

Your Experience of Service

Australia's National Mental Health Consumer Experience of Care Survey - Community Managed Organisation version

Guide for licensed organisations and organisations seeking a license to use the instrument

Endorsed by

Australian Health Ministers Advisory Council Mental Health Information Strategy Standing Committee

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1 PURPOSE – WHAT THIS DOCUMENT AIMS TO DO

This document has been prepared to provide guidance mental health community managed organisations (CMOs) planning to introduce the *Community Managed Organisations' Your Experience of Service (YES-CMO) survey*. The document:

- Provides background information on the survey, covering why and how it was developed, its content and structure, and the current status of development work
- Discusses the main design issues that need to be addressed by organisations considering implementing the survey
- Describes the recommended protocol for using the survey with individual consumers
- Outlines the recommended approach to scoring and interpreting survey results
- Provides details of the arrangements in place for organisations to obtain a licence to use the survey, along with conditions attached to the licence.

2 BACKGROUND TO AUSTRALIA'S NATIONAL CONSUMER EXPERIENCES OF CARE SURVEYS

2.1 Origin

Mental health consumers' experiences of health care have long been identified by services, consumers, carers and families as being important in understanding how health services are performing and to drive service quality improvement. Substantial work has been undertaken in Australia and internationally to establish processes that regularly capture information on the perspectives of consumers and their carers about the health care they receive.

At the national level, there has been strong interest amongst the states and territories in the development of a standardised, national measure of mental health consumer experiences of care which could support quality improvement, service evaluation and benchmarking between services.

In 2010, the Australian Government Department of Health funded the National Consumer Experiences of Care project to develop a survey specifically for use in state and territory funded clinical mental health services. This project resulted in the development of the original *Your Experience of Service* (YES) survey which consists of 35 standard items, structured around four content categories (Experience, Outcomes, Open Ended and Demographics). Additionally, the survey allows for local services to insert questions that cover areas of interest not covered by the existing items.¹

2.1.1 YES-CMO survey

Mental health non-government organisations are private organisations (both not-for-profit and for-profit) that receive Australian and/or state or territory government funding specifically for the provision of services where the principal intent is targeted at improving mental health and well-being and delivered to people

¹ Department of Health. Your Experience of Service: Australia's National Mental Health Consumer Experience of Care Survey. Canberra: Commonwealth of Australia, 2015

affected by mental illness, their families and carers, or the broader community. These services focus on providing well-being, support and assistance to people who live with a mental illness rather than the assessment, diagnostic and treatment tasks undertaken by clinically focused services. NGOs are typically not-for-profit, but some are for-profit. Not-for-profit organisations are also called community-managed organisations (CMOs), reflecting their governance structure. This document focuses on CMOs.²

Subsequent to the development of the YES survey, a collaborative project was undertaken between Community Mental Health Australia (CMHA) and the Australian Mental Health Outcomes and Classification Network (AMHOCN) to: establish the scope of routine outcome measurement within the mental health CMO sector; identify which measures were being used; and conduct a review of the literature identifying the psychometric properties of these measures. This project also aimed to identify a short list of measures that would be suitable for introduction in the CMO sector and that could be the basis for a nationally consistent outcome measurement collection.

In May 2013, a national workshop was convened to review the findings of this review and make recommendations on how routine outcome measurement may be progressed within the CMO sector. One of the key recommendations from this workshop was that the CMO sector should work towards the establishment of a nationally consistent approach to measuring the consumer experience of service.

2.1.2 The need for a CMO specific version of YES

CMO sector consultation highlighted an interest in the use of the YES survey, however it was identified that some of the items and language used did not reflect the types of services being provided by that sector. Modification of the measure to better represent activities in the CMO sector was therefore required. A project was undertaken to review and modify the YES, aiming to design a tool that gathers information from consumers of community managed organisations about their experiences of care. The tool would help community managed mental health services and consumers to work together to build better services.

2.2 The National YES-CMO Survey Project 2015-16

The Australian Mental Health Outcomes and Classification Network (AMHOCN) was tasked by MHISSC with modifying the YES survey for use by CMOs. The objectives of this project were to:

- Make minimal modifications to the existing YES survey so that it would be suitable for trial and use in the mental health CMO sector
- Test the suitability of the modified measure in the CMO sector
- Test the psychometric properties of the modified measure.

This project was conducted in two stages. Stage one involved the creation of a reference group made up of key stakeholders, including consumers, carers, technical experts on measure modification and development, CMO representatives. This reference group was tasked with:

- Reviewing the existing measure
- Making minimal modifications to the existing measure so that it would suitable for the use in the CMO sector
- Omitting items not suitable for the CMO sector or adding additional items if necessary

² AIHW. Mental health non-government organisation establishments NBEDS 2015-, METeOR item identifier: 494729.

• Providing advice on a trial of the measure in CMO sector.

Stage two involved a small test retest trial in NSW and Queensland and a state-wide field trial of the survey in Victoria with 1,040 consumers. The findings of this research were presented to MHISSC in 2016 and the YES-CMO survey was approved for public release.

2.3 Current status of the YES-CMO survey instrument

This national work, led by AMHOCN and guided by MHISSC, built a survey that was designed with consumers, reflects the current policy context and performed well in the psychometric testing. The YES-CMO survey met the requirements for reliability - there was a high degree of correlation between the test and retest scores, with good levels of intra-rater agreement. The stability of the results (that is, the consistency of the direction of rating between test and retest) was found to be extremely high. The research was also able to validate the underlying model of consumer experience.

Research is continuing on the development of a short-form version of the survey.

3 DESCRIPTION OF THE RELEASE VERSION OF THE YES-CMO SURVEY INSTRUMENT

3.1 Differences between the YES survey and the YES-CMO survey

The survey released for license incorporates a number of changes that were identified as desirable from the review of the original YES survey, the subsequent development of the YES-CMO survey, including testing and analysis of the implementation data. The amendments to the original YES survey include the deletion of redundant items (e.g. "You had access to your treating doctor or psychiatrist when you needed" was removed), introduction of CMO specific items and changes to the wording of specific items to better reflect the CMO environment and program types (e.g. the reference to "care" or "treatment" were replaced with "support or care"; "Staff talked with you about your physical health in a way that was useful" was added).

This section describes the release version of the survey provided at Appendix A.

