



Perinatal mental health consumer engagement

Position Statement

'I am proud now to be part of PANDA and to stand gently in front of other new parents and share with them my story... so that they don't feel the pain and shame as I once did. Talking about my experience with the other volunteers at PANDA has been a key part of my recovery.'

Community Volunteer

For 35 years PANDA has been supporting individuals and families to recover from perinatal anxiety and depression, and more recently, postnatal psychosis. Our Strategic Plan commits us to amplify the voices of those who have experienced perinatal mental illness to influence governments, health planners and providers, employers and the wider community to respond positively to people experiencing perinatal mental illness.

The purpose of this position statement is to highlight the importance of consumer engagement in all aspects of perinatal mental health planning, promotion, service delivery and evaluation, and to provide a brief overview of PANDA's consumer engagement strategies.

Consumers and Carers

The term 'consumer' is used in this statement to describe anyone who has been directly affected by perinatal mental illness. In our work this includes partners of expecting or new parents as they are directly involved in the parenting journey, and are at increased risk of experiencing perinatal mental illness themselves. We recognise that partners often take on a crucial carer role and enhanced responsibility for children. For this statement, and for all PANDA's consumer engagement activities, the term consumer is inclusive of the person experiencing perinatal mental illness, as well as their partner and/or carers.

We use the term 'lived Experience' interchangeably with 'consumer'.

Evidence to support consumer engagement

There is increasing global acknowledgement of the importance of meaningfully involving consumers in the development of health policy and priorities, as well as the design, implementation, and evaluation of health services and supports. Consumers have important insights to share, and should be at the centre of all health decisions¹. Safe, high quality health care requires a focus on consumers², with evidence to demonstrate that consumer centred care can improve health

outcomes³. Meaningful collaboration between consumers, health practitioners, policy makers, and governments can help to ensure health services and supports are accessible and effective, and improve consumer experiences⁴.

PANDA's consumer engagement experience

PANDA is a leading national consumer perinatal mental health organisation, and plays a crucial role in representing the experience of those affected by perinatal anxiety, depression, and postnatal psychosis. PANDA supports Australian families in a number of ways, including via the National Perinatal Anxiety & Depression Helpline, national awareness raising activities, health professional education, and two websites with lived experience stories and factsheets for consumers and health professionals. Consumers are integral to each of PANDA's services and supports, and are integrated throughout the organisation. While most are in volunteer roles, a number of paid staff also have lived experience of perinatal mental illness. PANDA's consumer engagement practices follow the guidelines for safe and effective participation outlined in the National Mental Health Commission's effective and safe engagement and participation guide: *Sit Beside Me, Not Above Me*⁵.

Community Champions

Central to PANDA's consumer engagement work is our national network of 280 Community Champions. Champions share their personal stories of perinatal anxiety, depression, and postnatal psychosis to break down stigma and help other expecting and new parents find the courage to seek help. Their stories also help to inform health professional education, policy, and health service planning.

Modelling Consumer Engagement

Meaningful consumer engagement is an iterative process, and requires an ongoing commitment of time and resources. Our experience of consumer engagement has demonstrated that these ongoing commitments are necessary if PANDA's services are to meet the needs of consumers.

As a consumer organisation, PANDA is committed to facilitating consumer engagement at every level of the organisation. The following examples demonstrate how we undertake consumer engagement in all aspects of our work.

Governance

- PANDA's constitution requires that at least two consumers are included on the PANDA Board.
- Currently a majority of PANDA's nine Board members have lived experience of perinatal mental illness.

Service Planning, Development, and Delivery

- All callers to PANDA's National Helpline are invited to provide anonymous qualitative and quantitative feedback regarding their Helpline experiences at the conclusion of service provision.
- Feedback from service users informs service evaluation and improvement. Feedback has helped to inform past service changes including adapted call intake processes and modified service hours.

- Peer support volunteers (with lived experience of perinatal mental illness) are highly valued members of PANDA's National Perinatal Anxiety & Depression Helpline team, working alongside professional counselling staff to provide peer support, information, and referral services.
- Quantitative data from PANDA's National Helpline is regularly used to develop our service response, contribute to awareness raising activities and health professional education.
- Feedback from PANDA's Community Champions is sought when we are planning new services or activities.
- Community feedback is also sought through our social media channels.

