AMHOCN

Australian Mental Health Outcomes and Classification Network

‘Sharing Information to Improve Outcomes’

An Australian Government funded initiative

Development of the
Mental Health Carer Experience Survey

FINAL REPORT

2018

Contents

EXECUTIVE SUMMARY

Background

The Fourth National Mental Health Plan included the development of consumer and carer experiences and perceptions of care as a priority quality improvement initiative. The plan recognised that carers and families should be actively engaged at all levels of policy and service development and that they should be fully informed of service options, anticipated risks and benefits. The National Standards for Mental Health Services reflected these statements and strongly supported consumer and carer involvement in the development, planning, delivery and evaluation of mental health services.

As information on carer experience of service provision was not collected in any systematic way, the national Mental Health Information Strategy Standing Committee (MHISSC) agreed to progress work on the development of a carer experience of service provision measure. The Australian Mental Health Outcomes and Classification Network (AMHOCN) was tasked with establishing and working with a project working group to drive the development work on the carer experiences measure.

Method

AMHOCN undertook a review of national and international literature to identify existing measures of carers' experiences of service provision. The measures identified were reviewed against seven criteria representing elements essential to a national measure of carers' experiences of service provision. Measures were excluded using a hierarchical, criterion-based method. One measure was identified as having potential to inform the development of a new national survey.

The project working group highlighted the need for any national survey to be strongly aligned to the National Mental Health Standards: Standard 7 - Carers. A draft carer experiences survey was subsequently developed, informed by the results of the literature review but with a foundation on Standard 7.

AMHOCN conducted sector consultations with the draft survey. The feedback form the sector, which included carers, consumers and clinicians, informed the development of the version of the survey suitable for field testing.

The next stage of work was then a field trial to understand how the survey performed when used in in services. Services in Queensland and New South Wales participated in the field trial, with the survey being offered to carers either by mail or face to face.

Findings

The survey tested well and was essentially fit for purpose. Some areas for limited modification were identified, which included moving, adding or removing questions and revision to the language in some questions. The modifications were to reduce ambiguity and improve clarity. One of the main challenges for the participating services related to the identification of carers, and this was relevant for carers of consumers who access both community mental health teams and inpatient units.

Conclusion

The Carer Experience Survey has been developed as a measure suitable for national use in public sector mental health services. The measure captures information about issues meaningful and relevant to carers and, given its strong alignment to Standard 7 of the National Standards for Mental Health Services, can be used by services to identify areas for quality improvement in service delivery.

1. BACKGROUND

The development of measures specifically for carers was identified as an initiative within 2nd National Mental Health Information Priorities document (Department of Health and Ageing, 2005). The Fourth National Mental Health Plan (Australian Health Ministers, 2009) included the development of consumer and carer experiences and perceptions of care as a priority quality improvement initiative. The Plan recognised that carers and families should be actively engaged at all levels of policy and service development and that they should be fully informed of service options, anticipated risks and benefits. It has been recognised that, within the requirements of privacy and confidentiality, carers should get information about the treatment and care provided to the consumer, the services available and how to access those services, and acknowledgment of the impact on carers of their role as a carer.

The National Standards for Mental Health Services (Commonwealth of Australia, Department of Health and Ageing, 2010), and associated Implementation guidelines, reflect these statements and strongly support consumer and carer involvement in the development, planning, delivery and evaluation of mental health services.

A National Framework for Recovery-oriented Mental Health Services (Commonwealth of Australia. Department of Health and Ageing, 2013) describes the practice domains and key capabilities necessary for providing services in accordance with recovery-oriented principles. Capability 2F - Responsive to families, carers and support people, highlights the role of carers and family in promoting wellbeing, providing care and fostering recovery.

Measures aimed at quantifying aspects of the carer experience have variously been developed in order to identify areas that are important to carers as they support consumers and to measure improvements in services. As information on carer experience of service provision was not collected in any nationally systematic way, the Mental Health Information Strategy Standing Committee (MHISSC) agreed, in 2011, to progress work on the development of a carer experience of service provision measure that would allow monitoring of carer engagement with mental health services and guide services in supporting quality improvement in relation to the involvement of carers. With funding from the Australian Government Department of Health, the Australian Mental Health Outcomes and Classification Network (AMHOCN) was tasked with leading this work.

2. PROJECT AIMS AND OBJECTIVES

The development of a nationally consistent tool for measuring carer experiences of mental health service provision will provide a mechanism for monitoring the implementation of Standard 7 of the National Standards for Mental Health Services (Commonwealth of Australia, Department of Health and Ageing, 2010):

> *“The MHS recognises, respects, values and supports the importance of carers to the wellbeing, treatment, and recovery of people with a mental illness.”*

Standard 7 Such a measure would also strengthen accountability, support quality improvement and sustained changes in service delivery and clinical practice, which result in the greater involvement of carers within a consumer's journey of recovery, ultimately improving consumer outcomes and decreasing the impact on both carers and services.

The objectives of the project were to:

- Develop a draft instrument, for use nationally, that focuses on carer experiences of care and which:
    - is aligned to the National Standards for Mental Health Services, notably Standard 7;
    - incorporates evidence form existing carer experiences of service measures, either within Australia or internationally;
    - is informed by the work undertaken on the identification of carer needs by the Mental Health Council of Australia (Mental Health Council of Australia, 2009);
    - is informed by the work undertaken on the identification of carers (Private Mental Health Consumer Carer Network, 2010) (Private Mental Health Consumer Carer Network, 2007); and
    - supports service-level quality improvement.
- Undertake a proof of concept trial to refine the draft instrument.

3. METHOD

The development of the experience of service survey for carers included:

- establishment of a project working group;
- literature review to determine whether any potential measures were currently available;
- measure development work;
- sector consultation; and
- field trial of draft measure.

3.1. Project working group

AMHOCN established a project working group, Chaired by Ms Jackie Crowe, MHISSC Carer Representative. Other members of the working group were: Ms Janne McMahon, Ms Judy Bentley, Ms Judy Hardy, Ms Kathryn Sequoia, Mr Lei Ning, Ms Lynette Pearce, Ms Rosemary Callander, Ms Julien McDonald, Mr Tony Fowke and Dr Mim Weber, Mr Tim Coombs, Dr Cheryl Reed and Ms Rosemary Dickson.

The project working group met several times, both face to face and via teleconference, providing advice on all aspects of the project, including scope and results of the literature review, measure development and review of survey drafts, and planning for field trials.

3.2. Literature review

AMHOCN undertook a review of national and international literature, both scholarly and grey, to identify existing measures of carers' experiences of care. Those measures identified were reviewed against seven criteria representing elements essential to a national measure of carers' experiences of service provision. The seven criteria were:

i. measures domains directly related to a carer’s experiences of service provision
ii. is completed by a carer
iii. is brief and easy to use (≤ 100 items)
iv. yields quantitative data (but would not exclude instruments that *also* capture qualitative data)
v. is applicable to the Australian context, relating to the Fourth National Mental Health Plan Priority Area 1, incorporating the recovery orientation of service provision and social inclusion, and aligns to key domains in Standard 7 (Carers) of the National Standards for Mental Health Services 2010, principally Access and Engagement, Carer Identification, Involvement in Treatment, and Planning for Ongoing Care (see Table 1 for specific domains)
vi. has undergone appropriate processes of development and piloting, including a process demonstrating that the measure is acceptable to carers; and, ideally, that the measure has been scientifically scrutinised; and
vii. demonstrates sound psychometric properties (e.g., of internal consistency, validity, reliability and sensitivity to change).

Measures were excluded using a hierarchical, criterion-based method. The literature search (see Appendix A) yielded 10 potential instruments for measuring carers’ experiences of service provision. Comparison of these measures against seven review criteria identified one measure that had some suitability as a basis for a national measure of carers’ experiences of service provision. This measure was the Victorian *Consumer and Carer Experiences Questionnaire (C&CEQ) – Carer Version;* but it would require additional modification.

Table 1: Carer experience domains from Standard 7 of the National Standards for Mental Health Services

Domain 1. Access and Engagement	
7.2	The MHS implements and maintains ongoing engagement with carers as partners in the delivery of care as soon as possible in all episodes of care.
7.4	The MHS provides carers with a written statement, together with a verbal explanation of their rights and responsibilities in a way that is understandable to them as soon as possible after engaging with the MHS.
7.5	The MHS considers the needs of carers in relation to Aboriginal and Torres Strait Islander persons, culturally and linguistically diverse (CALD) persons, religious / spiritual beliefs, gender, sexual orientation, physical and intellectual disability, age profile and socio-economic status.
Domain 2. Involvement in Treatment	
7.9	The MHS provides carers with non-personal information about the consumer's mental health condition, treatment, ongoing care and if applicable, rehabilitation.
7.10	The MHS actively seeks information from carers in relation to the consumer's condition during assessment, treatment and ongoing care and records that information in the consumer's health record.
Domain 3. Identification of Carers	
7.11	The MHS actively encourages routine identification of carers in the development of relapse prevention plans.
Domain 4. Planning for Ongoing Care	
7.12	The MHS engages carers in discharge planning involving crisis management and continuing care prior to discharge from all episodes of care.

A review by the Wallis Consulting Group (Victorian Department of Health, 2008) of the C&CEQ assessed both the ease of implementation of the measure and some of its psychometric properties. The results of this review led to the conclusion that exclusion of some of the original items from the questionnaire would improve its acceptability to carers and some of its psychometric properties would be enhanced with an alteration to the response format so that respondents had a greater choice of responses.

3.3. Measure development

The project working group reviewed the C&CEQ. To better understand the utility of the C&CEQ and to identify redundant and additional items, the measure was mapped to Standard 7 of the National Standards for Mental Health Services 2010.