3.2 Naming the instrument

The survey is being released under the title Your Experience of Service (YES) Community Managed Organisations (CMO) or YES-CMO survey. Assigning a national name to identify the survey instrument by organisations is considered essential to promote consistent use.

A condition of the license arrangements includes the requirement that the title be used in all local versions of the survey instrument.

3.3 Introductory wording to be added to YES-CMO survey

Alongside the requirement for the survey instrument to be named consistently, a set of standard words should be used on all forms to orient the consumer to the survey aims and conditions. These are shown below.

Your feedback is important. This survey was developed with mental health consumers. It is based on the Recovery Principles of the Australian National Standards for Mental Health Services. It aims to help community managed organisations and consumers to work together to build better services. If you would like to know more about the survey, please ask for an information sheet.

Completion of the survey is voluntary. All information collected in this survey is anonymous. None of the information collected will be used to identify you. It would be helpful if you could answer all questions, but please leave any question blank if you don't want to answer it.

3.4 Number and sequencing of items

The 36-item survey is structured into four sections:

Section 1 includes the experience items. The section includes 18 items measured on a five-point frequency scale (never, rarely, sometimes, usually, always).

Section 2 includes further experience items. These items are measured on the performance scale (poor, fair, good, very good, excellent).

Section 3 includes the outcome items. These items are measured on the performance scale (poor, fair, good, very good, excellent).

Section 4 includes two open-ended questions to elicit positive and negative experiences with the service.

Section 5 includes demographic items or *explanatory variables*.

Section 6 includes an item to identify the source of any assistance in completing the survey. This can then be used to weight for any effects identified on the data.

The survey allows for the inclusion of local or service-specific additional questions. This may be ad hoc or used over a number of administrations of the survey. These additional questions should be inserted <u>after</u> section 3 (the open-ended questions). Insertion of the additional questions at this point means that there is no order effect on the independent or dependent variables.

3.5 Domains

The YES CMO covers 6 broad domains:

- Making a difference
 - This domain describes how the service contributed to outcomes for individuals. It includes social and emotional wellbeing and physical health.
- Providing information and support
 - This domain describes how the service works for the individual. It includes resources such as written information, a care plan, and access to peer support.
- Valuing individuality
 - This domain describes how the service meets individual's needs. It includes sensitivity to culture, gender and faith and the importance of personal values and beliefs.
- Supporting active participation

- This domain describes how the service provides opportunities for engagement, choice and involvement in the process of service delivery.
- Showing respect
 - The domain describes how the service provides the individual with a welcoming environment where they are recognised, valued and treated with dignity.
- Ensuring safety and fairness
 - This domain describes how services provide individual's with a physically and emotionally safety environment.

Table 1: YES-CMO survey items

ltem sequence	Technical reference # ³	Question	Response type	Type of variable	Domain	Short form
Stem: Thin	king about the c	are you have received from this service within the last 3 months or less, what was your e	xperience in the foll	owing areas?		
1	C-1	1. You felt comfortable using this service	Frequency scale	Experience	Showing respect	Yes
2	C-2	2. Staff showed respect for how you were feeling	Frequency scale	Experience	Showing respect	Yes
3	C-3	3. You felt safe using this service	Frequency scale	Experience	Ensuring safety and fairness	No
4	C-4	4. Your privacy was respected	Frequency scale	Experience	Showing respect	No
5	C-5	5. Staff were positive for your future	Frequency scale	Experience	Showing respect	Yes
6	C-6	6. Your individuality and values were respected (such as your culture, faith or gender identity, etc.)	Frequency scale	Experience	Valuing Individuality	No
7	C-7	7. Staff made an effort to contact you when you wanted	Frequency scale	Experience	Showing respect	No
8	C-8	8. You had access to the staff involved in your support or care when you needed	Frequency scale	Experience	Supporting active participation	No
9	C-9	9. You would make a complaint to this service if you had a concern about your support or care	Frequency scale	Experience	Ensuring safety and fairness	No
10	C-10	10. You had opportunities for your family and friends to be involved in your support or care if you wanted	Frequency scale	Experience	Supporting active participation	Yes
11	C-11	11. Your opinions about the involvement of family or friends in your support or care were respected	Frequency scale	Experience	Supporting active participation	No
12	C-12	12. The facilities and environment met your needs (such as cleanliness, private space, toilets, access to facilities to make a drink, meeting rooms, etc.)	Frequency scale	Experience	Ensuring safety and fairness	No

³ For technical reference purposes, these items are referred to as C-1 to C-36. The core questions (C1-C30) must be positioned as the first, in the order provided, to standardise order effects. 33 items with any additional local or service-specific items follow. Technical reference numbers assigned to each item of the survey are intended for 'behind the scenes' use and not for display on printed or on-screen versions of the survey. It is possible that new questions may be included in future versions of the survey to update the content, capture local issues or new policy directions. To assist in managing this process, the technical reference numbers are designed to allow cross-mapping of items between versions.

ltem sequence	Technical reference # ³	Question	Response type	Type of variable	Domain	Short form
13	C-13	13. You had opportunities to help improve the service if you wanted (such as attending meetings to give your opinions or views)	Frequency scale	Experience	Showing respect	No
Stem: Thin	king about the ca	are you have received from this service within the last 3 months or less, what was your expression ${\sf A}$	perience in the foll	owing areas?		
14	C-14	14. You were listened to in all aspects of your support or care	Frequency scale	Experience	Showing respect	Yes
15	C-15	15. Staff worked as a team in your support or care (for example, sharing information and attending meetings with you)	Frequency scale	Experience	Supporting active participation	Yes
16	C-16	16. You had opportunities to discuss your support or care needs with staff	Frequency scale	Experience	Supporting active participation	No
17	C-17	17. The support or care available met your needs	Frequency scale	Experience	Valuing Individuality	Yes
18	C-18	18. Staff talked with you about your physical health in a way that was useful	Frequency scale	Experience	Valuing Individuality	No
Stem: Thinl	king about the ca	are you have received from this service within the last 3 months or less, what was your ex	perience in the foll	owing areas?		1
19	C-19	19. Information available to you about this service (such as how the service works, what to expect, how to make a complaint, upcoming changes that may affect you, etc.)	Performance scale	Experience	Providing Information and Support	Yes
20	C-20	20. Explanation of your rights and responsibilities	Performance scale	Experience	Providing Information and Support	Yes
21	C-21	21. Access to peer support (such as information about peer workers, referral to peer programs, advocates, etc.)	Performance scale	Experience	Providing Information and Support	Yes
22	C-22	22. Development of a plan with you that addresses all of your support or care needs (such as accommodation, advocacy, employment, health, etc.)	Performance scale	Experience	Providing Information and Support	Yes
23	C-23	23. Convenience of the location of the service for you (such as access to parking or transport, distance from your home, etc.)	Performance scale	Experience	N/A	Yes
Stem: As a	result of your ex	perience with the service in the last 3 months or less please rate the following?	1			
24	C-24	24. The effect of the service on your hopefulness for the future	Performance scale	Outcome	Making a difference	No
25	C-25	25. The effect of the service on your ability to manage your day to day life	Performance scale	Outcome	Making a difference	No

