Australian Government

Department of Health

PHN PRIMARY MENTAL HEALTH CARE FLEXIBLE FUNDING POOL IMPLEMENTATION GUIDANCE

CONSUMER AND CARER ENGAGEMENT AND PARTICIPATION

In 2016-17 PHNs are expected to:

- establish and foster collaborative partnerships with consumers and carers;

- identify and address the goals of consumers and carers at each point of the commissioning cycle;

- acknowledge the different consumer needs across a stepped care model, and consult with those consumers most likely to use particular service types on their needs and concerns;

- apply principles of co-design when commissioning services, with a focus on recovery-oriented approaches;

- require services to account for cultural and experiential differences in consumer and carer engagement and participation strategies;

- support workforce development and planning, which is inclusive of lived experience trainers and educators;

- recognise the rights of consumers and carers, and seek to eliminate stigmatising attitudes and discrimination in primary health care settings; and

- comprehensively identify consumer and carer support and advocacy services within the region, as well as any gaps.

Longer term PHNs will be expected to:

- embed consumer and carer co-design throughout the commissioning cycle, including in needs assessment; policy development; strategic planning; prioritisation; procurement of services; and monitoring and evaluation;

- establish collaborative partnership arrangements with Aboriginal and Torres Strait Islander communities and their health and mental health services;

- establish collaborative partnership arrangements with transcultural mental health services, or the alternatives in states and territories where such services do not exist; and

- move to contractual arrangements with service providers which require them to demonstrate a rights based approach to consumers and carers.

Who are consumers and carers?

Consumers and carers are people with a lived experience of mental illness and/or suicide and are at the heart of the mental health system. Consumers are people who access or could potentially access mental health services. Carers are people who provide personal care, support and assistance to another person who has a mental health difficulty or has suicidal ideation or has attempted suicide. Many people are both consumers and carers, and many carers provide support to more than one person.

The term consumer recognises a relationship with the mental health system that includes legal rights such as the right: to have up to date information; to make informed choices about treatment and care; to protection from unsafe services or treatments; to have support to resolve a problem; and to make a complaint. While many people do not identify as consumers or carers, they still have rights. PHNs should ensure that their processes for engagement and participation recognise and promote these and other rights, to guide the action of consumers and carers in every aspect of their treatment and care.

What is consumer and carer engagement and participation?

Consumer and carer engagement and participation refers to 'participation by consumers and carers in formal or informal planning, delivery, implementation, and evaluation of all activities associated with mental health services (voluntary or paid), as well as in all processes which affect the lives of consumers and carers, through sharing of information, opinions, and decision making power'.[1]

Collaborative partnerships with consumers and carers are central to meaningful consumer and carer engagement and participation. Such partnerships rely on participation by all parties to share and supplement knowledge and resources, working to achieve a common goal. Collaborative partnerships form the basis of co-design, a participatory process in collaboratively designing services, products or processes with the ultimate goal of creating benefits for all parties.[2] Consumers and carers will experience better outcomes where their participation is embedded in collaborative partnerships and co-design across the whole mental health system.

Consumer and carer engagement and participation means ensuring consumers and carers are 'active participants, not just sources of endorsement or information'.[3] Engagement and participation may be initiated by PHNs and services, or by consumers and carers themselves, or it may be represented by a commitment to an ongoing relationship with consumers and carers (as in a partnership between all parties).

---

[1] National Mental Health Consumer and Carer Forum (NMHCCF) Advocacy Brief Issue: Consumer and Carer Participation – Key Issues and Benefits (2010) https://nmhccf.org.au/sites/default/files/docs/final_cc_participation.pdf
[2] Co-design for Social Good (21 January 2016) Ingrid Burkett, Centre for Social Impact, www.design4socialinnovation.com.au/news/co-design-social-good-ingrid-burkett/
[3] NMHCCF (2010)

Engagement and participation underpins recovery oriented approaches. By engaging with and expecting the participation of consumers and carers, PHNs and services acknowledge that the system exists to provide services, support and programs that support people to lead contributing lives where they:
- are thriving not just surviving,
- have effective treatment and care when it is needed,
- have something meaningful to do and something to look forward to,
- have connections with family, friends, culture and community, and
- feel safe, stable and secure.