Subsequently, using Standard 7 as the foundation and informed by the C&CEQ and other measures identified in the literature review, the project working group developed the first draft of the new carer experiences survey. The development work not only focused on the content of each question but also considered issues such as consistency of response format and suitability for use, from the perspective of carers, consumers and services, across all age bands and service settings.

Throughout the development process, AMHOCN presented regular reports to the Mental Health Information Strategy Standing Committee (MHISSC), updating on progress, seeking guidance as required and endorsement for the planned development pathway.

The measure development process was very much an iterative process with ongoing review and modification to versions of the draft survey. These modifications resulted from the discussions and decisions of the project working group, particularly informed by several project activities described below.

3.4. Sector consultations

It was recognised that testing and sector consultation was required to ensure that the survey questions were understood by, and meaningful to, carers and could be used by services in Australian States and Territories to identify areas for quality improvement. Therefore sector consultations explored the language of the draft measure, the suitability of the questions and the importance of issues covered by the measure to carers.

The working group was also eager to ensure that the measure would provide useful information upon which service providers could act and drive quality improvement activities in relation to carer experiences of service provision and help services meet the National Mental Health Standards: Standard 7.

Working through MHISSC jurisdictional representatives, AMHOCN undertook a national consultation on the draft carer experiences measure, inviting carers, consumers and clinicians to attend a half day workshop with a view to testing the measure, its language, the scope and the meaning of the individual items.

In total, 71 carers, consumers and clinicians participated in these consultation workshops (Table 2). Each workshop included the background to the development of the measure, the importance of language and getting the language of the measure right, and ensuring that the issues or themes that were important to carers were captured by the measure.

Table 2: Forum composition

City	Carers	Consumers	Clinicians
Sydney	15	2	2
Brisbane	9	2	3
Melbourne	12	-	2
Adelaide	7	-	1
Perth	13	1	2
Total	56	5	10

Workshops then proceeded to work through the National Mental Health Standards: Standard 7 and the items in the measure that aligned with these Standards. This series of workshops resulted in a "snowballing" process where items were modified or added as issues were raised, items clarified or omissions identified. Changes were made to items or additional items were added and then presented to the next group. This process produced what was then called the Carer Experience of Service Provision survey.

As part of a quality improvement project, an intensive rehabilitation service in East Adelaide Metropolitan Mental Health Service utilised the measure in a small, time limited project. This provided some insight into the challenges that may present themselves during any pilot testing or subsequent implementation.

Carer identification was highlighted as an ongoing issue. This included: Who is the person best placed to be offered a measure of carer's experience of service provision? How are the carers identified and identified consistently?

Issues of mode of administration were also noted. This included: Should the measure be offered by a carer advocate, or a member of clinical staff? Should the survey occur online or posted to potential carers anonymously? This small pilot also highlighted the need to explain the purpose of the survey and its focus on quality improvement.

As a result of this sector consultation, additional modifications were made to the draft survey and the project working group, supported by MHISSC, determined that it was suitable for field testing.

3.5. Field trial

The field trial was undertaken in during late 2015 – early 2016.

3.5.1 Aim

The aim was to test the questionnaire with carers of consumers of mental health services. The objectives of this phase of development was to:

- expose the questionnaire to a range of carers and gain information on its psychometric properties and meaningfulness for carers;
- obtain feedback from service providers on their views on the meaningfulness and usefulness of the measure and the reports they receive; and
- using the results of the proof of concept trial, modify the measure to produce a final version that might be used by mental health services.

3.5.2 Method

AMHOCN liaised with MHISSC jurisdictional representatives to identify services who might participate in a field trial of the carer experiences survey. While more than 12 services expressed an interest in participating in the trial, many had challenges in identifying carers from the information that they held in databases. Ultimately, the following services participated in the field trial:

- Wide Bay Mental Health Service (QLD);
- Metro North Mental Health Service (QLD), encompassing units and services associated with Royal Brisbane and Women's Hospital; The Prince Charles Hospital and Redcliffe Caboolture Mental Health; and
- Illawarra Shoalhaven Local Health District (NSW)

Ethics approval was obtained for the conduct of the trial from the Royal Brisbane and Women's Hospital Human research Ethics Committee (Reference: HREC/14/QRBW/117) and the University of Wollongong / Illawarra Shoalhaven Health and Medical Human Research Ethics Committee (Reference: HREC/14/WGONG/88).

The trial had two phases:

- ***Phase One***
  Phase One of the trial asked carers to complete an anonymous Carer Experience of Service Provision survey. Services distributed the survey either by mail or "intercept" surveying, e.g. inviting the carer to complete the survey when they may be accessing the service with the consumer. Carers were given a Participant Information Sheet that provided all the necessary information for them to be fully informed about the trial, its goals and what was expected of them should they chose to participate, as well who to contact should they have any complaints. Consent was implied when the carer returned the completed survey. A stamped AMHOCN addressed envelope was provided to assist carers in returning the completed survey to AMHOCN.

- ***Phase Two***
  Carers were also invited to participate in Phase Two of the trial which involved completing the survey on a second occasion, approximately one week after the first completion. This allowed analysis of test retest reliability of the measure. Those participating in Phase Two provided contact details on a consent form and returned that to AMHOCN with the first completed survey. AMHOCN then sent a second copy of the survey to the participant with another stamped AMHOCN addressed envelope.

AMHOCN provided services with materials to support the conduct of the trial. In addition to the Participant Information Sheet, this included:

- posters and cards advertising the trial and inviting carer participation;
- a template for services to use if they wished to write to carers to invite participation;
- options for wording for clinicians to invite carer participation in the trial; and
- a clinician information sheet about the survey and the trial.

3.5.3 Key findings

3.5.3.1. Missing data

Analysis was undertake on 146 completed surveys. On average, 2% of the data was missing. This compares favourably to the YES survey Proof of Concept (PoC) test where the average rate of missing data was 6%. Gender of consumer had the highest proportion of missing data (8%). This may be because some respondents were caring for multiple people or had concerns about the use of the data.

3.5.3.2. Uniqueness of variables

Several variables were found to be highly correlated, suggesting that they are essentially measuring the same constructs:

- R=0.823 for Q 13 (Involved in planning) and Q14 (Level of support you were able to provide)
- R=0.813 for Q12 (Opportunities to discuss care) and Q9 (Opportunities to discuss progress)
- R=0.826 for Q12 (Opportunities to discuss care) and Q10 (You knew what was happening)

3.5.3.3. Mapping to policy

The items from the survey were mapped to the criteria articulated in Standard 7 (Carers) of the National Standards for Mental Health Services 2010. The mapping demonstrated how the measure could provide information that may be used by services to improve carer engagement in relation to the Carer Standard.

3.5.3.4. Demographics

There were initially 11 demographic questions. The survey assumed that the respondent is only caring for one person. For respondents caring for more than one person, the consumer age and gender questions are difficult to complete. These questions did not seem to add benefit to the interpretation of the rating questions in the survey and were removed.

Clerical review of data indicated that there was some confusion in the completion of questions relating to the nature of the relationship between the carer and consumer.

3.5.3.5. Test retest reliability

There were 41 completed surveys in the test retest analysis. The survey performed well on the test retest with a mean correlation across paired rating questions of r= 0.712 (substantial agreement) (compared to a mean of r=518 for the YES survey trial). The mean Kappa score was 0.459 suggesting the survey should expect moderate test retest reliability (compared to Kappa of 0.304 for the YES survey trial).

3.5.3.6. Theoretical model

The underlying theoretical model, that the experience questions can predict overall experience, was tested using linear regression. This analysis revealed that the overall model had moderate predictability (adjusted R^2 0.520). The best predictors were:

- Q7 Your opinion as a carer was respected (β=0.310)
- Q15 You were given the opportunity to enhance your abilities as a carer (β=0.293)
- Q16 Staff conveyed hope for the recovery of your family member, partner, or friend (β=0.278)

The results suggested that the predictability of the survey could be improved with the addition of a question to remove some of the unexplained variance in the data.

Additional question

In June 2016, a forum was held with 20 carers in Brisbane to review the draft carer experience survey. The experience of these carers included inpatient and community adult public mental health. Participants identified and prioritised a list of topics that were important to carers. These topics were then mapped against the draft survey. One gap was identified in this analysis, relating to carer access to the treating doctor, without the consumer present if need. Carers felt that this access was necessary at times to protect the consumer-carer relationship while still ensuring that doctors received accurate information around medication compliance and symptom presentation.

A question to address this gap was developed and refined by the forum participants and agreed by the project working group as suitable for inclusion in the final version of the carer experience survey. This question was:

> *You had opportunities to communicate confidentially with the treating doctor if you needed (such as by phone, email or in person)*

3.5.3.7. Participant evaluation of the survey

Participants rated the survey highly with most agreeing:

- They were comfortable completing the questions (89%)
- The survey asked important questions (78%)
- The survey was easy to complete (95%)

3.5.3.8. The challenge to implementation

AMHOCN provided approximately 2900 carer experience questionnaires to participating sites. The number distributed to carers cannot be actually determined but site coordinators worked to highlight the trial of the tool, liaising with relevant staff and leadership teams to facilitate the dissemination of the trial materials.

One of the key findings of the trial was that identification of carers remains a challenge for services and may be a primary reason for the comparatively low response to the completion of the survey. The issues of carer identification were highlighted in the work undertaken by AMHOCN in 2008 in the scoping of carer measures of burden or distress for potential use in the sector (Australian Mental Health Outcomes and Classification Network, 2008). That work also informed a carer identification project, undertaken in 2010 by the Private Mental Health Consumer Carer Network (Private Mental Health Consumer Carer Network, 2010), with a final report to the (then) Department of Health and Ageing.