ltem sequence	Technical reference # ³	Question	Response type	Type of variable	Domain	Short form
26	C-26	26. The effect of the service on the management of your physical health	Performance scale	Outcome	Making a difference	No
27	C-27	27. The effect of the service on your overall well-being	Performance scale	Outcome	Making a difference	No
28	C-28	28. Overall, how would you rate your experience with this service in the last 3 months?	Performance scale	Outcome	Making a difference	Yes
29	C-29	29. My experience would have been better if	Open-ended	Comment	N/A	Yes
30	C-30	30. The best things about this service were	Open-ended	Comment	N/A	Yes
31	C-31	31. What is your gender?	Categorical	Demographics	N/A	No
32	C-32	32. What is the main language you speak at home?	Categorical	Demographics	N/A	No
33	C-33	33. Are you of Aboriginal or Torres Strait Island origin?	Categorical	Demographics	N/A	No
34	C-34	34. What is your age?	Ordinal	Demographics	N/A	No
35	C-35	35. How long have you been receiving support or care from this service?	Ordinal	Demographics	N/A	No
36	C-36	36. Did someone help you complete this survey?	Categorical	Demographics	N/A	Yes

3.5.1 Local or service-specific items

Additional questions can be included to the YES-CMO survey if required. There is no set format for these items but it is recommended that the approach used adopt one of the existing measurement scales rather than introduce another set of response options. If a new set of response options is used, the preamble to the items and formatting should be designed to highlight the change.

It is recommended that the number of additional items be kept to a minimum to reduce overall response burden. Significantly increasing the number of questions can impact upon the response rate i.e. fewer people will start and/or complete the survey.

Any additional items added to the survey should be positioned following the first 30 'standard' items. This placement is designed to ensure that any new items added do not affect responses to the first 30 items. For reference purposes, service-specific items are referred to as S-1 to S-n, where n equals the number of items added.

3.5.2 Demographic items

The demographic items are included in the YES-CMO survey to help explain the results achieved by the service. For example, do some groups of consumers have different experiences than other groups of consumers? This will help the service target quality improvement initiatives to specific populations. The demographic items can also be used to identify changes in results over time that relate to changes in the characteristics of consumers rather than service provision.

3.6 Rating scales used for recording responses to the survey

The YES-CMO survey uses two five-point Likert-style rating scales for consumers to record their response to the individual items:

A frequency scale (never, rarely, sometimes, usually, always) is used for the experience questions (or independent variables) in this survey (C-1 to C-18). This is a positively weighted scale (two negative points and three positive points) to improve the distribution of responses which are known to be positively skewed. With the removal of categorical codes available for some items measured on this scale (i.e. don't know and not applicable) this is an interval scale.

A performance scale (poor, fair, good, very good, excellent) is used for the main independent variable, overall experience (C-28) and the outcome variables (C-24 to C-27). Again, this is a positively weighted scale (two negative points and three positive points) used to 'normalise' the distribution of responses which are known to be positively skewed. This scale has interval properties.

The scales are presented in the survey in a semantic rather than numeric form – that is, the response options offered to the consumer use only words as anchor points rather than assign numbers to any rating category. This was designed to ensure that consumers are asked to respond to well understood concepts, rather than just 'ticking a number'. However, the scales were found to have strong numeric properties, meaning that they can be used to generate a score that allows the survey data to be analysed quantitatively.

3.7 Domains covered by the YES-CMO survey items

The YES CMO was developed from the YES Survey. The historical development of the YES survey is detailed in

the YES Guidance for Licensed Organisations. The YES CMO domains are consistent across the suite of experience measures YES, YES CMO and Carers Experience Survey (CES).

The domain structure of the YES CMO covers 6 broad areas:

- Making a difference
- Providing information and support
- Valuing individuality
- Supporting active participation
- Showing respect
- Ensuring safety and fairness

Table 2 shows how each of the 23 experience items are mapped to the domains.

Policy domains covered by the 23 'experience' questions ¹	Number of items primarily mapped to	Survey questions that primarily map to the domain
Making a difference	5	Q.24, Q.25, Q.26, Q.27, Q.28
Providing information and support	4	Q.19, Q.20, Q.21, Q.22
Valuing individuality	3	Q.6, Q.17, Q.18
Supporting active participation	5	Q.8, Q.10, Q.11, Q. 15, Q. 16
Showing respect	7	Q.1, Q.2, Q.4, Q.5, Q.7, Q.13, Q.
Ensuring safety and fairness	3	Q.3, Q.9, Q.12

Table 2: Questions mapped to policy domains

3.8 Short form version of the YES-CMO survey

The short-form version of the YES-CMO survey has been developed from the full version of the survey, based on those items that were most predictive of overall experience for the total sample and sub groups (including service types and programs). The YES-CMO short form survey is a subset of the full survey which has known psychometric properties, but the YES-CMO short form survey has not been separately tested. The psychometric properties of the YES-CMO short form survey will be tested after its first round of implementation.

4 LICENSING ARRANGEMENTS

A licensing process has been set up to enable mental health service organisations to use the YES survey for specified purposes. These arrangements were developed in recognition that there is considerable interest across the Australian mental health sector in trialling or implementing the instrument. While such use is to be supported, the licensing arrangements aim to achieve a controlled release whilst further refinement and development work is undertaken. The arrangements are designed to promote consistency of use and discourage unnecessary modification to the tool. The latter is necessary to minimise the risk that multiple and varied versions with no comparability are produced following public release. The licence also aims to prevent use of the instrument for profit.