Recovery oriented approaches recognise and respect all people for the experience, expertise and strengths that they contribute, with an emphasis on self-determination, self-management, empowerment and advocacy.[4] Such approaches can support people to find and maintain hope, re-establish a positive identity, build a meaningful life, and take responsibility and control. They also recognise that recovery may mean the continued presence of symptoms but without their negative impact[5]. These approaches acknowledge a distinction between clinical recovery and personal recovery but recognise that they are interconnected and complementary[6].

Recovery can mean different things to different people, particularly given cultural and experiential diversity. For Aboriginal and Torres Strait Islander peoples, social and emotional wellbeing connected to culture is central to recovery. For people from culturally and linguistically diverse (CALD), multicultural, migrant and refugee backgrounds, the concept of recovery may be linked to trauma, loss and grief.

What is expected of PHNs?

PHNs should engage consumers and carers, including parents in the co-design of systems and processes in line with the maxim 'nothing about us – without us'[7]. In a stepped care approach, the consumer and carer perspective is vital for ensuring that services are person-centred and holistic. To be effective, diversity among consumers and carers must also be recognised and accommodated. For example, the design of low intensity services would require consultation with people with common forms of mental illness such as mild depression and anxiety. The cultural safety of engagement processes for Aboriginal and Torres Strait Islander peoples should be ensured. PHNs should work proactively with consumers and carers to identify and address any barriers to engagement, particularly for vulnerable groups, such as young people and people with intellectual disability.

PHNs should work collaboratively with a range of consumers and carers on:
- local needs assessments
- annual Activity Work Plans

---

[4] Commonwealth of Australia (2013) A national framework for recovery-oriented mental health services: Policy and theory www.health.gov.au/internet/main/publishing.nsf/content/B2CA4C28D59C74EBCA257C1D0004A79D/$File/recovpol.pdf
[5] Wood et al (2010) cited in Commonwealth of Australia (2013)
[6] Glover (2012) and Slade (2009a) cited in Commonwealth of Australia (2013)
[7] National Mental Health Commission (2014) Contributing Lives, Thriving Communities: Report of the National Review of Mental Health Programmes and Services, Volume 1

- approaches to developing and gaining agreement on the Regional Mental Health and Suicide Prevention Plan
- development of clinical governance and quality assurance arrangements to guide primary mental health care activity
- models of data collection and reporting
- systems to share consumer history
- the development of consumer and carer feedback procedures.

Across primary mental health care, and in its linkages with LHNs and other parts of the system, PHNs should demonstrate organisational commitment to recovery-oriented services, in line with *A national framework for recovery-oriented mental health services (2013)*, the *National Standards for Mental Health Services (2010)* and the *National Safety and Quality Health Services Standards (2012).*

This includes supporting workforce development and planning that recognises the rights of consumers and carers. There is a need to support the workforce to be recovery focussed and work towards understanding how consumer and carer engagement and co-design influences best practice. A key outcome of this is to address and ultimately eliminate stigmatising attitudes and discrimination.

While the Community Advisory Committees, required to be established within each PHN, are central to any community consultation[8], the role and contribution of these committees does not replace the need for PHNs to co-design specific mental health and suicide prevention consumer and carer engagement strategies and to monitor their effectiveness[9].

PHNs are expected to embed consumer and carer engagement in designing each step of the stepped care approach to service delivery and within each phase of the commissioning cycle through comprehensive consumer and carer co-design strategies. Each phase of the commissioning cycle provides opportunities for working closely with relevant groups of consumers and carers in order to achieve a more integrated, coordinated and comprehensive system of mental health services across the PHN region[10].