A recent collaborative project has also been undertaken by Mind Australia, Helping Minds, Mental Health Carers Arafmi, Mental Health Australia and the Private Mental Health Consumer Carer Network (Australia) to produce a new resource for services that provides guidance and information about engaging and working with carers (Mind Australia, Helping Minds, Private Mental Health Consumer Carer Network (Australia), Mental Health Carers Arafmi and Mental Health Australia, 2016).

The identification of carers is central to engaging carers and involving them in the care and treatment provided to the consumer.

3.5.3.9. Summary of trial findings

The survey tested well in the field trial. The results of the data analysis identified some limited modification of the draft survey including the moving, removal and addition of some questions to improve the design, plus some minor adjustments to wording to remove ambiguity.

Following the trial, some adjustments were made to the survey and reviewed by a small number of carers. The survey was then identified as suitable for implementation.

3.6. Survey name

Early in 2016, two forums were held in regional Victoria and in Brisbane to test the name of the survey with carers. In total, 30 carers participated in these forums. The general consensus was that the provisional working title (Carer Experience of Mental Health Service Provision Survey) should be shortened, but still maintain reference to mental health, even if as a by-line. The key words from the forums were: *Mental Health, Carer Experience Survey.*

MHISSC subsequently endorsed the naming of the survey to be the Mental Health Carer Experience Survey, with the acronym to be CES.

4. CONCLUSION

The CES was found to perform well in the field trial and be fit for purpose as a tool that:

- focuses on carer experiences of service delivery;
- can be used nationally across service settings in public mental health services;
- is aligned to the National Standards for Mental Health Services, notably Standard 7 (see mapping of CES to Standard 7 in Appendix B); and
- supports service-level quality improvement.

MHISSC endorsed the release of the CES for use by the sector. A copy of the CES is provided in Appendix C. The release of the CES was supported by a guidance for use of the Carer Experience Survey (Australian Government Department of Health, 2017). The CES has been made available under a free licence. Further information is available at http://www.amhocn.org/mental-health-carer-experience-survey-0 .

The questions of the CES have been mapped to the domain structure used in the YES suite of surveys (Australian Mental Health Outcomes and Classification Network, 2018) and an interim approach to development of an index has been included in the guidance for use, noted above.

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6. APPENDICES

Appendix A: Carer Experiences of Service Provision: A Review of Measures

AMHOCN

Australian Mental Health Outcomes and Classification Network

‘Sharing Information to Improve Outcomes’

An Australian Government funded initiative

Carer Experiences of Service Provision: A Review of Measures

Version 1.0
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national
mental
health
strategy

A joint Australian, State and
Territory Government Initiative

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Executive summary

Background

Australia, like many other western countries, has increasingly recognised the need for carer involvement in the delivery of mental health services, and this had been reflected in changing mental healthcare policy. Measures aimed at quantifying aspects of the carer experience have been developed in order to identify areas in which carers need assistance and to measure improvements in services as a result of policy change. Currently, however, there is no nationally consistent tool for measuring carer experiences of mental health service provision across Australia. The review outlined here represents a first step in identifying or developing a nationally consistent measure for the assessment of carer experiences of service provision across Australia.

Aims

At the behest of the Mental Health Information Strategy SubCommittee (MHISS), a carers' working group supported by the Australian Mental Health Outcomes and Classification Network (AMHOCN) was tasked with the following:

1. Undertaking a literature review that can inform the selection of an existing, or, if required, development of a new draft, instrument that:
    - Incorporates evidence from existing carer experience of services measures both nationally and internationally;
    - Is informed by the work undertaken on the identification of carer needs by the Mental Health Council of Australia[5] and the work on identification of carers undertaken by the Private Mental Health Consumer Carer Network[6] [7];
    - Is suitable for measuring the recovery orientation of services from a carer perspective based on Standard 7 of the revised *National Standards for Mental Health Services*[3];
    - Informs service-level quality improvement.

2. Providing advice to the MHISS on options to advance future work for the development of a carers' experiences of service measure, realising the commitments under the Fourth National Mental Health Plan.

Method

A review of national and international literature, both scholarly and grey, was conducted to identify existing measures of carers' experiences of care. Those measures identified were reviewed against seven criteria representing elements essential to a national measure of carers' experiences of service provision. Measures were excluded using a hierarchical, criterion-based method.

Results

The literature search yielded 10 potential instruments for measuring carers' experiences of service provision. Comparison of these measures against seven review criteria identified just one measure that may be suitable for further development as a standard measure of carers' experiences of service provision across Australia. This measure was the Consumer and Carer Experiences Questionnaires (C&CEQ).

Recommendations to MHISS

- Modifications to the Consumer and Carer Experience Questionnaires—Carer version, be undertaken so that it is suitable for use across age groups. See example instrument in Appendix 3.

- Pilot and field testing work should be undertaken with this modified measure.

- The approach to the administration of the measure should be an important consideration in any pilot testing. This would assist in gathering unbiased responses and reflect a true picture of a carer's experience within the mental health service.

- The pilot phase should be completed within 12 months.

- A jurisdiction, or any other suitable organisation, should be sought to undertake the pilot testing of the measure.

Chapter 1: Introduction

Background

Australia, like many other western countries, has increasingly recognised the need for carer involvement in the delivery of mental health services. Understanding of the challenges of caring for a person with a mental illness has also grown, and this recognition and understanding has been reflected in changing mental healthcare policy. In order to measure improvements in services as a result of policy change, measures aimed at quantifying aspects of the carer experience, including the carer's well-being, their experience of caregiving and their need for professional support[1] have been developed.

However, while many current measures of the carer experience address the burden of care placed on the carer and their feelings about caring[1], fewer comprehensive measures have been developed to measure carers' own experiences of the mental health services provided to the consumer for whom they provide care—who may be a family member or friend. Currently, there is no nationally consistent tool for measuring carer experiences of service provision across Australia, despite the need for such a measure being articulated in *Australia's Fourth National Mental Health Plan*[2]. The development of such a tool would allow monitoring of carer involvement in service delivery, strengthen accountability and support quality improvement and change in clinical practice.

Relevant policy and practice developments in Australia

The Fourth National Mental Health Plan

The Fourth National Mental Health Plan, Priority Area 4: Quality improvement and innovation[2], articulates the need to improve the carer and consumer experience of engagement with mental health services. This is also reflected in the *National Standards for Mental Health Services 2010*[3] which recognises the role played by carers, as well as their capacity, needs and requirements as being separate from those of consumers. The development of measures specifically for carers was identified as an initiative within the *National Mental Health Information Priorities 2nd Edition* document[4].

National Standards for Mental Health Services

One of the primary quality assurance mechanisms in mental health services is the *National Standards for Mental Health Services 2010*[3]. The *National Standards* are currently used in a range of ways: as a checklist for service quality, as a guide for service enhancement and continuous quality improvement, to guide the development of new services, and as a tool to inform consumers and carers about what to expect from a mental health service.

The *National Standards for Mental Health Services 2010*[3] currently make specific reference to carers. Standard 7 indicates that:

> The MHS recognises, respects, values and supports the importance of carers to the wellbeing, treatment, and recovery of people with a mental illness (p.16).

Standard 7 then specifies 17 criteria for mental health services to better align their practices with the principle articulated above. Seven of these seventeen criteria are most applicable to this review and are outlined in Text Box 1. These criteria fit within the four domains of Access and Engagement, Carer Identification, Involvement in Treatment, and Planning for Ongoing Care.

Text Box 1. Criteria from Standard 7 of the National Standards for Mental Health Service 2010 included in the current review

Domain 1. Access and Engagement

7.2 The MHS implements and maintains ongoing engagement with carers as partners in the delivery of care as soon as possible in all episodes of care.

7.4 The MHS provides carers with a written statement, together with a verbal explanation of their rights and responsibilities in a way that is understandable to them as soon as possible after engaging with the MHS.

7.5 The MHS considers the needs of carers in relation to Aboriginal and Torres Strait Islander persons, culturally and linguistically diverse (CALD) persons, religious / spiritual beliefs, gender, sexual orientation, physical and intellectual disability, age profile and socio-economic status.

Domain 2. Involvement in Treatment

7.9 The MHS provides carers with non-personal information about the consumer's mental health condition, treatment, ongoing care and if applicable, rehabilitation.

7.10 The MHS actively seeks information from carers in relation to the consumer's condition during assessment, treatment and ongoing care and records that information in the consumer's health record.

Domain 3. Identification of Carers

7.11 The MHS actively encourages routine identification of carers in the development of relapse prevention plans.

Domain 4. Planning for Ongoing Care

7.12 The MHS engages carers in discharge planning involving crisis management and continuing care prior to discharge from all episodes of care.

The current review

At the behest in of the Mental Health Information Strategy SubCommittee (MHISS), a carers' working group supported by the Australian Mental Health Outcomes and Classification Network (AMHOCN) developed a project plan in order to determine whether a suitable measure currently exists that could be used as a standard measure across Australia for assessing a carer's own experiences of service provision. The development of such a tool would provide a mechanism for monitoring the implementation of Standard 7 of the *National Mental Health Standards 2010*, particularly relating to the domains of Access and Engagement, Identification of Carers, Involvement in Treatment, and Planning for Ongoing Care, allowing regular monitoring of carer involvement in service delivery as it relates to those domains. This measure would also strengthen accountability and support quality improvement and change in clinical practice. The project plan outlined the parameters for a literature review of available measures relating to carer experiences of service provision, the results of which were to be provided to the MHISS for consideration at its November 2011 meeting.

