



Australian Mental Health Outcomes and Classification Network

'Sharing Information to Improve Outcomes'

An Australian Government funded initiative

Stakeholder participation in mental health information development

Version 0.1

June 2018

Contents

Introduction	1
Living in the Community Questionnaire (LCQ)	2
NOCC Strategic Directions 2014-2024	3
Mental Health Carer Experience Survey (CES).....	3
Your Experience of Service (YES)	4
Your Experience of Service Community Managed Organisation (YES CMO) Survey	5
Your Experience of Service Primary Health Network (YES PHN) Survey.....	6
Reporting domains of the YES.....	7
New consumer rated measure (CRM)	8
Health of the Nation Outcome Scales for Infants (HoNOSI)	8
Australian Mental Health Outcomes and Classification Network (AMHOCN)	9

Introduction


The National Mental Health Strategy, and the documents that underpin it, have acknowledged the vital role of mental health consumers and carers in the design, delivery and evaluation of programs, policy, and services. As noted in *A National framework for recovery-oriented mental health services: policy and theory*:

Bringing lived experience together with the expertise, knowledge and skills of mental health practitioners offers opportunities to challenge traditional notions of professional power and expertise.

The Mental Health Information Strategy Standing Committee (MHISSC), its subcommittees and expert panels, and the Australian Mental Health Outcomes and Classification Network (AMHOCN) have ensured that all stakeholders - consumers, carers and clinicians – are active participants in all mental health information development activities that have been undertaken. This has included the development of new measures, identification of how best to report the results of measures and mental health information gathered by services and the development of new training and information resources.

It is acknowledged that consumers and carers can have various levels of involvement. Table 1 describes a hierarchy of involvement of consumer and carer participation.

Table 1: Consumer engagement

	Type of engagement	Example of activities	Implied view of the consumer
	Inform	Survey results are shared with consumers through posters, newsletters, presentations and reports	Consumers are seen as passive recipients of information
	Consult	Consumers are asked for their opinions and perspectives of the survey results and how the service could be improved	Consumers are seen as stakeholders with a unique perspective to share
	Co-design	Consumer representatives are involved in the survey governance process, including participation in decision making about activities resulting from the review of the findings	Consumers are seen as capable of contributing to decision and governance processes
	Co-produce	Consumers are involved in implementing activities resulting from the review of the survey findings	Consumers are seen as capable of contributing to the design, planning, delivery and evaluation of mental health services

This paper summarises stakeholder participation, particularly consumers and carers, in key projects undertaken by MHISSC and AMHOCN.

Living in the Community Questionnaire (LCQ)

Background:

A project was undertaken that aimed to give effect to the commitments in the 4th National Mental Health Plan to strengthen the focus of the mental health sector on social inclusion and recovery. To achieve this, the project was required to develop a consumer self-report measure that provides information relevant to social inclusion outcomes for youth and adults, using the Activity and Participation Questionnaire 6 (APQ-6) as a foundation. The final measure developed is the Living in the Community Questionnaire (LCQ).

Stakeholder engagement:

A 13 member technical advisory group was established to provide specific advice on the development of the LCQ. The technical advisory group included consumers, carers and other invited experts.

Following initial development work, sector consultations occurred across states and territories with a range of key stakeholders including consumers, carers, clinicians and jurisdictional representatives. Consultations also took place with members of the Mental Health Information Development Expert Advisory Panels (Expert Panels), which also all had consumer and carer representation. These facilitated face to face consultations were held in ACT, NSW, QLD, VIC, SA and WA. Consultations were also held with a specially convened group of consumers and carers who represented state and territory consumer/carers peak bodies.

This sector consultation, supported by a set of resources, provided valuable feedback on the range of key issues that consumers, carers, clinicians and others within the mental health sector saw as important when considering the social inclusion aspects of recovery.

Following development of the penultimate version of the LCQ, the measure was subject to several stages of testing and development which informed the final version of the LCQ. Following relevant ethics approvals, a proof of concept trial was conducted with 244 consumers (from 10 public mental health services) and 1001 members of the general public through an online panel to test the validity and reliability of the draft LCQ. This general public sample was also administered the K-10 to measure psychological distress. A sample of n=400 of the general public survey also completed a retest survey.