A copy of the licence⁴ is available at <u>https://mhsa.aihw.gov.au/committees/mhissc/YES-survey/</u>. The sections that follow summarise its main components.

4.1 Who can obtain a licence?

Mental health service organisations operating in the non government sector can obtain a licence to use the survey. Authorised use is tied to specific service entities itemised in Schedule A of the Agreement which is completed by the licensee. Limitation of the scope to specific service entities is believed appropriate, as opposed to an individual person being licensed to use the instrument in any organisation or setting.

The Agreement is designed for licensing a single organisation or a whole jurisdiction. In the case of jurisdictions, Schedule A does not require a comprehensive listing of all organisations funded by the specific state or territory. Instead, the Schedule can be completed by indicating that the organisations to be covered are all clinical mental health services managed by Local Hospital Networks (or equivalent) that are funded by the relevant state or territory government. For NGOs, a similar arrangement can be adopted where the organisation is large and has multiple components. However, in all cases the descriptions of organisations listed in Schedule A must be specific enough to identify the particular entity or class of entities.

4.2 What are the specified uses allowed by the licence agreement?

The licence is for defined purposes are set out at clause 3.2 – specifically, organisations are licensed to use the YES survey for the purpose of:

- "... undertaking regular or ad hoc surveys of the experience of consumers" of the Service Organisations as listed in Schedule A and to
- "... produce Results derived from such surveys for the purpose of internal or external reporting and publication".

4.3 What conditions are specified in the licence agreement?

Clause 4 of the licence agreement outlines a number of conditions. In summary:

- Licensed organisations are permitted to use the survey in its existing form layout (as set out in Appendix C of this document) or to place it within a different form created by the licensee but only if no changes are made to:
- the wording of individual items;
- the name of the survey, in particular the heading 'Your Experience of Service' must be retained;
- the ordering of items; or
- the response options to each item;

4.4 What conditions are specified in the licence agreement?

Clause 4 of the licence agreement outlines a number of conditions. In summary:

⁴ The actual instrument used is technically referred to as a 'sub-licence agreement' because this more accurately reflects the powers of the Department of Health under the original funding agreement with Victoria. However, for the purpose of improving readability, it is referred to as 'licence' throughout this document.

- Licensed organisations are permitted to use the survey in its existing form layout (as set out in Appendix C of this document) or to place it within a different form created by the licensee but only if no changes are made to:
 - the wording of individual items;
 - the name of the survey, in particular the heading 'Your Experience of Service' must be retained;
- Licensed organisations are permitted to make the following specified modifications:
 - remove items that are not relevant to the service setting in which the survey is used;
 - add a local or jurisdictional logo or other form of agency identification;
 - add items that are of interest to the organisation under an identifiable 'additional questions heading'; and
 - make technical and formatting changes that are necessitated by the choice of medium chosen by the organisation.
- Licensed organisations are required to:
 - refer to the survey as the *Your Experience of Service* survey on all forms;
 - include an acknowledgment on all survey forms by adding the following words: "©
 2013 The Secretary to the Department of Health (Vic) developed with funding from the Australian Government Department of Health."
 - use the survey for non-commercial purposes only;
 - to maintain communication and share experience of use of the survey with the Commonwealth. Licensed organisations also are required to provide the Commonwealth with copies of any published reports prepared from use of the survey;
 - ensure that officers and employees of the organisation who will be using the survey are made aware of this Agreement and its contents; and
 - not further sub-sub-license the survey to a third party, but are permitted to allow a Service Organisation to make copies of, reproduce and download the survey on the condition that the licensed organisation authorises that use in writing and the use is necessary or desirable in order for the organisation to collect survey results.

Licence agreements terminate in June 2019, unless terminated by either party at an earlier time.

4.5 Who issues the licence?

While Intellectual Property rights over the YES survey are held by Victoria, the terms of the funding agreement between Victoria and the Commonwealth Department of Health provided to the Commonwealth "a perpetual, irrevocable, royalty-free and licence fee-free, world-wide, non- exclusive licence (including a right of sub-licence) to use, copy, modify, publish, communicate and exploit the survey instrument." The Victorian and Commonwealth Governments therefore each have the right and authority to set conditions on the public release of the survey instrument.

For the national release of the instrument, licences will be issued by the Commonwealth Department of

Health following completion and acceptance of a licence application.

4.6 What is the process for obtaining a licence?

The licensing process has been designed to be as streamlined as possible and will be managed on behalf of the Commonwealth Department of Health by the Australian Institute of Health and Welfare acting in its capacity as Secretariat to the National Mental Health Information Strategy Standing Committee.

Licence application forms and copies of the licence agreement can be downloaded from the National Mental Health Information Strategy Committee website managed by the AIHW at https://mhsa.aihw.gov.au/committees/mhissc/YES-survey/ A range of other resource materials is also available on the website.

4.7 Is there a licence fee?

The YES survey is being released with no fees charged to licensed organisations.

5 ISSUES FOR ORGANISATIONS TO CONSIDER BEFORE IMPLEMENTING THE YES-CMO SURVEY

This section of the document covers the range of design issues organisations will need to address when considering a planned implementation of the YES-CMO survey within services under their management. There are multiple aspects to designing a surveying approach, including what services should be in scope, the approach to sampling, the period over which survey data collection occurs, the mode of survey administration, the frequency of data collection and whether any additional content will be added to the 'standard' survey questions. Each of these is considered below.

The issues canvassed are not intended to be exhaustive, nor are the approaches outlined intended to be prescriptive. Organisations will need to develop solutions to each of the issues that suit their circumstances and meet the objectives they are pursuing through use of the survey.

5.1 Scope of services to be covered

Organisations need to consider which services under their management are in scope for implementing the YES-CMO survey. In determining scope and eligibility, organisations need to be mindful that the release version of the survey is based on a national project that aimed to develop a tool for monitoring consumers experience across the CMO mental health sector. It was not designed or tested for specific populations such as older or younger persons. Nor was it designed to meet the specific needs of culturally and linguistically diverse communities or Aboriginal and Torres Strait Islander communities. Organisations considering implementing the YES-CMO survey will need to assess the suitability of the survey for use within their own environments.

In making these decisions, it is important to note that:

- The public release version of the survey was developed for use across CMO mental health services. A single version is released, with all items having been tested as suitable for use in all settings
- The licence agreement conditions are permissive, allowing licensed organisations to add items that are of interest to the organisation under an identifiable 'additional questions heading'.