Overarching aims

The objectives of the project were to:

1. Undertake a literature review that can inform the selection of an existing, or, if required, development of, a new draft instrument that:

   - Incorporates evidence from existing carer experience of services measures both nationally and internationally;
   - Is informed by the work undertaken on the identification of carer needs by the Mental Health Council of Australia[5] and the work on identification of carers undertaken by the Private Mental Health Consumer Carer Network [6] [7];
   - Is suitable for measuring the recovery orientation of services from a carer perspective based on Standard 7 of revised National Standards for Mental Health Services;
   - Informs service-level quality improvement.

2. Provide advice to MHISS on options to advance future work for the development of a carer experiences of service measure, realising the commitments under the Fourth National Mental Health Plan.

Parameters of the review

The parameters of the review were the following:

- To review key Australian and international literature, both scholarly and grey, that focus on key learnings in the area of carer experiences of care measures, including developments in the general health sector.

- To consider key data sources, including any jurisdictions that have tested carer experiences of care measures.

- To assess potential measures against the following key criteria:

  1. measures domains directly related to a carer's experiences of service provision
  2. is completed by a carer
  3. is brief and easy to use (≤ 100 items)
  4. yields quantitative data (but would not exclude instruments that *also* capture qualitative data)
  5. is applicable to the Australian context, relating to the *Fourth National Mental Health Plan* Priority Area 1, incorporating the recovery orientation of service provision and social inclusion, and aligns to key domains in Standard 7 (Carers) of the *National Standards for Mental Health Services 2010*[3], principally Access and Engagement, Carer Identification, Involvement in Treatment, and Planning for Ongoing Care (see Text Box 1 for specific criteria)
  6. has undergone appropriate processes of development and piloting, including a process demonstrating that the measure is acceptable to carers; and, ideally, that the measure has been scientifically scrutinised
  7. demonstrates sound psychometric properties (e.g., of internal consistency, validity, reliability and sensitivity to change).

- To seek advice and recommendations on the results of the review from the Carer Expert Panel and the National Mental Health Information Development Expert Advisory Panel. The Panels will consider whether any existing instruments may have utility for wider application in Australia or whether development work needs to occur to modify an existing measure or develop an entirely new measure.

The literature review and recommendations from the Expert Panels will then be provided to MHISS for its November 2011 meeting.

Our approach to the review was similar to that adopted in three previous reviews: one of the National Outcomes and Casemix Collection suite of consumer outcome measures[8], one of outcome measures for carers of people with mental illness[9] and the third of measures of individual recovery and the recovery orientation of services[10]. This review involved recourse to both the published scientific literature and the 'grey' literature, as well as some limited consultation with experts in the field.

Structure of the current report

The remainder of this report outlines our approach in more detail, describes our findings and makes suggestions about future directions. Chapter 2 describes our methodology, Chapter 3 presents an overview of the identified instruments and Chapter 4 reviews the instruments designed to measure carer experiences of service provision against the seven review criteria. Chapter 5 discusses the findings in the context of progressing the carer experiences of service provision measurement agenda and Chapter 6 states the recommendations made following on from the outcomes of this review.

Chapter 2: Method

Identification of instruments to be included in the review

Our identification of potential instruments drew on a search of Medline and PsycInfo, an Internet search of the grey literature, and limited recourse to local and international colleagues who were regarded as experts in the field.

The literature search was deliberately broad, including search terms that would identify measures of carers' experiences of service provision in areas of health outside of mental health. This broad search was conducted to allow identification of measures that could be adapted to mental health services if they met a number of the review criteria, or that could inform future development of a new measure. Search terms used for Medline and PsycInfo searches were (‘mental’ OR ‘psychiatri*’) AND (‘carer’); (‘carer’) AND (‘services’); (‘carer’) AND (‘survey’ OR ‘questionnaire’); (‘carer’) AND (‘satisfaction’); (‘carer’) AND (‘experience’); and (‘carer’) AND (‘participation’). Reference lists of relevant articles were also searched for further relevant measures.

An Internet search for relevant grey literature was undertaken in the Google search engine using the search terms ‘carer satisfaction and services’, ‘carer survey’, ‘carer questionnaire’ and ‘carer experience’. The NICE and Cochrane Review databases were also searched using ‘carer’ as the search term. Measures were excluded from further review if they were targeted primarily at carer wellbeing and included only one question on carers' experience of services, or if questions relating to carers' experiences of services were very general (i.e. were not targeted at specific domains of service provision).

Evaluation of identified instruments

Stage one: Assessing criteria 1 to 6

Following the literature search, we then used a hierarchical criterion-based approach to assess whether given instruments might be candidates for measuring carers' experience of service provision in Australian public and private sector mental health services. The criteria were as follows:

1. measures domains directly related to a carer’s experiences of service provision
2. is completed by a carer
3. is brief and easy to use (≤ 100 items)
4. yields quantitative data (but would not exclude instruments that *also* capture qualitative data)
5. is applicable to the Australian context, relating to the *Fourth National Mental Health Plan* Priority Area 1, incorporating the recovery orientation of service provision and social inclusion, and aligns to key domains in Standard 7 (Carers) of the *National Standards for Mental Health Services 2010*[3], principally Access and Engagement, Carer Identification, Involvement in Treatment, and Planning for Ongoing Care (see Text Box 1 for specific criteria).
6. has undergone appropriate processes of development and piloting, including a process demonstrating that the measure is acceptable to carers; and, ideally, that the measure has been scientifically scrutinised.

The criteria were used in a hierarchical fashion to exclude instruments: any instrument excluded on the basis of one of the early criteria was not assessed against any subsequent criteria.

Stage 2. Assessing criteria 7

Those instruments that met the first six criteria were then used as the basis for further literature searching to identify the psychometric properties of that measure in order to assess the measure’s performance against criterion 7:

7. demonstrates sound psychometric properties (e.g., of internal consistency, validity, reliability and sensitivity to change).

The names of these measures were included as search terms in Medline and PsycInfo and as search terms in a grey literature search using the Google search engine. Analysis of the psychometric properties of each measure considered the validity, reliability, sensitivity to change and feasibility/utility of the instrument (see definitions in Table 1).

Table 1: Psychometric properties examined in critical appraisal of candidate instruments

Source: Dare, Hardy, Burgess, Coombs, Williamson, Pirkis (2008)[9].

PSYCHOMETRIC PROPERTY	**DEFINITION**
Validity	Refers to the extent to which the instrument measures what it intends to measure
• Content validity	Refers to the instrument's comprehensiveness (i.e., how adequately the sampling of items reflects its aims)
• Construct validity	Involves conceptually defining the construct to be measured by the instrument and assessing the internal structure of its components and the theoretical relationship of its item and subscale scores
• Criterion validity	Assesses the extent to which the instrument correlates with a 'gold standard' or more established measure of the same theme and can be split into content validity and predictive validity
• Concurrent validity	Pits the instrument against a comparable measure or measures at the same point in time
• Predictive validity	Assesses the instrument's ability to predict a future outcome, such as resource use or treatment response
Reliability	Can be viewed as the extent to which a given instrument gives stable, consistent results, or can be considered as the inverse of the degree of error obtained from any measurement
• Test-retest reliability	Defined as the degree of agreement when the same instrument is completed by the same individual (or administered to the same individual by the same interviewer) at two different points in time
• Inter-rater reliability	Defined as the degree of agreement when the same instrument is administered to the same individual by different interviewers at the same point in time
Sensitivity to change	Related to both validity and reliability – an instrument that is both valid and reliable, and which demonstrates change over time, can be regarded as being sensitive to change
Feasibility and utility	Related to concepts such as ease of administration, acceptability to stakeholders etc.

Chapter 3: Overview of identified instruments

Table 2 provides a brief description of the measures identified by the literature review.

Table 2: Overview of identified instruments

INSTRUMENT	DATE	COUNTRY	DESCRIPTION
Mental Health Carers' Survey[11] (MHCS)	2010	Australia	The Mental Health Carers' Survey was developed by the Mental Health Council of Australia as part of an ongoing commitment to assess whether the lives of carers of people with a mental illness 'are improving, the extent of that improvement, as well as the quality and availability of services available to assist them and the person they care for'[11] (p.13). The domains measured relate to those identified in *Adversity to Advocacy*[5] and to issues raised by carers in workshops held to hear their concerns. The questionnaire consists of 50 questions, some of which comprise a number of items such that carers may provide responses on up to 113 items. The 15 carer concerns addressed by the survey are the following: *listen to and respect carers; integrated recovery-based care for the consumer; more and better trained staff at all levels; knowledge and information for carers; carer and consumer education for all professional groups and agencies; support systems, services and processes established for carers; acute care to be therapeutic and accessible; stigma, discrimination and isolation for carers and consumers; accommodation options for consumers at all levels of care; financial costs to carers; physical and mental health of carers; flexible respite options for carers; privacy and confidentiality issues; early intervention at each episode of care; and employment options for carers.*
The Personal Social Services Survey of Adult Carers in England 2009-2010[12] (PSSS-Adult Carers)	2009-2010	England	The Personal Social Services Survey of Adult Carers in England 2009-2010 was developed to provide information to English Councils with Adult Social Services Responsibilities on their progress towards the goals set out in the Government's Carer Strategy. The survey consists of 58 self-report questions assessing the impact of caring on the carer's quality of life and their experiences of using social services. Domains assessed in this regard include *information and advice quality, service quality,* and *experiences of health services as a carer*— assessed using nine questions. Response options vary per question but are generally responded to on a scale such as 'very easy' to 'very difficult', or 'never' to 'always'.

