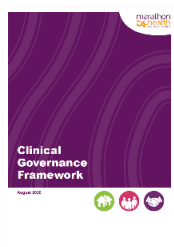
Marathon Health's ICARE values are at the centre of our organisational culture and guide how we develop policies and procedures to suit the needs of our consumers and their carers. Marathon Health's ICARE values fit hand in hand in how consumer and carer engagement can create a space for quality service delivery and enhanced client experience with the overall goal of better outcomes for rural Australians.

How does engagement and participation align with our Strategic Plan?

Our Strategic Plan is central to organisational culture and guides the development of operational procedures. Marathon Health is committed to facilitating consumer and carer engagement in line with the Strategic Plan – which is built on three pillars – quality workforce, quality knowledge and quality services. The below table highlights how consumer and carer engagement aligns with the organisation's strategic direction and ultimate vision of enabling country Australians to thrive.

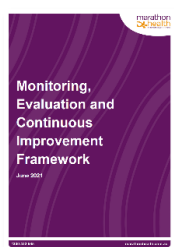


Organisational level	Training supports Employing lived experience consumers and carers	Delivering evidence based best practice services	Informed development of design and delivery of services
Program level	Programs have feedback on delivery of services and how to best meet the need of consumer base	Programs understand consumer and carer needs and can adapt delivery to suit needs	Programs are reflective of community needs, and meets expectations of consumers and carers
Consumer level	Staff can support consumer in making client-centred goals	Consumers and carers are provided education and opportunity to be engaged in their care	Consumers are receiving appropriate services in line with their personal goals



Clinical Governance Framework – Our Clinical Governance Framework places the consumer journey at the centre of everything we do, and explains our commitment to delivering quality services.

Consumer and carer engagement and participation is directly linked to improving the experience and outcomes of the consumer journey – supporting consumers to have a good experience by participating in their care planning and goal setting.



Monitoring, Evaluation and Continuous Improvement Framework – This Framework is key in the collection, review, and improvement of service delivery across the organisation. Consumer and carer engagement fit in closely with this; aiming to also collect information to provide quality services. These documents work together to ensure the continued improvement of Marathon Health's quality workplace, knowledge, and services.



Peer Workforce Practice Model – The Peer Workforce Practice Model directs a culture of inclusion for people with a lived experience; valuing the knowledge and perspective this can provide to the organisation in providing informed services. This is in line with the goals of the Consumer and Carer Engagement Framework weaving the lived experience perspective into the design and delivery of Marathon Health services.



Diversity and inclusion

Marathon Health's Diversity and Inclusion Policy outlines our commitment to providing equal opportunities for prospective staff, along with respect and dignity for service users. Marathon Health aims to create engagement opportunities, and work with diverse groups to improve services and support, reflective of the needs of local communities.

Lived experience

People with a lived experience provide valuable insight into how Marathon Health can support the needs of the community and continue to provide quality services. Marathon Health aims to include people with a lived experience of a health or wellbeing challenge to inform our service design and delivery.

Aboriginal and Torres Strait Islander peoples

Marathon Health recognises Aboriginal and Torres Strait Islander peoples as Australia's first people, and endeavours to provide culturally safe services and a welcoming workplace. Staff are provided cultural sensitivity awareness training and we ensure we work in partnership with First Nations individuals, communities, and organisations to design, create and deliver services that focus on the physical, social, emotional, cultural, and spiritual wellbeing, for both the individual and as a community.

LGBTIQA+

All Marathon Health and headspace offices are ACON registered Safe Places and strive to create a visibly welcoming environment for the LGBTIQA+ community. Staff are encouraged to familiarise themselves with LGBTIQA+ safe terms and are provide resources and training to ensure inclusive practice. Engagement with the LGBTIQA+ community can support Marathon Health to continue providing inclusive and appropriate services.

Culturally and linguistically diverse people

Marathon Health aims to employ a diverse workforce, reflective of local communities. Translation options are provided, both verbally and written, to ensure informed consent and understanding from service users. Staff are also upskilled to understand how to offer culturally and linguistically diverse services. In our journey to provide culturally inclusive services, Marathon Health seeks ongoing feedback and consultation to increase cultural awareness and enhance the experience of consumers and their carers.