5.1.1 Using the survey with Aboriginal and Torres Strait Islander consumers

As noted, the YES-CMO survey has not previously been tested specifically for Aboriginal and Torres Strait Islander consumers. However, Aboriginal and Torres Strait Islanders should not be excluded and any feedback received will inform further targeted investigation into the appropriateness of the survey tool for this population.

5.1.2 Using the survey with people from a Culturally and Linguistically Diverse (CALD) background

Similarly, the YES-CMO survey has not been tested specifically for CALD populations. However, CALD consumers should not be excluded and any feedback received will inform further targeted investigation into the appropriateness of the survey tool.

5.1.3 Using the survey with young consumers

The YES-CMO survey was developed and tested with adults and has not been tested with consumers who are under 18 years of age. Organisations considering implementing the YES-CMO survey with younger consumers will need to assess the suitability of the survey within their own environments and decide whether it is fit for the purposes intended. Additional questions may be required around family support services and social inclusion.

5.2 Approach to sampling

The YES-CMO survey was developed to be a self-completion survey administered to consumers at the start of a quality improvement cycle, *say* every six months or annually. However, organisations intending to introduce the survey will need to decide their approach to sampling and aggregating responses. The main decisions to be made concern how the survey will be administered (e.g. mail, face to face, etc) and whether administration will be routine or annual.

A range of approaches is available, each with different administrative implications:

- The YES-CMO survey can be implemented on an ongoing basis where all consumers are routinely offered the survey at pre-determined points in the service provision cycle (for example, all consumers are offered the survey after the consumer has received 3 months of care, or at regular reviews, at discharge of the consumer or annually for ongoing relationships)
- Alternatively, the YES-CMO survey could be implemented on a comprehensive annual census basis, where all consumers seen over a given period (e.g. the last three months) are offered the survey. Annual administration allows sufficient time to identify improvements, implement changes and for those changes to be experienced by consumers
- Implement the survey on a selected sample basis, where only a defined proportion of all consumers are offered a survey (for example, one in every 10 consumers are randomly selected to participate). A cautionary note to add here is that, typically, many consumers are keen to share their experiences of surveys. Sampling or screening based on consumer characteristics or

a random selection process may appear as exclusionary to those people who are not invited to participate.

The sampling options are numerous. The key considerations for organisations are to select an approach that:

- Ensures consumers can be identified
- Ensures that consumers completing the survey are representative of the total population of consumers associated with the organisation
- Is sustainable over the longer term (to enable changes over time to be monitored)
- Provides minimal response burden on the consumer
- Ensures the data can be readily aggregated and used within the organisation.

5.3 When to offer the survey

The collection points at which the survey is offered to consumers depend on the sampling approach taken by the organisation and the service setting in which the survey is administered. Where the survey is being implemented as part of routine practice (that is, offered to all consumers), development of a local protocol should be undertaken that specifies the points in the care pathway at which the survey should be offered. For example, in community settings, the local protocol could specify that the survey should be offered three months after admission or at discharge (whichever comes first). Where there is an ongoing relationship, consumers could be offered an annual survey. The important requirement is that a local protocol should be developed that ensures consistency across the organisation and that every consumer has an equal opportunity to receive a survey *irrespective of their level of contact with the organisation*.

Where the survey is being implemented periodically rather than as part of routine service delivery, equivalent decisions need to be made about when the survey is offered to consumer. For example, in community settings, the local protocol could specify that the survey is offered to all consumers who have received a service in the last three months.

5.4 Mode of administration

The YES-CMO survey was designed as an instrument to be *visually presented* to consumers and has not been tested in other presentation modes (for example, auditory presentation via telephone or other interviewing techniques). Visual modes present the response scales to the consumer in a way that allows them to see the options all-at-once and record their responses. This can be achieved by paper-based forms or via electronic means through surveying on a computer tablet, or on-screen formats.

Organisations implementing the survey will need to resolve the presentation mode to be used, noting that the preferred mode is visual until additional modes are tested.

5.5 Adding content to the survey

The YES-CMO survey allows for organisations to add items to the survey content from time to time that are designed to address local issues of interest. As noted earlier (section 3.3.1), these items should be positioned at the end of the core items (after C-30) before the demographics so that responses to core items are not affected by the presentation of the new items. Ideally, any additional items should use the same response scales that are used in the existing items and be kept to a minimum (recommended maximum of five

additional items).

5.6 Consent issues

As a research project, the national Proof of Concept study was required to obtain clearance by a National Health and Medical Research Council (NHMRC)-approved ethics committee. This is not required where health service organisations use the YES-CMO survey for quality improvement initiatives. However, organisations should review the purposes that are being pursued to ensure compliance with any relevant NHMRC guidelines and their own local policies.

5.7 Maximising response rates

Response rate is the term used to describe the relative number of completed surveys received as a proportion of those that were expected to have been offered the survey. Understanding response rates for any survey is critical to interpreting the representativeness of the results and the extent to which they can be generalised to the population.

Careful consideration needs to be given by organisations to developing an implementation approach that maximises participation and response rates. The protocol used for inviting individual consumers to complete the survey is most critical and is covered in section 3.9. There are also system-wide elements of implementation that need to be considered by the organisation. These include, for example:

- Establishing suitable governance arrangements that provide a central point for coordination and monitoring the progress of the survey
- Ensuring any people offering the survey are fully trained in the local survey protocols, research ethics and techniques to avoid influencing the results
- Monitoring the implementation of the YES-CMO survey by different teams and giving them feedback
- Inclusion of consumer and peer workers (where available) in all aspects of the survey planning, promotion and implementation to promote ownership and ensure that the approach taken is responsive of local consumer views
- Establishing organisation-wide processes to promote the survey through staff briefings and educational material
- Preparation of brochure and promotional material to raise awareness of the survey and its aims with consumers
- Routinely making available the aggregated survey results to all stakeholder groups at regular periods.

There is no expected response rate for the YES-CMO survey, although if organisations are going to use the aggregated results for quality improvement a 50% response rate (of those offered the survey) is generally considered very good. However, it is also important to ensure the sample is representative by comparing the characteristics of the sample to the population of consumers at the organisation (if known).