INSTRUMENT	**DATE**	**COUNTRY**	**DESCRIPTION**
Carer Well-being and Support Questionnaire [13] (CWS)	2009	United Kingdom	The Carer Wellbeing and Support Questionnaire (CWS) is a 49-item questionnaire (plus 14 items collecting background information) developed to assess outcomes for carers of people with a mental illness or with dementia. The CWS is the result of the redevelopment of the earlier Carers' and Users' Expectations of Services – Carer survey (CUES-C)[14]. The CWS consists of two scales: *Carer Support* and *Carer Well-being*, the former factor being the most relevant to this review. Measured by the *Support* scale are five domains: *information and advice for carers, involvement in treatment and care planning, support from medical and/or care staff, support from other carers,* and *taking a break (respite).* The *Support* scale is made up of 17 items. The redevelopment of the CUES-C involved testing of the questionnaire items for acceptability with carers. The support scale of the CWS is currently being used as the measure for the UK National Audit of Schizophrenia 2011[15].
Consumer and Carer Experience Questionnaires[16] (C&CEQ)	2008	Australia	The Consumer and Carer Experiences Questionnaires were developed for the Department of Human Services, Victoria in order to seek consumer and carer perspectives of service quality regarding Victorian public mental health services. Different versions of the questionnaires have been adapted for Child and Adolescent, Adult, and Aged Persons Mental Health Services and for Psychiatric Disability Rehabilitation and Support Services. Survey questions require Yes/No/Not Sure responses. The survey questions 'reflect consumer and carer identified priorities, needs and expectations of services, and are linked to the *National Standards for Mental Health 2010* to provide specific guidance for quality improvement and meaningful benchmarks for consumers, carers and service providers.'[17] Depending on their circumstances, carers may complete up to 56 items. Questions cover topics such as time taken to access services, whether service providers listened to and respected carers, support and information provided for carers, and involvement in discharge planning.

INSTRUMENT	**DATE**	**COUNTRY**	**DESCRIPTION**
Carer Participation Survey[18](CPS)	2008	Australia	The Carer Participation Survey was developed as part of a study to determine if the introduction of practice standards into a district mental health service had an effect on the level and quality of carer participation. The survey consists of eight statements rated on a Likert scale from 1 'strongly disagree' to 10 'strongly disagree'. The eight items relate directly to aspects of the practice standards, including mental health workers' consultation with carers, provision of information to carers, and whether carer involvement enhanced care and treatment.
Questionnaire for carers of people who use social services (Wales)[18] (QPSS-Wales)	2008 (?)	Wales	The Social Services Inspectorate for Wales and the Audit Commission in Wales regularly conduct audits of social services, including mental health services. The carers' survey developed for this purpose comprises 32 self-report questions (including demographics and free text comments) assessing seven aspects of service provision: access to services, assessment, care management and review, range of services provided, quality of services provided, arrangements to protect vulnerable people, and success in promoting independence and social inclusion. Questions about services are answered on a four-point Likert scale from 'strongly agree' to 'strong disagree'.
Carer survey of Victorian Public Mental Health Services 2003-04[20]. (VPMHS)	2003	Australia	In 2003/2004, the Victorian Department of Human Services conducted an audit of consumer and carer experiences of Victorian public Adult Mental Health Services and Victorian Child and Adolescent Mental Health Services. Carers completed self-report questionnaires comprising up to 72 items. The survey measured seven indicators of service quality relating to the carer experience of service provision: *getting help to carers when needed*, *enabling carers to get help, provision of information when needed, helping carers understand general information about the service*, *providing treatment information when needed*, *ensuring carers understand treatment,* and *helping carers to meet their needs.* Carers use a five-point Likert scale (poor to excellent) to answer most questions. The domains measured were identified through consultation with consumers and carers and the questions were linked to the *National Standards for Mental*

			Health Services 1997 —current at that time.

INSTRUMENT	**DATE**	**COUNTRY**	**DESCRIPTION**
Verona Service Satisfaction Scale – European Version[21]	2000	England	The Verona Satisfaction with Services Scale – European version is translated from the original Italian version and is designed to measure user satisfaction with mental health services for people with schizophrenia. The scale consists of 54 self-report items assessing *overall satisfaction, professional skills and behaviour, information, access, efficacy, types of intervention,* and *relative's involvement* – measuring satisfaction with help given to their closest relative (five items).
Experience of Caregiving Inventory[22] (ECI)	1996	Australia	The Experience of Caregiving Inventory (ECI) is an 87-item self-report scale developed from a 'stress-coping framework' rather than from a perspective of the 'burden of care'. The ECI is based on ten scales relating to carers' experiences of care: *difficult behaviours, negative symptoms, stigma, problems with services, effects on family, need to backup, dependency, loss, positive personal experiences and aspects of relationships*. The *problems with services* scale is the only scale relevant to this current review. Themes for inclusion in the inventory were developed from interviews with 120 relatives of people with a mental illness.
Carers' Assessment of Difficulty Index [23] (CADI)	1989	England	The Carers' Assessment of Difficulty Index measures a number of dimensions of carer burden: *social life, economic situation, relationship with the dependant and wider family, professional and family support, dependency factors* and *the carer's reaction to the demands of caregiving.* Of the 30 items included in the scale, just two items relate to professional support. Items are rated on the scale 1 'never applies', 2 'sometimes applies', or 3 'always applies'.

Chapter 4: Comparison of measures against the review criteria

Criterion 1: The measure measures domains directly related to a carer's experience of service provision

Two measures were excluded when compared to criterion 1.

The Experience of Caregiving Inventory[22] (ECI) asks carers to rate, 'During the past month how often have you thought about …' (the items that follow) on a scale of 0-never to 4-nearly always. The items relating to service provision include statements such as 'how to deal with mental health professionals' (item 26) and 'the difficulty getting information about his illness' (item 52). While these items relate to carers' thoughts or concerns about certain aspects of service provision, they do not specifically relate to the carer's *experience* of services that have been provided. For this reason, the items relating to service provision on the ECI were considered too broad to meet Criterion 1, and the ECI was excluded from further analysis.

The Carers' Assessment of Difficulty Index[23] (CADI) was also excluded from further analysis based on comparison with Criterion 1. The CADI contains just two general statements related to service provision: 'Professional workers don't seem to appreciate problems carers face' (item 7) and 'I don't get enough from the Health and Social Services' (item 27), for which carers then rate how much the statements apply to them (Never applies/Sometimes applies/Always applies). The inclusion of just these two items and the generality of these statements meant that the CADI was not considered to measure domains directly related to a carers' experience of service provision and was excluded from further review.

Exclusion of the CADI and the ECI left eight remaining measures to be compared with Criterion 2.

Criterion 2: The measure is completed by a carer

Seven of the eight remaining measures met Criterion 2, with responses being self-reported by the carer. The Verona Service Satisfaction Scale – European version[21] is completed by the consumer, who rates their satisfaction with support provided to their carer from mental health services. Therefore, this measure does not meet criterion 2 and was excluded from analysis against further criteria, leaving seven measures for further review.

Criterion 3: The measure is brief and easy to use (≤100 items)

The Mental Health Carers' Survey[11] (MHCS) was excluded from further analysis based on comparison with Criterion 13. While the MHCS has 50 primary questions (including demographic questions), a number of questions require the carer to respond to a number of sub-items. For example, question 20 of the survey asks the carer to rate 'how well do you think carer and consumer issues are understood by the following professionals (tick all that apply)'. The question is followed by a list of 19 different professionals, meaning that, depending on the number of listed professionals the carer has encountered, they may then have to respond to up to 19 additional sub-items. Including these sub-items, the MHCS consists of a possible 118 items that would need to be completed by the carer. Therefore, the MHCS was seen to exceed the brevity criteria of 100 or less items and was excluded from further review.

After comparison with criterion 3, six measures were retained for comparison with further criteria.

Criterion 4: The measure yields quantitative data (but would not exclude instruments that *also* capture qualitative data)

The six remaining measures each yield predominantly quantitative data, with some including additional qualitative questions, and were retained for comparison with criterion 5.

Criterion 5: The measure is applicable to the Australian context, relating to the *Fourth National Mental Health Plan* Priority Area 1, incorporating the recovery orientation of service provision and social inclusion, and aligns to key domains in Standard 7 (Carers) of the *National Standards for Mental Health Services 2010*[3], principally Access and Engagement, Identification of Carers, Involvement in Treatment, and Planning for Ongoing Care.

Table 3 shows the comparison of items from the remaining six measures with the seven chosen criteria from Standard 7 of the *National Standards for Mental Health Services 2010*. The items from each measure that matched the Standard 7 criteria are shown in full in Appendix 2, with only the item number included in Table 3. A cut-off score for comparison with the Standard 7 criteria was set at five out of the seven criteria. Any measure that did not contain items measuring at least five of the seven Standard 7 criteria was excluded from further review. Table 2 shows that just two of the remaining measures met this criterion and were retained for comparison with criterion 6.

The two remaining measures after comparison with Criterion 5 were the Consumer and Carer Experience Questionnaires (C&CEQ), and the Carer Survey of Victorian Public Mental Health Services (VPMHS).