Policy Development

- Identification of policy priorities is informed by feedback from Community Champions and Helpline caller experiences.
- Feedback on draft policy is actively sought from Community Champions.
- Consumers are considered a key audience for PANDA's policy activities.
- Policy documents include quotes from Community Champions and service users to ensure the lived experience voice is personally expressed in PANDA's policies.

Resources and Information

- Establishing priorities for the development and dissemination of consumer and health professional resources is undertaken in collaboration with consumers and staff providing consumer services on the Helpline.
- Content for PANDA's websites, factsheets and other resources are developed collaboratively with consumers, and also draw on the experience of staff providing consumer services on the Helpline.
- PANDA resources include quotes and, where agreed, images from Community Champions.

Raising Awareness

- PANDA recruits and supports a national program of Community Champions who engage in activities within their local communities to raise awareness, reduce stigma, and share a message of hope and recovery.
- Our annual PANDA Awareness Week draws on the stories of our diverse Community Champions to focus national discussion on the impact of perinatal mental illness.
- We consistently prioritise the inclusion of consumer stories alongside research and PANDA service data when raising awareness through traditional and social media.
- In Victoria, PANDA trains and supports Community Education Volunteers to share their stories and information about perinatal mental health with expecting and new parents. This Community Education is undertaken with structured groups where professional support is available to support group participants if required.

Health Professional Education

- PANDA draws on data from the National Helpline to help health professionals understand the lived experience of perinatal mental illness. We also include anonymous service feedback to reinforce key education messages.
- We prioritise and facilitate consumer voices in health professional education activities, including direct presentations by consumers, development of multimedia training resources with consumer stories, and consumer representation on conference and workshop panels

- PANDA includes quotes, stories and photos from Community Champions in health professional education.

Advocacy

- Where possible PANDA provides training and support for consumers to participate in advocacy and consumer participation with government, policy makers and health services. This work remains limited due to a lack of funding and resources. We are seeking additional funding to expand this important work.
- PANDA is committed to amplifying consumer voices through formal submissions to Government inquiries. We have submitted consumer informed responses to the National Productivity Commission Inquiry into Mental Health, the Victorian Royal Commission into Mental Health, the Legislative Assembly Committee Inquiry into support for new parents and babies in New South Wales and the Victorian Inquiry into Perinatal Services. Our submissions have included direct input from our Community Champions and Community Education Volunteers. We have also encouraged community engagement with inquires through social media promotion and direct promotion to our Community Champions.

Research

- PANDA advocates for meaningful consumer engagement in perinatal mental health research projects, including project design, implementation, and reporting.
- Our own research priorities are informed by Community Champion and service user experiences, and provide opportunities for effective consumer engagement.

Diversity

- PANDA acknowledges that diverse consumer voices are important in the development and delivery of perinatal mental health. We are committed to ensuring diverse voices of those with lived experience of perinatal mental illness are heard.
- While we have made some progress in recruiting Community Champions with diverse backgrounds and experiences, we acknowledge that we can do more and this remains a strong priority for the organisation. To this end, we are building relationships with Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse Organisations to better understand and meet the needs of key minority populations at increased risk of perinatal mental illness.

Recommendations

It is vital that organisations working in perinatal service delivery, research, and policy have in place systems to meaningfully engage with consumers.

Recommendation 1: The design, implementation, and evaluation of perinatal services should be undertaken *with* consumers.

Recommendation 2: Broader activities, including awareness raising, information, and support should be informed by the lived experience of those who have been affected by perinatal mental illness

Recommendation 3: Health and government policy and planning should meaningfully incorporate diverse consumer experiences and expectations.

References

1. The Consumers Health Forum Australia. *Shifting Gears - Consumers Transforming Health: A White Paper*. Canberra; 2018.
2. Australian Commission on Safety and Quality in Health Care. *Australian Safety and Quality Framework for Health Care*; 2010.
3. Australian Commission on Safety and Quality in Health Care. *Partnering with Consumers Action Guide: Australian Safety and Quality Goals for Health Care*; 2012.
4. Consumers Health Forum of Australia. The Real People Real Data Toolkit.
5. The National Mental Health Commission. *Sit beside Me, Not above Me: Supporting Safe and Effective Engagement and Participation of People with Lived Experience*. The National Mental Health Commission; 2018.

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PANDA – Perinatal Anxiety & Depression Australia