5.8 Managing risk

At times consumers may add responses to surveys that raise issues that have legal or safety implications. For example, a consumer may report a staff member engaged in illegal activity, or make a serious complaint.

Organisations should establish appropriate governance arrangements to manage and respond to such occurrences. The information sheet prepared for consumers should also emphasise that the survey is not for lodging complaints or raising allegations, and alert consumers to the existing complaint mechanisms in place.

6 RECOMMENDED PROTOCOL FOR USING THE YES-CMO SURVEY WITH INDIVIDUAL CONSUMERS

How the survey is offered to individual consumers is crucial to achieving participation. Additionally, for comparisons between and within organisations to be accurate and fair, it is essential that surveys are carried out using comparable procedures. This section outlines the recommended protocol for organisations embarking on use of the YES-CMO survey.

6.1 How should consumers be invited to complete the survey?

The key to achieving a high response rate will be the manner in which the surveys are offered to consumers, particularly the extent to which they feel that the organisation values their feedback. One way organisations can demonstrate that they value feedback is to commitment to sharing the aggregated results of the survey with consumers and showing how the organisation will address the key survey findings. Organisations may choose to publish a summary report on their website, distribute results in a newsletter or use posters to highlight the highest and lowest areas of experience and how consumers can get involved to help improve the later.

Different methods of survey administration have different strengths and weaknesses:

- Mail surveys ensure that all consumers have equal opportunity to receive a survey, including those consumers who do not regularly attend a facility or have contact with staff. However, this assumes that the organisation has contact details for all consumers and that consumers have a reasonable level of literacy. Furthermore, mail surveys can have a low response rate. The response rate can be improved by sending out a priming letter and following up with reminder/ thank-you letters.
- Face to face surveys may achieve a better response rate of those offered a survey, but are usually
 only available to those consumers who have direct contact with the organisation. It is also important
 to ensure that the person offering the survey is not directly involved in supporting the consumer,
 and that they do not inadvertently influence the results. All people offering the survey should be
 fully trained before they commence. Generally, this is a much preferable though more expensive
 method of surveying than a mail survey.

The processes used when offering and collecting the survey needs to achieve three objectives:

- Emphasise the voluntary nature of the survey
- Reinforce the confidentiality and anonymity of responses
- Promote how the survey can be used to help the organisation improve the experience for all consumers.

6.2 Should a fact sheet be prepared for consumers?

Good practice dictates that a summary statement of the aims the survey be prepared for all consumers

invited to participate which also addresses the basic issues of confidentiality, the voluntary nature of participation, and where to obtain any additional information.

A draft consumer information sheet is provided at Appendix B that can be used by organisations as a basis for their local fact sheets.

6.3 What should be said to the consumer?

Organisations should also prepare a standard set of words that can be used by staff when introducing the survey to consumers. The words used will depend on the implementation approach adopted by the organisation. The script below provides an example of what might be drafted by organisations. The language is somewhat formal in expression. As staff become familiar with what needs to be said, it is expected that they will be able to convey the essential points convincingly in their own words.

Begin by stating that:

"I'd like to invite you to complete a survey that asks your views about the quality of the services and care provided by this organisation. Your feedback will be highly valued.

Your Experience of Service is a new survey that has been developed with lots of input from mental health consumers. It is about your experiences of care in this service. By completing the survey you can provide feedback on what's been good and what's not been so good about your experience. Your experiences are important. The information obtained from the survey will be used to help us work together to improve services.

It's voluntary and completely confidential. No one, including staff at this service, will know whether or not you completed the survey. They will only get overall results based on all the responses to the survey. The service will only get the survey results so that they can improve this service based on your feedback.

This form explains a bit more about the survey [give brochure/information sheet]. You can keep this, and take some time to read it now or take it with you to read later if you like. It includes more information about why we're doing the survey, and has some contact numbers if you want to ask questions later on.

Then clearly explain to the person what they should do with their completed survey. It is likely that some consumers will ask more detailed questions about the survey and the use of the results. It is important that the person offering the survey be familiar with the aims, and in a position to answer any questions asked.

6.4 Can assistance be provided?

Assistance can be provided to consumers to complete the survey. Assistance should be limited to reading out the questions, explaining words unfamiliar to consumer and/or writing consumer's responses. In many cases, it will be found that simply hearing the question read out loud can help the consumer form a clear understanding of what is meant with no further comment being needed. Under no circumstances should the surveyor provide or influence answers on behalf of the consumer or rephrase the question. Where the consumer requires assistance, if at all possible the person who assists should be someone who has not been involved in the direct care of the consumer.

Even where assistance is being provided, the consumer should always be given a copy of the survey to work through as the survey has been designed for visual administration and an interview-style of administration may affect the results.

A specific item is included in the survey to indicate whether assistance was provided to the consumer.

6.5 Should some consumers be excluded?

As noted earlier, the YES-CMO survey was specifically built for use in CMO mental health services. As such, the survey was not designed to cater for the breadth of mental health populations, such as very young people, culturally and linguistically diverse communities or Aboriginal and Torres Strait Islander communities. However, there are no prima facie reasons that consumers in any of these groups should be excluded from the survey offering process. In fact, use of the survey with these groups will provide valuable evidence about how to improve the survey to better capture the views of these consumers.

Organisations should aim to offer the survey to as many consumers as possible, recognising that care should always be exercised to not cause distress. Judgement will need to be exercised by those offering the survey to consumers to determine whether presentation of the survey at this time could cause distress (e.g. if the consumer has experienced an adverse event, or the consumer is unwell).

6.6 Is formal consent required?

By completing the survey, the consumer is implicitly giving their consent for the information they are providing to be used by the organisation. In most instances, it is expected that implementation of the survey will be for service improvement purposes rather than research. As such, the formal consent requirements stipulated in the National Health and Medical Research Council guidelines for human research are not required.

7 USING AND INTERPRETING SURVEY RESULTS

This section of the document provides general guidance on how organisations can use the information collected from the survey to explore patterns, compare performance to similar organisations or identify trends in local organisation performance over time.

7.1 Individual item analysis

Assigning numeric values to consumer responses to individual survey items will facilitate item-level analysis. The item values for the scales were demonstrated in the Proof of Concept study to have sufficient numeric properties to allow scores to be assigned to responses. Table 3 shows the scores assigned to the two scales used in this survey.