Disability

Marathon Health supports equal opportunities for everyone as consumers, carers or employees and aims to achieve an organisational culture that reflects this. Marathon Health provides advocacy in this area to the best of our ability, and shares information about independent advocates where out of scope. Marathon Health strives to support the voice of all disability types to be engaged in developing our service design and delivery. This includes assisting consumers and carers where needed who may not be able to provide feedback or consultation independently.

Young people

Marathon Health recognises the right of young people to participate in all realms of life. Marathon Health will provide a safe environment enabling young people to participate in service design, service delivery and feedback ensuring the voice of young people is heard and incorporated into our practices.

Marathon Health will adapt services to suit age appropriate engagement. Children and young people who are Marathon Health clients should be involved in making decisions and choices about things that affect them, to a level which is appropriate for their capacity to understand and their decision-making skills.

Older people

Similar to young people, older people may also need additional considerations in service delivery to assist engagement with Marathon Health. These considerations include alternate options for technology-based activities and considerations for accessibility based on individual needs. Marathon Health will work with these people in case by case scenarios to deliver services appropriate to their capacity for understanding and decision-making.

Rural and remote communities

Within our corporate vision and mission is a strong emphasis on the importance of servicing rural and remote communities, and ensuring quality services are easily accessible for country Australians. Service delivery needs are often unique to these communities who have additional barriers to engagement. Marathon Health endeavours to address these barriers through engagement of consumers and carers. Creating space for varying levels of engagement can inform how to continue modifying supports to meet community needs.

The consumer journey

Consumer and carer engagement across the consumer journey

The consumer is central to Marathon Health's services, and we partner with consumers and carers to develop and deliver safe and high-quality services at every stage of their journey with us.

We value the input of consumers and carers in improving our service design and delivery to enhance consumer experience within the organisation. Figure 2 shows how consumer and carer engagement is embedded in the consumer journey across the six stages.



Figure 2. A consumer journey with Marathon Health with an engaged consumer and carer approach



Program and organisational information is understandable, available, and consumers and carers can easily access services when in need. Consumers and carers are instrumental in providing insight for how information is marketed and distributed to ensure accessibility for different groups.



Marathon Health designs intake and assessment processes in a way that makes the consumer and their carers feel comfortable, respected, and heard; while making informed decisions on eligibility with the help of consumers and carers.



Partnering with consumers and carers at the care planning stage leads to consumer-focused goals, increased engagement, and better service experience. This is a key aspect of delivering consumer-centred supports. Staff provide education around available options for the consumers and carers and work together to implement the most suitable for the individual.



Marathon Health want consumers and carers to feel engaged in their care and are receiving services that meet their needs and the needs of the community. Consultation for service design and collecting ongoing feedback helps guide service delivery to achieve this.



Consumer and carer feedback and consultation is used to evaluate service design and delivery and provide knowledge on areas for development. Service users are an integral part of evaluating services, having been engaged in the program for each of these stages.



Consumers and carers can use their experience of the organisation to provide feedback and consultation for future direction and continuous improvement. Through creating partnerships with consumers and carers we engage in a space of empowerment that continues with the consumers and carers past Marathon Health.

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Appendix A:

Relevant frameworks and policies

	Frameworks
020	Monitoring, evaluation and continuous improvement framework
192	Peer workforce practice model
143	Clinical governance framework
050	Marathon Health Strategic Plan

	Policy & Procedure
041	<i>Draft</i> Safeguarding Policy
094	Carers Procedure
111	Client Consent Policy and <i>Draft</i> Client Consent Procedure
028	Diversity and Inclusion Policy
118	Human Rights Policy
119	Human Rights Procedure
120	Participation and Inclusion Policy

Appendix B:

Community and organisation consultations

During the development of this document Marathon Health conducted consultation across 3 stages including internal, external organisations, and consumers and carers.

Marathon Health gives thanks to all internal staff who worked on the document, reviewed and gave feedback during this development phase. Marathon Health also gives thanks to external organisations, consumers and carers who provided consultation throughout various stages of development.

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Rebecca Edwards, Consumer and Community Engagement Expert Advisor, Consumers Health Forum of Australia

Youth Reference Group, headspace Dubbo

Marathon Health consumers and carers who participated in our consultation group