Table 3. Items from identified measures relating to the seven chosen criteria from Standard 7 of the *National Standards for Mental Health Services 2010.*

	C&CEQ– (Adult)	PSSS (Adult)	CWS	CPS	QPSS (Wales)	VPMHS (Adult)
Access and Engagement						
7.2 The MHS implements and maintains ongoing engagement with carers as partners in the delivery of care as soon as possible in all episodes of care.	5b * 5p 4f	43	B10 B16	1 6	11	7d 7e 7f
7.4 The MHS provides carers with a written statement, together with a verbal explanation of their rights and responsibilities in a way that is understandable to them as soon as possible after the consumer engages with the MHS, particularly at first admission.	4e 5t 7j	-	-	-	-	4b 4c 4d 4h 4i 4j
7.5 The MHS considers the needs of carers in relation to Aboriginal and Torres Strait Islander persons, culturally and linguistically diverse (CALD) persons, religious / spiritual beliefs, gender, sexual orientation, physical and intellectual disability, age profile and socio-economic status.	7i 7n	-	-	-	21 22	4e 4f 5g 5h 5i 5j 5k
Involvement in Treatment						
7.9 The MHS provides carers with non-personal information about the consumer's mental health condition, treatment, ongoing care and if applicable, rehabilitation.	4d 5c	-	B1	3		6a 6b 6c 6e 6f 6g 6h
7.10 The MHS actively seeks information from carers in relation to the consumer's condition during assessment, treatment and ongoing care and records that information in the consumer's health record.	4b 5d	37	B9	2	-	7b 7c 7h

Carer Identification						
7.11 The MHS actively encourages routine identification of carers in the development of relapse prevention plans.	-	-	-	-	-	-
Planning for ongoing care						
7.12 The MHS engages carers in discharge planning involving crisis management and continuing care prior to discharge from all episodes of care.	5i 5l	-	B2		-	7j 7k
TOTAL NUMBER OF CRITERIA MET (from a possible 7)	**6**	**2**	**4**	**3**	**2**	**6**

*The complete items can be found in Appendix 2.

Criterion 6: The measure has undergone appropriate processes of development and piloting, including a process that demonstrates the measure is acceptable to carers; and the measures has ideally been scientifically scrutinised.

The two measures remaining after comparison with Criterion 5 were the Carer version of the Consumer and Carer Experience Questionnaires (C&CEQ) and the Carer Survey of Victorian Public Mental Health Services (VPMHS). It is worth noting at this point that both of these measures were developed in conjunction with the Victorian Department of Human services, and that the C&CEQ, tested in 2008, was developed in response to a review[24] of the earlier VPMHS Survey. While the C&CEQ essentially supersedes the VPMHS Survey, these two measures have been reviewed independently as, should the results of this review reveal that a new measure is needed for use as an Australian standard measure of carer experiences of care, the relative strengths and weaknesses of each of the surveys have the potential to inform the development of a new measure.

The development, piloting and review processes undertaken for each of these two measures are outlined below.

The 2003-04 Victorian Surveys of Consumer and Carer Experiences of Public Mental Health Services (VPMHS)

Survey development

The development of the 2003-04 Victorian Surveys of Consumer and Carer Experiences of Public Mental Health Services illustrated a significant shift away from the measurement of carer 'satisfaction' with services to the measurement of 'perspectives of service quality'[24] that had occurred in early surveys. This shift to measurement of perspectives of service quality is maintained as the preferred approach in this review.

To inform survey development, the survey developers—Taylor, Nelson and Sofres—used information gained from an international and national literature review of approaches to consumer and carer evaluation to identify current approaches to the measurement of consumer and carer perspectives of service quality[24]. The literature review highlighted the importance of involving consumers and carers in the survey development process. Consequently, consumers, carers and service providers were involved in the development and testing of the 2003-04 VPMHS Surveys through a series of networks, focus groups, interviews and pilot studies.

Piloting

Following development of the surveys, the various forms were distributed across Victoria through Child and Adolescent, Adult, and Aged Persons Mental Health Services, using the various forms. During and following the Survey implementation period, information was gathered from service managers, staff, consumers and carers regarding the strengths and weaknesses of both the Surveys themselves and the implementation process[24].

Review of the Surveys

The review of the Surveys conducted throughout and following their implementation[24] led to the following recommendation:

> The existing questionnaires need to be revised in light of suggestions to simplify the language, improve the format, reduce the length and amend the rating scale before they are used again. Amendments need to be validated by interviews with consumers and carers from each target group prior to implementation[24] (p.30).

The review also recommended substantial changes to the way that the survey was to be implemented, stating that the survey tool should be largely administered through interviews or focus groups conducted by telephone or face-to-face[24] (p.30), with written questionnaires only being provided to consumers and carers upon request or being distributed directly by service staff. This is in significant contrast to the mail-out-mail-back methodology largely employed for the 2003-04 surveys. This recommendation was made in reaction to low response rates (with carers' average response rate of less than 20 per cent), and the view that the written questionnaire format did not encourage diversity of respondents.

Comparison of the VPMHS Surveys against Criterion 6

In summary, the development process of the VPMHS Surveys of 2003-04 used an inclusive approach, consulting consumers, carers and service providers, as well as international and national literature to develop a survey tool that was relevant and that aimed to directly measure domains of service related to the *National Standards for Mental Health (1997),* current at that time. It could, therefore, be considered that the surveys had undergone a suitable development and piloting process.

Despite this approach, however, the review of the survey tool and implementation process[24] highlighted significant weaknesses that needed to be overcome in future iterations of the survey tool and its implementation. The noted problems with the survey tool—the survey length, language, rating scale and appearance—combined with the low response rate (less than 20 per cent for carers) seem to indicate that this survey was not acceptable to carers, nor to consumer respondents and service providers. The VPMHS Surveys were therefore excluded at this point in the review on the grounds that the substantial problems with the survey format meant that it was not acceptable to carers.

Consumer and Carer Experiences Questionnaires (C&CEQ)

Development

The Consumer and Carer Experience Questionnaires (2008)[16] represent a redevelopment of the earlier VPMHS (2003-04) Surveys. The redevelopment of the 2003-04 surveys aimed to develop both a survey tool and data collection methodology that overcame the concerns raised in the review discussed in the preceding section[24].

The redevelopment involved consumer and carer groups in the development phase. Consumer and carers were consulted in state-wide discussion groups regarding the themes that they thought most important to capture in the surveys and regarding those methodologies that could best capture the experiences of consumers and carers[25].

This consultation process and further testing resulted in significant changes to the both the questionnaires themselves, compared with the 2003-04 surveys, and to the data collection methods used to collect the information asked for by the survey questions. Rather than the mail-out-mail-back methodology used with the VPMHS Surveys, the C&CEQ used Computer Assisted Telephone Interviewing (CATI) as the primary survey methodology. Written questionnaires were supplied only upon request from participants and accounted for just 10 per cent of survey responses[25]. In order to achieve the overarching aim of assessing consumers' and carers' experiences of care, the CATI survey methodology was also used in conjunction with individual interviews and focus groups with consumers and carers, and focus groups involving service staff[26].

Piloting

The Wallis Consulting Group[16] undertook a pilot implementation of the newly developed C&CEQ using the CATI methodology. The one service that opted to use paper-based surveys eventually defaulted to the CATI methodology due to the small number of responses gained through the paper-based method[16]. A total of 526 carers completed the Child and Adolescent, Adult and Aged Persons versions of the Questionnaires.

Review

A review of the pilot implementation process led the Wallis Consulting Group to conclude that the CATI methodology was the more efficient and more cost-effective approach to data collection (over the paper method) and should therefore be adopted for future data collection[16].

The researchers also undertook a series of practical and statistical tests to determine the suitability of some of the survey questions as psychometric scales. First, researchers observed interviewers administering the CATI's and discussed with them the practicability of the questions used. This process identified those questions that were applicable only to a minority of respondents and those that respondents often found difficult to answer. This resulted in some recommendations for removal of certain items.

The researchers then undertook some psychometric testing. The items that were involved in this testing were those included as questions 4 and 5 of the carer surveys (Appendix 1), as the remaining items request demographic and 'factual' information rather than questions based on carer perceptions. Results from this testing led to the exclusion of some further survey items, and the resulting, shorter, surveys were then re-tested with a group of carers.

Summary

The consultative approach to survey development, involving carers, consumers and service users at various points in the survey development process, combined with the piloting of the resulting surveys with a relatively large sample of carers (526) suggest that the C&CEQ have undergone a suitable development and piloting process. Psychometric and practical testing of the surveys led to the exclusion of some of the original survey items by the researchers, and the resulting surveys were then re-tested with a small group of carers. These processes would imply that the surveys have been scientifically scrutinised and have demonstrated acceptability to carers. Therefore, the C&CEQ was the only measure retained for comparison with the final criterion.

Criterion 7: The measure demonstrates sound psychometric properties (e.g., of internal consistency, validity, reliability and sensitivity to change.

The original Consumer and Carer Experiences Surveys (Appendix 1) were revised by the Wallis Consulting Group[16] based on a series of practical and statistical tests used to exclude items that were not suitable for inclusion in a psychometric scale. Data for these psychometric tests was gained from pilot testing of the surveys (using CATI methodology) with the following:

- 187 carers from adult mental health services
- 93 carers from aged persons mental health services
- 246 carers from child and adolescent mental health services.

Researchers initially conducted a skewness analysis (using Kendall's tau-b) and an examination of inter-correlations which resulted in the exclusion of a number of questions from the original questionnaires due to a skewed distribution, lack of validity or because they did not correlate with other variables[25].

The remaining items were then included in the questionnaires (scales) that underwent preliminary factor analysis and categorical principal components analysis. The results of these analyses showed that the included questions were all measuring just one main factor, which the author cited as 'the effectiveness of interpersonal care'[16] (p.18).

All the surveys were then tested again with their relevant respondent groups and the distribution of responses examined (ie., how often respondents answered yes or no to a question). From these tests, the authors concluded that all of the resulting carer measures could be considered useful scales for the intended purpose.

It is also of note that the researchers concluded that the similarities between the child and adolescent, adult and aged persons versions of the surveys would likely allow these forms to be combined into one standard form. This single form would then require further psychometric testing.

The Wallis Consulting Group Report[16] does not include the exact results of the statistical tests conducted throughout the testing process; rather, it primarily discusses the conclusions of this testing with some references to how these conclusions were reached. Therefore, the veracity of these conclusions cannot be assessed. However, based on the conclusions discussed in the report, the psychometric tests undertaken on the surveys are summarised in Table 4.