Consumer and carer feedback procedures should be developed to include a focus on the quality of consumer and carer experience, and the recovery focus, as well as addressing stigma and discrimination. Such feedback should be available to practices to support workforce development and practice planning so that these issues continue to be addressed.

PHNs should recognise the role of family, friends and community in supporting recovery. Parents, in particular, as carers, should be supported to participate in services targeting children and young people. Similarly, carers of people with intellectual disability should be

---

[8] Department of Health (2015) PHN Needs Assessment Guide www.health.gov.au/internet/main/publishing.nsf/Content/PHN-Needs_Assessment_Guide
[9] Stephen Duckett (2014) Consumer and community engagement in primary health networks, Consumers Health Forum Australia, Issue 16 www.chf.org.au/pdfs/chf/HV_April2015_-Duckett.pdf
[10] Department of Health (2016) Mental Health Reform PHN Circular 2-3 March 2016 www.health.gov.au/internet/main/publishing.nsf/Content/PHN-Circular2_Mental

supported to participate in services. PHNs should also acknowledge and promote connections to local community, clubs, schools, workplaces and places of spiritual practice[11]. For Aboriginal and Torres Strait Islander peoples, connections to culture are equally important. In taking a person-centred recovery-oriented approach, PHNs should have a view to services outside of the health system that can support primary health care, and as appropriate, develop cross-sectoral mappings of services that can be used with primary health care to promote broader connections, as well as for needs assessment, services planning and advocacy.

Effective consumer and carer engagement and participation recognises diversity and supports inclusion and participation of vulnerable or hard to reach population groups. This can include: Aboriginal and Torres Strait Islander peoples; people from CALD, multicultural, migrant and refugee backgrounds; people living in rural and remote areas; people who identify as lesbian, gay, bisexual, transgender, intersex and queer; people with intellectual disability; and other vulnerable groups. Targeted approaches to engagement and participation will be needed for some of these groups, which may be through advocacy based groups and community organisations, and/or require preparation of tailored, translated and culturally appropriate information. Where information is translated it should be done with consideration of MHiMA's draft *Principles Document for Translation and Interpreting of Mental Health and Suicide Prevention Information Resources into Languages other than English for People of CALD Backgrounds*.[12]

PHNs are also expected to identify where there are benefits from linking to centralised specialist services and respond accordingly. For example, evidence suggests that not all devolved services are well placed to address CALD issues in primary health care, due to resource limitations.[13]

What flexibilities do PHNs have?

The extent and focus of consumer and carer engagement and participation strategies will vary across PHNs. A flexible approach, built on the principles of collaborative partnerships and co-design, is necessary to best meet the unique needs of consumers and carers across individual PHN regions.

Why is this a priority activity for PHNs?

Consumer and carer engagement and participation is at the core of a person-centred mental health system. Such a system is designed around the needs of people, rather than people having to organise themselves to find their way around what the system provides. It shifts the locus of control away from providers and towards meeting the needs of consumers and carers, recognising their diverse cultural and experiential needs.

---

[11] Commonwealth of Australia (2013)

[12] MHiMA, Principles Document for Translation and Interpretation of Mental Health and Suicide Prevention Information Resources into languages other than English for people of CALD backgrounds www.mhima.org.au/LiteratureRetrieve.aspx?ID=196994 (Currently Draft)

[13] Jiménez-Rubio, Smith, and Van Doorslaer (2008). Equity in health and health care in a decentralised context: evidence from Canada. *Health economics*, 17(3), 377-392. http://arno.uvt.nl/show.cgi?fid=86840

Research indicates that consumer engagement and participation in health services results in higher quality, cost effective, accountable services and improved health outcomes for consumers.[14]

As stated in the PHN Needs Assessment Guide, consumer and carer engagement is essential in order to obtain information about the perceived needs of local communities and individuals, insight into the experiences of consumers and carers, and their perspectives on how primary health care should be improved and where it is already working well[15]. Funding for primary mental health care services should be targeted at, and support, the choices of the individual consumer, in partnership with their carers and other support people, based on the level and type of need.