Table 3: Assigning numeric values to the Frequency and Performance scales

		Numeric value to be assigned					
Scale	1	2	3	4	5		
Frequency scale	Never	Rarely	Some-times	Usually	Always		
Performance scale	Poor	Fair	Good	Very Good	Excellent		

The most basic use of the survey data is to undertake analysis at the individual item level. This involves examining aggregate responses to each item, usually based on simple frequencies and averages. For questions measured on the five-point scales, frequencies can involve summing top-two and bottom-two responses as shown on Table 4. For frequencies and mean, both of which require the exclusion of non-scaled codes, 'don't know', 'not applicable' and missing data should be reported separately so that results are comparable between items.

Table 4: Example of how the YES-CMO survey can be used for individual item analysis

Item	Question	Percent consumers responding	Percent consumers responding 'poor'	Average response (out of 5)
C-5	Staff were positive for your future	55%	35%	3.91
C-6	Your individuality and values were respected (such as your culture, faith or gender identity, etc.)	65%	20%	4.23

Analysis of individual items can assist organisations in focusing on specific areas of service delivery that are perceived as problematic by consumers.

7.2 Can an overall experience score be derived from the survey?

Individual item analysis provides useful insights into how the organisation is perceived by its consumers across the full range of areas covered by the survey but has limitations. Typically, organisations look for ways to summarise the data into an overall index of performance that can be used for simple comparisons between organisations or over time.

In order to be able to produce aggregate scores, the semantic scales used in the survey must be converted into numeric values. As noted above, the Proof of Concept study demonstrated that the scales do in fact have numeric properties and function like an interval scale – that is where each of the assigned values are separated by an equal distance. While further work is needed to develop an empirically-derived overall index12 the following approach is outlined as an interim solution for organisations seeking to convert consumers' responses to numeric summary indices. Organisations seeking to use this interim solution to scoring should note that work has not yet been undertaken to validate the approach, including testing of

scoring algorithms that differentially weight individual items and methods for handling missing data. Caution should therefore be exercised in using the proposed approach.

Note that the proposed approach generates two rather than a single summary score - one for the Experience group of items and the second for the Outcome item group. It is not sensible to add the two into a single score because the underlying scales measure different attributes.

Step 1: Assign numeric values to consumer ratings

Table 3 above shows the scores assigned to the scale values in the two item groups.

Step 2: Sum the total scores for the Experience and Outcome items separately

The total sum of numerically assigned values for each of the Experience items (C-1 to C-23) and Outcome items (C-24 to C-27) should be added separately to yield two overall scores. Table 5 shows the score range possible for the two item groups.

Scale	Domains	Number of items	Minimum score	Maximum score
Experience items	Providing information and support Valuing individuality Supporting active participation Showing respect Ensuring safety and fairness	23	23	115
Outcome items	Making a difference	4*	4	20

Table 5: Score range for the Experience and Outcome item groups

=

* Suggested total score for the Outcome items covers only items C-24 to C-27. Item C-28 ('Overall, how would you rate your experience with this service in the last 3 months?') is excluded because it captures overall experience rather than the consumer's views about the effect the service had on outcomes.

Step 3: Convert the total score for each of the Experience and Outcome item groups to a standard score based on maximum possible score

This third and final step involves converting the total score to a standardised score that takes account of missing data and items recorded by the consumer as 'Not Applicable'. The formula to be applied is as follows:

		100 x Total score for consumer's
Total standardised score for items	=	responses
(Experience or Outcome group,		Maximum score possible adjusted for missing and
%)		'Not Applicable' responses

¹² An empirically derived index would be based on an analysis of the relative weighting across all items, because they may not all be equally important. The interim solution outlined here assigns equal weight to each item, separately for each of the Experience and Outcome item groups.

7.3 Can sub scores for different domains be generated?

While total scores have intrinsic value, they can hide important patterns. For example, poor performance by an organisation in a particular area can be masked by good performance in another, generating an overall 'average' performance score. When that organisation compares itself to another 'like' organisation, they both might have similar overall scores but very different patterns of performance. These differences are important to explore in a service quality improvement environment and point to the need to unbundle overall scores to their various components.

An additional benefit in breaking down total scores to component parts is that service provider groups are more engaged with the detail than is hidden in 'bottom line' scores.

The approach outlined above can also be used to yield a total standard score (percentage maximum possible score) for each of the six experience domains, using as the denominator in the formula the maximum score possible for each of the domains as shown in Table 6.

Policy domains covered by the 23 'experience' questions	Number of items primarily mapped to this domain	Survey questions that primarily map to the domain	Minimum Score	Maximum score
Making a difference*	5	Q.24, Q.25, Q.26, Q.27, Q28	5	25
Providing information and support	4	Q.19, Q.20, Q.21, Q.22	4	20
Valuing individuality	3	Q.6, Q.17, Q.18	3	15
Supporting active participation	5	Q.8, Q.10, Q.11, Q. 15, Q. 16	5	25
Showing respect	7	Q.1, Q.2, Q.4, Q.5, Q.7, Q.13, Q. 14	7	35
Ensuring safety and fairness	3	Q.3, Q.9, Q.12	3	15

Table 6: Score range for the six Experience domains

* The items that comprise the Making a Difference domain do not contribute to the overall Experience score

7.4 Development of a CMO Consumer Experience Index

A consumer experience index can provide a useful method of summarising the changes in consumer experience overtime or between groups. Such a consumer experience index could be used to rank services or units in order of performance or to compare, say by demographics, how different groups of consumers experience the service. This information can then be used to inform activities such as quality improvement and stakeholder communication.

A simple and reliable index can be developed from the survey data by calculating the arithmetic average of scores (excluding don't know, not applicable and missing data). More specifically, this calculation would be the average of questions 1 - 23. The score can be presented as a proportion out of 100 by multiplying the result by 20.

8 FURTHER INFORMATION

More information on the YES-CMO survey project is available at: <u>http://www.amhocn.org/special-projects/your-experience-service-questionnaire-cmo-version</u>

APPENDIX A: YES-CMO SURVEY

Your Experience of Service

(Community Managed Organisations)

SERVICE NAME

Service code stamped here

STATE OR SERVICE LOGO

Your feedback is important. This questionnaire was developed with mental health consumers. It is based on the Recovery Principles of the Australian National Standards for Mental Health Services. It aims to help mental health services and consumers to work together to build better services. If you would like to know more about the survey, please ask for an information sheet.