Table 4: Outcomes of psychometric testing of the Consumer and Carer Experiences Questionnaires

PSYCHOMETRIC PROPERTY TESTED	OUTCOME
Validity	Comparison with the Standard 7 criteria of the *National Standards for Mental Health Services 2010*, discussed under comparison with criterion 5 in this review, shows that the surveys contain a number of items that assess six of the seven Standard 7 criteria. Further, the surveys were developed in conjunction with carers, who assisted in determining those themes that it was important to assess. Both of these points suggest good content validity. Wallis Consulting excluded items that did not correlate with others and conducted both principle components analysis and categorical principal components analysis on the resulting scales. They reported that the items loaded onto one single main factor (factor loading of 0.5 or greater), which they characterised as 'the effectiveness of interpersonal care'. These tests indicate good internal consistency and construct validity of the revised scales (with items excluded).
Reliability	The test-retest and inter-rater reliability of the scales were not tested. The latter would be particularly important if the scales were administered via CATI or any other type of interview where the administrator may directly affect the result.
Sensitivity to change	Sensitivity to change was not determined; however, the scales were tested to determine the distribution of responses (ie., that participants provide a range of responses and not just predominantly 'yes' to most items or 'no/not sure' to most items). Remaining items show an acceptable range of responses.

Summary

Testing on the surveys with excluded items removed shows good content and construct validity, and internal consistency. However, the resulting scales would require re-testing with a group of carers who had not previously completed the original surveys. Furthermore, reliability of this instrument remains to be determined.

Chapter 5: Discussion

This review aimed to identify a measure or measures designed to assess mental health carers' experiences of service provision that may be used, or adapted for use, as a standard measure across Australian public and private mental health services. Such a measure would allow monitoring of carer involvement in service delivery, strengthen accountability and support quality improvement and change in clinical practice. In particular, a standard measure of carers' experiences of service provision would allow monitoring of service progress against the benchmarks set by the *National Standards for Mental Health Services 2010*[3] Standard 7, which stipulates a number of criteria for the immediate and ongoing involvement of the carer as a partner in all episodes of consumer care.

Initially, a literature review was conducted of both the international literature and grey literature to identify existing measures of carers' experiences of services provided to the consumer for whom they provide care. This review identified ten measures from the United Kingdom and Australia that either contained questions assessing carers' experiences of care within a larger measure, or that were designed purely to assess carers' experiences. Table 5 provides a brief summary of characteristics of the ten measures included in this review.

The ten measures were then reviewed against seven primary criteria assessing the measure's relevance, ease of use, acceptability to carers, the legitimacy of its development process, and the measure's psychometric properties. The measures were also reviewed against seven criteria from Standard 7 of the *National Standards for Mental Health Services 2010*. The Standard 7 criteria operationalise service benchmarks for the inclusion of the carer as a partner in all episodes of mental health care provided to the consumer for whom they provide care. Measures were assessed to determine whether they provided a measure of these important service benchmarks. Table 6 shows the process of exclusion of measures for each of the seven criteria.

Identification of a single measure

Comparison against the six criteria set for this review identified just one measure that remained as a possible candidate for use as a standard Australian measure of the carer's experience of care. This measure—the Consumer and Carer Experiences Questionnaires

(Carer versions; C&CEQ)—was developed in conjunction with the Victorian Department of Human Services specifically for the purpose of measuring aspects of the carer’s experience of care against Standard 7 criteria, providing it with great relevance to the current purpose.

The C&CEQ has four alternative forms designed for carers involved in Child and Adolescent, Adult, and Aged Persons Mental Health Services, as well as with Psychiatric Disability Rehabilitation Support Services; the latter of which was outside the scope of this review. The primary mode of implementation for the C&CEQ was Computer Assisted Telephone Interviews (CATI).

A review of the C&CEQ was conducted throughout and following its initial implementation. The review assessed both the ease of implementation of the measure and some of its psychometric properties. The results of this review led to the conclusion that exclusion of some of the original items from the questionnaires would improve its acceptability to carers and some of its psychometric properties, and that overall, the resulting scales would be acceptable both from a carer perspective and from a psychometric perspective.

Furthermore, the authors of the review suggested that the similarities between the Child and Adolescent, Adult and Aged Persons versions of the Questionnaires would allow the creation of a single measure across all three service types; although this single form would require further testing.

This review therefore concludes that, of the ten measures identified through the initial literature review, the revised version of the C&CEQ, (which excludes some of the original items) is the most suitable measure identified for use as a basis for the development of a standard measure for assessing carers’ experience of service provision across Australia.

Table 5: Summary of key features of candidate instruments designed to assess carer experiences of care

INSTRUMENT	DATE	COUNTRY	VERSIONS	AREAS OF ASSESSMENT	NO. OF ITEMS	RESPONSE FORMAT	ADMINISTRATION
Mental Health Carers' Survey	2010	Australia	-	Listen to and respect carers, integrated recovery-based care, staff, knowledge and information, education, support, acute care, stigma, discrimination and isolation, accommodation, financial costs, health of carers, respite, privacy and confidentiality, early intervention, employment.	118	3, 4 and 5-point Likert scales	Carer self-report
Personal Social Services Survey of Adult Carers in England 2009-2010	2009-2010	England	-	Information and advice quality, service quality, experiences of health services as a carer	58	3, 4 and 5-point Likert scales	Carer self-report
Carer Well-being and Support Questionnaire	2009	United Kingdom	-	Information and advice for carers, involvement in treatment and care planning, support for medical and/or care staff, support from other carers, taking a break (respite).	49	4 and 5-point Likert scales	Carer self-report
Consumer and Carer Experiences Questionnaires	2008	Australia (Victoria)	CAMHS, Adult, Aged, PDRSS	Access to services, carers listened to and respected, carer involvement in treatment and planning, support and information.	Up to 56	Yes/No/Not sure	Computer-Assisted Telephone Interview (written form available upon request)
Carer Participation Survey	2008	Australia	-	Consultation with carers, information provision, carer involvement.	8	10-point Likert scale	Carer self-report

Questionnaires for carers of people who use social services	2008	Wales	-	Access to services, assessment, care management and review, range and quality of services, protecting vulnerable people, promoting independence and social inclusion.	32	4-point Likert scale	Carer self-report
Carer survey of Victorian Public Mental Health Services	2003-2004	Australia (Victoria)	Adult, CAMHS, Aged persons, PDRSS	Carer help, information provision, involvement of carers in treatment, carer support.	Up to 72 items	5-point Likert scale	Carer self-report or assisted by a professional
Verona service satisfaction scale – European version	2000	England	-	Overall satisfaction, professional skills and behaviour, access, information, efficacy, types of intervention, relative's involvement.	54	5-point Likert scale	Consumer self-report
Experience of Caregiving Inventory	1996	Australia	-	Difficult behaviours, negative symptoms, stigma, problems with services, effects on family, need to backup, dependency, loss, positive personal experiences and aspects of relationship.	87	5-point Likert scale	Self-report
Carers' Assessment of Difficulty Index	1989	England	-	Social life, economic situation, relationship with the dependent and wider family, professional and family support, dependency factors and the carer's reaction to the demands of caregiving.	30	3-point Likert scale	Self-report

Table 6: Summary of instruments excluded at each review criterion.

Criteria	Measure excluded	Reason for exclusion
1. measures domains directly related to a carer's experiences of service provision	Experience of Caregiving Inventory Carers Assessment of Difficulty Index	Does not directly measure experiences of service provision. Contains just two general items relating to experience of service provision
2. is completed by a carer	Verona Service Satisfaction Scale – European Version	Consumer survey asking about satisfaction regarding services' treatment of the carer
3. is brief and easy to use (≤ 100 items)	Mental Health Carers' Survey	Required completion of up to 118 items
4. yields quantitative data	No measures excluded	All yielded quantitative data
5. is applicable to the Australian context, relating to the Fourth National Mental Health Plan Priority Area 1, and aligns to key domains in Standard 7 (Carers) of the National Standards for Mental Health Services 2010	Carer Well-being and Support Survey. Personal Social Services Survey of Adult Carers in England Carer Participation Survey Questionnaire for People who use Social Services Survey (Wales)	Meets 4 of 7 Standard 7 criteria Meets 2 of 7 Standard 7 criteria Meets 3 of 7 Standard 7 criteria Meets 2 of 7 Standard 7 criteria
6. undergone appropriate processes of development and piloting, is acceptable to carers and has been scientifically scrutinised	Carer Survey of the Victorian Public Mental Health Services (Adult, CAMHS and Aged Persons versions)	Survey format, length and language were not acceptable to carers.
7. demonstrates sound psychometric properties	Retained: Carer and Consumer Experiences Surveys (Carer versions for Adult, Child and Adolescent and Aged persons mental health services)	Requires further testing.

Conclusion

The outcomes of this review lead to the recommendation that the Consumer and Carer Experience Questionnaires—Carer version, with those items excluded as recommended by the Wallis Consulting Group[16], undergo further testing for development of a standardised measure for the measurement of carers' experiences of care provision across Australia. In order to create a measure specifically designed to assess services against the benchmarks set out in Standard 7 of the *National Standards for Mental Health Services 2010,* additional items that do not relate to these standards may also be removed. The re-developed scale would then require further psychometric testing to ensure its continued integrity. A potential instrument, including the relevant items, is presented in Appendix 3.

The demographic and 'factual' service questions that were included in the carer surveys will also require review to ensure they meet the current, and national, requirements. Any changes to these questions will require practical testing to ensure that they are understood by, and meaningful to carers.

Furthermore, following the recommendations of the review by the Wallis Consulting Group[16], the Child and Adolescent, Adult and Aged persons versions of the Carer Questionnaires should be developed into a single form for use as a standard measure. The resulting measure would require further testing across a sample of carers involved with the various service types to establish both acceptability to carers of the standardised measure, and its psychometric properties.