Definitions

Carers are persons who have a support role for someone living with a mental health difficulty. They may be a family member, friend or have another close relationship with the person.[16] Carers may participate as individuals, groups, organisations of carers, carer representatives or communities.

Co-design is a participatory process in collaboratively designing services, products or processes. It is about engaging consumers and carers in design processes with the ultimate goal being to create benefits for all parties.[17]

Consumers are those who access or could potentially access mental health services. Consumers may participate as individuals, groups, organisations of consumers, consumer representatives or communities.

Consumer engagement and participation is used to describe participation by consumers and carers in formal or informal planning, delivery, implementation, and evaluation of all activities associated with mental health services (voluntary or paid), as well as in all processes which affect the lives of consumers and carers, through sharing of information, opinions, and decision making power'.[18]

Contributing Life is a fulfilling life where people living with a mental health difficulty can expect the same rights, opportunities and health as the wider community. It is a life enriched with close connections to family and friends, supported by good health, wellbeing and health care. It means having a safe, stable and secure home and having something to do each day that provides meaning and purpose, whether this is a job, supporting others or volunteering.

---

[14] NMHCCF (2010)
[15] Department of Health (2015) PHN Needs Assessment Guide
[16] National Mental Health Commission (2014) Contributing Lives, Thriving Communities: Report of the National Review of Mental Health Programmes and Services, Volume 2
[17] Burkett (2016)
[18] NMHCCF (2010)

Cultural safety means an environment that is spiritually, socially and emotionally safe, as well as physically safe for people; where there is no assault challenge or denial of their identity, of who they are and what they need. It is about shared respect, shared meaning, shared knowledge and experience of learning together.[19]

Recovery oriented means supporting people to recognise and take responsibility for their own recovery and wellbeing, as well as in defining their goals, wishes and aspirations. Recovery oriented approaches are underpinned by hope, self-determination, self-management, empowerment and advocacy.[20]

Social and emotional wellbeing, used in the context of Aboriginal and Torres Strait Islander mental health, is a culturally shaped understanding of health as holistic and that connects the health, mental health and wellbeing of an individual to the health of their family and kin, community, culture, country and the spiritual dimension of existence.[21]

---

[19] Williams, R. (1999) Cultural safety – what does it mean for our work practice? *Australian and New Zealand Journal of Public Health*, 23(2), 213-214 http://onlinelibrary.wiley.com/doi/10.1111/j.1467-842X.1999.tb01240.x/epdf
[20] Glover (2012) and Slade (2009a) cited in Commonwealth of Australia (2013)
[21]Dudgeon, P, Milroy, H and Walker, R (2014) *Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice – Revised Edition*

Useful resources

A national framework for recovery-oriented mental health services: Policy and theory, 2013, Commonwealth of Australia
www.health.gov.au/internet/main/publishing.nsf/content/B2CA4C28D59C74EBCA257C1D0004A79D/$File/recovpol.pdf

Australian Government Response to *Contributing Lives, Thriving Communities—Review of Mental Health Programmes and Services*, 2015, Department of Health
www.health.gov.au/internet/main/publishing.nsf/Content/mental-review-response

Centre for Mental Health UK
Informs policy and practice based on high-quality evidence
www.centreformentalhealth.org.uk/Pages/Category/recovery-pubs

Co-design for Social Good, 2016, Burkett
www.design4socialinnovation.com.au/news/co-design-social-good-ingrid-burkett/

Consumer and community engagement in primary health networks, 2014, Duckett
www.chf.org.au/pdfs/chf/HV_April2015_-Duckett.pdf

Contributing Lives, Thriving Communities: Report of the National Review of Mental Health Programmes and Services, 2014, National Mental Health Commission
www.mentalhealthcommission.gov.au/our-reports/contributing-lives,-thriving-communities-review-of-mental-health-programmes-and-services.aspx