AMHOCN also worked with the NSW Consumer Advisory Group (NSWCAG) and the Victorian Mental Illness Awareness Council (VMIAC) to engage mental health consumers in a separate test-retest component of the trial.

AMHOCN also presented on the LCQ at several conferences attended by consumers, carers, clinicians, managers, academics and policy makers. These conferences included The Mental Health Services Conference (TheMHS), the 4th Australasian Mental Health Outcomes and Information Conference, AMHOCN National Forum. Each presentation provided the opportunity to engage with stakeholders and obtain further feedback on the development and use of the LCQ.

NOCC Strategic Directions 2014-2024

Background:

The NOCC Strategic Directions 2014-2024 project was undertaken by the National Mental Health Information Development Expert Advisory Panel, supported by AMHOCN. NOCC Strategic Directions reviewed the progress to date and identified future strategies to promote routine outcome measurement and the use of the data in public mental health services. The primary area of focus was the National Outcomes and Casemix Collection (NOCC) and the aim was to gather a broad variety of input to ensure that any recommendations for the future of the NOCC were practical and met the varied needs of its users.

Stakeholder engagement:

The NOCC Strategic Directions 2014 - 2024 project therefore included extensive consultation with over 1500 individuals. Forums and face to face consultations were held in all states and territories with consumers, carers, clinicians, managers and staff of community managed organisations. 866 participants attended consultations including 47 forums, 22 consultation meetings, 25 site visits and 5 videoconference consultations.

Additional consultations were held with peak bodies including: National Mental Health Commission, (NMHC), Australian Council on Healthcare Standards (ACHS), headspace, the Private Mental Health Alliance (PMHA), the College of Mental Health Nursing, the Royal Australian and New Zealand College of Psychiatrists (RANZCP) and the Australian Association of Social Workers (AASW). Consultation with state and territory Chief Psychiatrists occurred through presentations to the Safety and Quality Partnership Standing Committee (SQPSC).

Two online surveys were conducted with responses received from 511 clinicians and 134 consumers/carers.

Consultations and presentations were also conducted at The Mental Health Services (TheMHS) Conference. TheMHS provides a forum for the exchange of ideas and debate for professionals, consumers, families and carers, managers and policy makers. AMHOCN also presented at various conferences and forums including the 4th Australasian Mental Health Outcomes and Information Conference, AMHOCN National Forum. The presentations provided the opportunity for participants to provide feedback on the use and future directions for outcome measurement in Australia.

Mental Health Carer Experience Survey (CES)

Background:

The 4th National Mental Health Plan and the 2nd National Mental Health Information Priorities recognised that carers and families should be actively engaged at all levels of policy and service development. It was identified that information on carer experience of service provision was not collected in a systematic way. Therefore, it was decided that a national project would be undertaken to develop a tool to support mental health services to monitor and improve carer experience as part of an evidence-informed quality improvement program.

Stakeholder engagement:

Working with the MHISSC Carer Representative, Ms Jackie Crowe, an expert working group was established to provide advice on the development of the Mental Health Carer Experience Survey (CES). The 14 member working group comprised mostly carers from various states and territories, and also included consumer participation.

A draft survey was developed and taken to a series of consultations in QLD, NSW, VIC, SA and WA. AMHOCN collaborated with carer and consumer peak bodies to engage participants in the consultation process. The consultations involved 71 participants - mostly carers, but also consumers and clinicians. These facilitated ½ day consultations provided the opportunity for participants to give feedback on the scope and language of the draft survey, and to also identify issues that are important to carers that should be captured by the measure.

Following development of the penultimate version of the CES, the measure was subject to field testing. Following relevant ethics approvals, a trial was undertaken in several services which aimed to expose the survey to a range of carers and gain information on its psychometric properties and meaningfulness for carers. AMHOCN worked closely with the carer / consumer consultants in the services to support the conduct of the trial.

Guided by the expert working group, the results of the trial then informed modifications to the measure to produce a final version that could be used by mental health services. The trial also provided useful information about issues in service use of the tool e.g. identifying carers, contacting carers.