Completion of the survey is voluntary. All information collected in this questionnaire is anonymous. None of the information collected will be used to identify you. It would be helpful if you could answer all questions, but please leave any question blank if you don't want to answer it.

Please put a cross in just one box for each question, like this . . .

These questions ask *how often* we did the following things . . .

Thinking about the care you have received from this service within the last 3 months or less, what was your experience in the following areas:				Sometimes	Usually	Always	Not applicable
1.	You felt comfortable using this service						
2.	Staff showed respect for how you were feeling						
3.	You felt safe using this service						
4.	Your privacy was respected						
5.	Staff were positive for your future						
6.	Your individuality and values were respected (such as your culture, faith or gender identity, etc.)						
7.	Staff made an effort to contact you when you wanted						
8.	You had access to the staff involved in your support or care when you needed						
9.	You would make a complaint to this service if you had a concern about your support or care						
LO.	You had opportunities for your family and friends to be involved in your support or care if you wanted						

Thinking about the care you have received from this service within the last 3 months or less, what was your experience in the following areas:

- 11. Your opinions about the involvement of family or friends in your support or care were respected
- 12. The facilities and environment met your needs (such as cleanliness, private space, toilets, access to facilities to make a drink, meeting rooms, etc.)
- You had opportunities to help improve the service if you wanted (such as attending meetings to give your opinions or views)
- 14. You were listened to in all aspects of your support or care
- 15. Staff worked as a team in your support or care (for example, sharing information and attending meetings with you)
- 16. You had opportunities to discuss your support or care needs with staff
- 17. The support or care available met your needs
- 18. Staff talked with you about your physical health in a way that was useful

These questions ask **how well** we did the following things . . .

is service within te in the following	Poor	Fair	Good	Very Good	Excellent	Not applicabl	
e (such as how							
ke a complaint,							
bout peer							
s, etc.)							
es all of your							
on, advocacy,							
you (such as							
your home, etc.)							

Thinking about the care you have received from this service within the last 3 months or less, what was your experience in the following areas:

- 19. Information available to you about this service (such as how the service works, what to expect, how to make a complaint, upcoming changes that may affect you, etc.)
- 20. Explanation of your rights and responsibilities
- 21. Access to peer support (such as information about peer workers, referral to peer programs, advocates, etc.)
- 22. Development of a plan with you that addresses all of your support or care needs (such as accommodation, advocacy, employment, health, etc.)
- 23. Convenience of the location of the service for you (such as access to parking or transport, distance from your home, etc.)

5	Never	Rarely	Sometimes	Usually	Always	Not applicable
				۲		ы
		Н				

	result of your experience with the service in the last 3 months or please rate the following:	Poor	Fair	Good	Very Good	Excellent
24.	The effect of the service on your hopefulness for the future					
25.	The effect of the service on your ability to manage your day to day life					
26.	The effect of the service on the management of your physical health					
27.	The effect of the service on your overall well-being					
28.	Overall, how would you rate your experience with this service in the last 3 months?					

Please provide any extra comments

29. My experience would have been better if...

30. The best things about this service were ...

The information in this section helps us to know if we are missing out on feedback from some groups of people. It also tells us if some groups of people have a better or worse experience than others. Knowing this helps us focus our efforts to improve services. No information collected in this section will be used to identify you.

31.	What is your gender?	Male	Female		Other	
32.	What is the main language you speak at home?	English	Other			
33.	Are you of Aboriginal or Torres Strait Island origin?		riginal es Strait Islande riginal and Torr		t Islander	
34.	What is your age?	Under 18 25 to 34 y 45 to 54 y 65 years a	ears ears		18 to 24 years 35 to 44 years 55 to 64 years	
35.	How long have you been receiving support or care from this service?	Less than 1 day to 2 1 to 3 mo More than	weeks		3 to 4 weeks 4 to 6 months	
36.	Did someone help you complete this survey?	No Yes - family or friend Yes - language or cultural interpreter Yes - consumer worker or peer worker Yes - another staff member from the service Yes - someone else				

This area would be modified depending on state/territory or organisation, to add

Instructions for where to send completed questionnaire
Contact details for extra information

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APPENDIX B: SUGGESTED WORDING FOR CONSUMER INFORMATION SHEETS

1. What are community managed mental health services?

Community managed organisations (CMOs) play an important role in Australia's mental health system. Mental health CMOs are not-for-profit organisations that receive funding from Australian governments to provide a wide range of mental health services to people with mental health conditions, their families and carers, and the broader community. The services provided by mental health CMOs include accommodation services, employment services, rehabilitation services, social and educational support, daily living support and respite services among others.

2. What is the Your Experience of Service Questionnaire?

The Your Experience of Service (YES) community Managed Organisation (YES-CMO) survey is designed to gather information from consumers about their experiences of care with community managed organisations. It aims to help community managed mental health services and consumers to work together to build better services.

The YES-CMO survey was developed in consultation with mental health consumers throughout Australia. It is based on the recovery principles of the 2010 National Standards for Mental Health Services. The project to develop the YES-CMO survey was funded by the Commonwealth Department of Health, and was led by the Australian Mental Health Outcomes and Classification Network (AMHOCN). A trial of the questionnaire occurred in 2016.

More information about the YES survey project can be found at www.health.gov.au

3. Are my answers confidential?

The YES-CMO survey does not record your name, date of birth or any other personal identifiers such as your medical record number. Your answers will not be used to identify you.

4. Where can I get help to complete the YES-CMO survey?

Feel free to ask a friend, family member, carer or staff including a Consumer Worker to help you complete the YES-CMO survey.

5. What do I do with my YES questionnaire when I have finished?

Follow the instructions you received with the survey. Usually this will include opportunities to post the survey using a reply-paid envelope, or putting your completed survey in a collection box at the service.

6. What will happen to my feedback?

Services across Australia are using the same survey which will help us develop better services regardless of where you live. Your feedback will be combined with other consumers' feedback in a report that helps services to identify what it is they do well and what they could do better. Services will then use these reports to identify areas where they can improve their service.

7. Are there other ways I can provide my feedback about services?

The YES-CMO survey provides anonymous feedback to services. If you need to lodge a complaint, raise a specific issue, or want feedback on your concerns, you should consider discussing this directly with staff or management at the service.