Cultural safety – what does it mean for our work practice? 1999, *Australian and New Zealand Journal of Public Health*
http://onlinelibrary.wiley.com/doi/10.1111/j.1467-842X.1999.tb01240.x/epdf

Equity in health and health care in a decentralised context: evidence from Canada, 2008, Jiménez-Rubio, Smith, and Van Doorslaer
http://arno.uvt.nl/show.cgi?fid=86840

Fourth National Mental Health Plan: An agenda for collaborative government action in mental health 2009–2014, Commonwealth of Australia
www.health.gov.au/internet/main/publishing.nsf/content/9A5A0E8BDFC55D3BCA257BF0001C1B1C/$File/plan09v2.pdf

Framework for Mental Health in Multicultural Australia: Towards culturally inclusive service delivery 2014, Mental Health in Multicultural Australia (MHiMA)
http://framework.mhima.org.au/framework/index.htm

Meaningful Engagement Consensus Statement 2016, MHiMA National CALD Consumer and Carer Working Group (NCCCWG)
https://mhaustralia.org/sites/default/files/docs/ncccwg_meaningful_engagement_consensus_statement_april_2016_0.pdf

Mental Health in Multicultural Australia Project (MHiMA)
Provides a national focus for advice and support to providers and governments on mental health and suicide prevention for people from CALD backgrounds
https://mhaustralia.org/mental-health-multicultural-australia-project

Mental Health Reform PHN Circular 2 3 March 2016, Department of Health
www.health.gov.au/internet/main/publishing.nsf/Content/PHN-Circular2_Mental

National Aboriginal and Torres Strait Islander Leadership in Mental Health
A group of senior Aboriginal and Torres Strait Islander peoples associated with the Australian mental health commissions
http://natsilmh.org.au.

National Mental Health Consumer and Carer Forum (NMHCCF)
Gives mental health consumers and carers a united, national voice focused on creating a more responsive service system that will improve their quality of life
http://nmhccf.org.au/

NMHCCF Advocacy Brief Issue: Consumer and Carer Participation – Key Issues and Benefits, 2010
https://nmhccf.org.au/sites/default/files/docs/final_cc_participation.pdf

National Register of Mental Health Consumers and Carers
An ongoing project of Mental Health Australia and is made up of 60 mental health consumer and carer representatives
https://mhaustralia.org/report/national-register-mental-health-consumers-and-carers

National Safety and Quality Health Services Standards 2012, Australian Commission on Safety and Quality in Health Care
www.safetyandquality.gov.au/wp-content/uploads/2011/09/NSQHS-Standards-Sept-2012.pdf

National Standards for Mental Health Services 2010, Department of Health
www.health.gov.au/internet/main/publishing.nsf/content/CFA833CB8C1AA178CA257BF0001E7520/$File/servst10v2.pdf

National Suicide Prevention Strategy, 2014, Department of Health
www.health.gov.au/internet/main/publishing.nsf/content/mental-nsps

Paid Participation Policy: for people with a lived experience of mental health difficulties, their families and support people, 2014, National Mental Health Commission
www.mentalhealthcommission.gov.au/media/112410/Paid%20Participation%20Policy%20%20-%20Final%2027%20August%202014.pdf

PHN Needs Assessment Guide, 2015, Department of Health
www.health.gov.au/internet/main/publishing.nsf/Content/PHN-Needs_Assessment_Guide

Principles Document for Translation and Interpretation of Mental Health and Suicide Prevention Information Resources into languages other than English for people of CALD backgrounds, MHiMA
www.mhima.org.au/LiteratureRetrieve.aspx?ID=196994

Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice, 2014
http://aboriginal.telethonkids.org.au/kulunga-research-network/working-together-2nd-edition-(1)/

Your Voice Can Make a Difference: Service Improvement Report 2014/2015, Neami National
www.neaminational.org.au/sites/default/files/2014-15_neami_national_service_improvement_report_web.pdf