AMHOCN also presented on the CES at several conferences attended by consumers, carers, clinicians, managers, academics and policy makers. These conferences included The Mental Health Services Conference (TheMHS), the 4th and 5th Australasian Mental Health Outcomes and Information Conferences, AMHOCN National Forums. Each presentation provided the opportunity to engage with stakeholders and obtain further feedback on the development and use of the CES.

Your Experience of Service (YES)

Background:

The 4th National Mental Health Plan and the 2nd National Mental Health Information Priorities identified the need to monitor consumer perceptions of care in public mental health services, with the aim of developing a national standard set of indicators for use by all states and territories. MHISSC agreed that a project should be undertaken to progress this work and the Victorian Department of Health was engaged to lead the project.

Stakeholder engagement:

The project team consisted of staff from the Department of Health, technical experts from Ipsos Social Research Institute and consumer researchers from the Consumer Research and Evaluation Unit at the Victorian Mental Illness Awareness Council (VMIAC).

An expert advisory group was established to oversee the project comprising, jurisdictional representatives, consumer and carer representative and other experts. National consultations and workshops with consumer and carer peak organisations were undertaken throughout the life of the project.

A trial of the draft survey was undertaken and used a face to face offering of the tool by consumer workers. These consumer workers were provided training on offering the measure during the trial and conduct a simple evaluation of the trial from a consumer worker perspective. The aim was to enhance consumer participation in the tool development and identify strategies which would support use of the survey by services.

The results of the trial were considered by the expert advisory group, which then made some further modifications to the survey. The refined survey structure, reflecting a consumer journey, was developed following a further consumer workshop.

Your Experience of Service Community Managed Organisation (YES CMO) Survey

Background:

Following the finalisation of the YES Survey, MHISSC agreed that capturing experiences of care was also important for the mental health community managed organisation (CMO) sector. It was also one of the recommendations from the CMO outcome measures project undertaken by AMHOCN and Community Mental Health Australia (CMHA). MHISSC agreed that this work should be progressed, supported by AMHOCN.

Stakeholder engagement:

A MHISSC working group was established to focus on modifications to the existing YES Survey so that it would be suitable for use in the mental health CMO sector. The working group comprised MHISSC members, including the CMO representative, the consumer representative and the carer representative. The Victorian Department of Health also participated given their role in the development of the public sector version of the YES.

Following initial development of a draft YES CMO Survey, AMHOCN collaborated with the Mental Health Coordinating Council (MHCC) and Psychiatric Disability Services of Victoria (VICSERV) to undertake a series of consultations in city areas (Sydney, Melbourne) and a regional area (Shepparton), aiming to engage with consumers who accessed services provided by community organisations. These discussions aimed to identify any gaps or redundancies in the survey and the relevance of the language that had been used.

Separately, AMHOCN also collaborated with the Victorian Mental Illness Awareness Council (VMIAC) to engage consumers, who had used CMO services in the last 3 months, to participate in one on one interviews about the revised questionnaire.

The comments about the measure gathered during these consultations were fed back to the project's working group and informed further revisions to the survey. This penultimate version of the YES CMO survey was then tested in a field trial in Mental Health Community Support Service (MHCSS) providers in Victoria (facilitated by the Victorian Department of Health as part of a broader sector implementation of the YES suite). Following relevant ethics approval, AMHOCN also undertook a test – retest trial in other jurisdictions. AMHOCN liaised with consumer organisations and some services in QLD and NSW to invite consumers who had recently used CMO services to participate in the test-retest study. Consumers attended a centrally located venue, completed the tool and returned one week later to complete it again and participate in a discussion about the tool.

Consideration of the results of the survey by the working group, and subsequent MHISSC discussions, informed the final version of the YES CMO Survey that was made available for sector use.

AMHOCN also undertook work that resulted in a YES CMO Short Form (YES CMO SF). In order to test the YES CMO SF, AMHOCN collaborated with Mr Geoff Harris (MHISSC Community Mental Health Australia Representative) to undertake a project with several SA CMO services, including Uniting Care, MIND, NEAMI and Centacare. These organisations offered the survey in various ways - via support workers, peer workers, volunteers and other members of staff. In addition, some surveys were completed by telephone as part of an interview.

AMHOCN conducted workshops prior to the trial and upon completion of the trial to assist services in understanding the results and how they might be used to support quality improvement within their organisation.

Your Experience of Service Primary Health Network (YES PHN) Survey

Background:

Given its role in the ongoing development of the YES tools, AMHOCN has been tasked by the Australian Department of Health to lead work on the development of a YES survey for use in Primary Health Networks (PHNs). PHNs have expressed an interest in using an experience tool for the mental health services that they commission.

Stakeholder engagement:

Working with the Australian Department of Health (DoH), AMHOCN contacted all PHNs inviting the nomination of a representative to participate in a reference group that would support the development of the tool. The reference group was subsequently established with representatives from PHNs in QLD, NSW, VIC, ACT and SA.

AMHOCN noted the need for this work to be based on the principles of co-design, consulting with reference group participants about appropriate methods in which to do this. AMHOCN subsequently liaised with the National Mental Health Consumer and Carer Forum (NMHCCF) to engage additional consumer and carer representatives to participate in the reference group.

The reference group identified key elements important to a consumer's experience with a PHN and then reviewed the YES CMO Survey as the basis for highlighting items that might be used in a YES PHN version. A draft tool was subsequently developed and used in consultations with the sector.

AMHOCN undertook a series of face-to-face consultations with PHNs in Queensland, Victoria and Western Australia. Initial feedback on a draft measure was positive but also provided valuable advice regarding refinement. These consultations were organised in PHNs that have representatives on the project reference group. The aim was to ensure that consumers, carers and clinicians were involved in the measure development process. A consultation with members of the National Mental Health Consumer and Carer Forum and National Register is also planned to take place on 21 June 2018.

These initial face-to-face consultations have shown that it is somewhat more difficult to access and engage PHN consumers, carers and clinicians. A second stage of consultations, in an online format, will also be undertaken in July - August 2018.

In order to gain an understanding of current or proposed PHN strategies in the area of consumer experience, AMHOCN liaised with the Australian Department of Health to contact all PHNs inviting them to complete a stocktake survey. The results of the stocktake survey provided useful information about the use of experience tools. The stocktake identified that the majority of respondents were already using tools that they had developed or were using a member of the YES suite of measures. The stocktake also identified items that were not in the current YES suite of measures and included items focusing on access and timeliness of service provision as well as items asking about referral to, or recommendation of, the service.

Reporting domains of the YES

Background:

Jurisdictions identified that domains are a useful way of reporting the results of the YES survey to stakeholders. The initial Proof of Concept Trial for the YES survey presented nine domains, based on a policy review, as an interim measure to report data from the YES survey. It was anticipated that this structure would be reviewed when more data was available.

Stakeholder engagement:

MHISSC subsequently reviewed available YES jurisdictional data and agreed upon a potential new domain structure, noting the need to engage stakeholders in the naming the new YES domains, focusing particularly on consumers and carers. The aim was to ensure that the reporting of YES would be meaningful to all groups.

AMHOCN undertook a series of consultation forums with consumers, carers and clinicians. 51 people took part in the consultation sessions. All group and individual responses were collated and, using a modified constant comparative methodology, themes were identified and domain names generated. This process also enabled the generation of more detailed descriptions of each domain name.

MHISSC discussed the results of these consultation sessions and agreed upon a final domain framework that would better support the process of quality improvement, making clear the link between reporting and active practice change based upon the survey results.

New consumer rated measure (CRM)

Background:

The National Mental Health Information Development Expert Advisory Panel (NMHIDEAP) has been progressing Recommendation 6 of the NOCC Strategic Directions on the development of a nationally consistent consumer self rated measure for adults and older persons, there already being a consistent national self rated measure for children, adolescents and their parents. This new measure would use the K-10, a brief measure of psychological distress (or a component of the K-10) as a foundation and would include domains that were important to consumers and reflect contemporary practice.

Stakeholder engagement:

A NMHIDEAP working group, which included the NMHIDEAP consumer and carer representatives, was convened and developed an initial draft of the measure. It was also recognised that the development of the new consumer rated measure should be progressed based upon the principles of co-design. To that end, AMHOCN on behalf of the NMHIDEAP, worked through the NMHCCF to engage consumer representatives for Adults and Older Persons to participate in the working group and the measure development process.

The new consumer representatives held a special teleconference with the NMHIDEAP Chair, Dr Rod McKay, and AMHOCN representatives to orient them to the work to be undertaken.

To ensure that a draft tool meets the needs of those who would complete it and those who would offer it, consultation sessions will be undertaken with consumers, carers and clinicians. An initial consultation was held at the AMHOCN National Forum in March 2018. Another consultation session will take place with the National Mental Health Consumer and Carer Forum and National Register on 21 June 2018.

Health of the Nation Outcome Scales for Infants (HoNOSI)

Background:

During the NOCC Strategic Direction sector consultations, a gap in the current collection was identified in relation to the health and well being of infants, with a number of services indicating that they had begun using a variety of measures. As a result, Recommendation 11 of the NOCC Strategic Directions Final Report noted the need for work in relation to a suitable outcome measure for infants and pre-schoolers.

Stakeholder engagement:

The Child and Adolescent Mental Health Information Development Expert Advisory Panel (CAMHIDEAP) has progressed Recommendation 11, establishing an expert working group to develop

the Health of the Nation Outcome Scales for Infants (HoNOSI). A draft version of the HoNOSI underwent face validity testing to inform further development of the tool. Face to face focus groups were held across 5 jurisdictions. As some participants could not make it to the face to face focus groups, an additional 5 focus groups / interviews were conducted via teleconference and videoconference. Participants suggested improvements, from a user perspective, that would inform the next stages of development. The working group made revisions to the tool based on the results of the face validity testing.

A penultimate version of the HoNOSI was then taken to a field trial in services across several jurisdictions. The trial will include rating the HoNOSI as part of routine clinical practice and rating the HoNOSI against case vignettes.

Presentations on the HoNOSI development work have been given at several forums including the AMHOCN National Forums and the 5th and 6th Australasian Mental Health Outcomes and Information Conferences.

Australian Mental Health Outcomes and Classification Network (AMHOCN)

Background:

AMHOCN has worked to provide leadership in the use of routine outcome measurement and the use of mental health information within the sector. This has included: the development of training resources and online training modules; targeted forums and workshops; conferences; the development of new measures; and activities that support sector use and reporting of measures.

Stakeholder engagement:

In all activities, AMHOCN has ensured that consumers, carers and clinicians have been an integral part of the work program. AMHOCN has also worked collaboratively with all states and territories and with international colleagues (particularly New Zealand).

AMHOCN has undertaken a variety of different ways of engaging with consumers, carers and clinicians - from ensuring that they are part of the governance arrangements for any AMHOCN initiated project to actively being involved in the design, delivery and evaluation of the project deliverables.

As an example, AMHOCN is currently undertaking work on the development of a resource that aims to support quality improvement activities within services using the results of the YES, YES CMO and the CES. This resource will highlight ways of supporting co-design and co-production of quality improvement activities within services. The project is being led by consumer and carer representatives and a consultation on the development of the resource is being held with members of the National Mental Health Consumer and Carer Forum (NMHCCF) and National Register. A consumer / carer advisory group is being formed to support the work, with a series of consumer and carer consultations planned.

REFERENCES

1. Australian Health Ministers' Advisory Council. A National framework for recovery-oriented mental health services: policy and theory. Canberra: Commonwealth of Australia, 2013.
2. Australian Health Ministers. Fourth National Mental Health Plan 2009-14. Canberra: Commonwealth of Australia, 2009.
3. Department of Health and Ageing. National Mental Health Information Priorities 2nd Edition. Canberra: Commonwealth of Australia, 2005.
4. Australian Mental Health Outcomes and Classification Network and Community Mental Health Australia. National Community Managed Organisation (CMO) Outcome Measurement Project: Final Report to the Mental Health Information Strategy Standing Committee Ver 1.1. Sydney: Australian Mental Health Outcomes and Classification Network, 2013.