The Consumer and Carer Experiences Questionnaires have been developed specifically for use within Victorian Mental Health services and some re-development may also be required to ensure applicability to mental health services across Australia. This will require testing in sample across all states and territories.

The Wallis Consulting Group tested the Consumer and Carer Experiences Questionnaires using Computer Assisted Telephone Interviewing as its primary mode of implementation. If the re-developed C&CEQ is to be used primarily in written form, it will need to undergo testing as a primarily written measure. Furthermore, those implementing the revised measure should also consider the findings of the review of the 2003-04 Carer Surveys of

Victorian Mental Health Services that resulted in the change from written surveys to the CATI format; this change in methodology resulted from low response rates, limits on the diversity of carers who responded to the survey, and overall, a lower cost-effectiveness than the CATI method. The administration of any modified C&CEQ should be considered in any pilot or field testing, potentially incorporating carers who are trained, independent administrators.

Recommendations to MHISS

- Modifications to the Consumer and Carer Experience Questionnaires—Carer version, be undertaken so that it is suitable for use across age groups and States and Territories. See example instrument in Appendix 3.
- Pilot and field testing work should be undertaken with this modified measure.
- The approach to the administration of the measure should be an important consideration in any pilot testing. This would assist in gathering unbiased responses from the range of carers and reflect a true picture of a carer's experience within the mental health service.
- The pilot phase should be completed within 12 months.
- A jurisdiction, or any other suitable organisation, should be sought to undertake the pilot testing of the measure.

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Appendix 1: Measures

Copies of the measures have not been included here to ensure that there is adherence to copyright. For further information about the measures, please contact AMHOCN by email: contact@amhocn.org .

Appendix 2: Items from identified measures relating to the seven chosen criteria from Standard 7 of the National Standards for Mental Health Services 2010.

Domain 1: Access and Engagement

Criterion 7.2 The MHS implements and maintains ongoing engagement with carers as partners in the delivery of care as soon as possible in all episodes of care.

Consumer and Carer Experience Questionnaires – Adult

5b. Were you involved in treatment decisions affecting your family member/friend?

5p. Did staff check to see if you were confident and prepared to keep on caring for your family member/friend?

4f. Did staff explain how **you** could help your family member/friend during their treatment?

The Personal Social Services Survey of Adult Carers in England 2009-2010

43. Do you feel that you were involved as much as you wanted to be in discussions about the care and treatment of the person you care for, when you have been in contact with health professionals at a NHS hospital in the last 12 months?

Carer Well-being and Support Questionnaire

B10. In general how satisfied are you with…your ability to influence important decisions?

B16 I.n general how satisfied are you with…how seriously staff take what you say to them?

Carer Participation Survey

1. Mental health workers consulted me as they planned services and medication.

6. I was satisfied with the level of involvement of family/carers during this admission/period.

Questionnaire for Carers of People who use Social Services (Wales)

11. I have been involved in deciding what help or services the person I support/care for should receive.

Carer Surveys of Victorian Mental Health Services -Adult

How good was the service at...

7d. Providing opportunities for you to discuss the person's illness if the person consents or permitted by law?

7e. Providing opportunities for you to discuss the person's medication if the person consents or permitted by law?

7f. Providing opportunities for you to discuss the person's other treatment (not medication) if the person consents or permitted by law?

Criterion 7.4 The MHS provides carers with a written statement, together with a verbal explanation of their rights and responsibilities in a way that is understandable to them as soon as possible after the consumer engages with the MHS, particularly at first admission.

Consumer and Carer Experience Questionnaires – Adult

4e. Did staff explain to you want to expect from the adult mental health service?

5t. Were you told of any legal issues that might affect you as a carer (e.g guardianship, power of attorney etc)?

7j. Did staff explain how to make a complaint about the adult mental health service?

Carer Well-being and Support Questionnaire

B4. In general how satisfied are you with…how easy it is to understand the information you have?

Carer Surveys of Victorian Mental Health Services - Adult

How good was the service at letting YOU know . . .

4b.What they expect from you and the person you care for

4c. Your right and the person's right to privacy

4d. Your right and the person's right to confidentiality

4h.Your right and the person's right to feel safe where you are seen by the service

4i.How to comment or complain about the service

4j. How to participate in overall service planning, improvement and review

Criterion 7.5 The MHS considers the needs of carers in relation to Aboriginal and Torres Strait Islander persons, culturally and linguistically diverse (CALD) persons, religious / spiritual beliefs, gender, sexual orientation, physical and intellectual disability, age profile and socio-economic status

Consumer and Carer Experience Questionnaires – Adult

7i. Did staff respect your cultural beliefs?

7n. Were you offered an interpreter?

Questionnaire for carers of people who use social services (Wales)

21. I feel that social services understand important matters about racial or cultural background.

22. I have been able to use the language of my choice when dealing with social services.

Carer Surveys of Victorian Mental Health Services -Adult

How good was the service at letting YOU know ...

4e.Your right and the person's right to speak to someone in your preferred language?

4f. Your right and the person's right to written information in your preferred language?

4g.That either of you can speak to a male or female staff member if preferred?

How good was the service at…

5h.Providing you with written information in your preferred language?

5i.Arranging an interpreter for you when needed?

5j.Respecting your cultural beliefs and practices?

5k. Arranging for you to see a male or female staff member if asked for?

Domain 2: Involvement in treatment

Criterion 7.9 The MHS provides carers with non-personal information about the consumer's mental health condition, treatment, ongoing care and if applicable, rehabilitation.

Consumer and Carer Experience Questionnaires – Adult

4d. Did staff explain to you what was happening to your family member/friend?

5c. Were you informed about the progress of your family member/friend?

Carer Well-being and Support Survey

B1. In general how satisfied are you with…that you have enough information about the condition/illness of the person you care for to enable you to feel confident caring for them?

Carer Participation Survey

3. Mental health workers gave detailed information about the illness to me.

Carer Surveys of Victorian Mental Health Services - Adult

How good was the service at ***…***

6a. Providing you with information about mental illness or problems?

6b. Providing you with information about the range of treatments available for mental illness or problems?

6c. Providing you with information about other services and supports that may help the person you care for?

6e. Providing you with information about the Mental Health Act (including Community Treatment Orders and the Mental Health Review Board)?

6f. Providing you with information about the assessment process?

6g. Providing you with information about the treatment planning and review process?

6h. Providing you with information about the discharge process?

7.10 The MHS actively seeks information from carers in relation to the consumer's condition during assessment, treatment and ongoing care and records that information in the consumer's health record

Consumer and Carer Experience Questionnaires – Adult

4b. Did staff take time to listen to your opinion as a carer about what was happening?

5d. Did staff ask for your opinion about the progress of your family member/friend?

Carer Surveys of Victorian Mental Health Services - Adult

How good was the service at…

7b. Asking you what might help the person you care for from your experience and knowledge of them?

7c.Respecting your opinion of what might help the person you care for?

7h. Involving you in treatment decisions if the person consents or permitted by law?

The Carer Well-being and Support Survey

B9 In general how satisfied are you with… your involvement in important decisions (e.g. medication, hospitalisations)?

Carer Participation Survey

2. Mental health workers were interested in what I could tell them.

The Personal Social Services Survey of Adult Carers in England 2009-2010

37. In the last 12 months, so you feel that you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for?

Domain 3: Carer Identification

Criterion 7.11 The MHS actively encourages routine identification of carers in the development of relapse prevention plans.

No relevant items.

Domain 4: Planning for ongoing care

Criterion 7.12 The MHS engages carers in discharge planning involving crisis management and continuing care prior to discharge from all episodes of care.

Consumer and Carer Experience Questionnaires – Adult

5i. Did you understand what had to happen before your family member/friend could be discharged from the adult mental health service?

5l. Did staff explain what to do if your family member/friend started to feel unwell again?

Carer Well-being and Support Survey

In general, how satisfied are you …

B2. that you have enough information about how their condition/illness is likely to develop in the longer-term?

B7. that you are clear about who to contact if there is an emergency and you need help right away?

Carer Surveys of Victorian Mental Health Services - Adult

How good was the service at …

7j. Helping you to recognise and manage early signs of deterioration in the person you care for?

7k. Helping you to prepare for when the person no longer uses the service?

Appendix 3: Potential carer experiences of service provision measure

	Australian Carers Experience of Service Provision	Yes	No	Not Sure
1	Were you involved in treatment decisions affecting your family member/friend	○	○	○
2	Did staff check to see if you were confident and prepared to keep on caring for your family member/friend?	○	○	○
3	Did staff explain how **you** could help your family member/friend during their treatment?	○	○	○
4	Did staff explain to you want to expect from the adult mental health service?	○	○	○
5	Were you told of any legal issues that might affect you as a carer (e.g guardianship, power of attorney etc)?	○	○	○
6	Did staff explain how to make a complaint about the adult mental health service?	○	○	○
7	Did staff respect your cultural beliefs?	○	○	○
8	Were you offered an interpreter?	○	○	○
9	Did staff explain to you what was happening to your family member/friend?	○	○	○
10	Were you informed about the progress of your family member/friend?	○	○	○
11	Did staff take time to listen to your opinion as a carer about what was happening?	○	○	○
12	Did staff ask for your opinion about the progress of your family member/friend?	○	○	○
13	Did you understand what had to happen before your family member/friend could be discharged from the adult mental health service?	○	○	○
14	Did staff explain what to do if your family member/friend started to feel unwell again?	○	○	○
15	Identification of carer in relapse prevention (to be developed)	○	○	○

Appendix B: CES and Standard 7 of the National Standards for Mental Health Services

Appendix B: CES and Standard 7: National Standards for Mental Health Services

	National Mental Health Standard	Questionnaire Items
Identification of carers	7.1 The MHS has clear policies and service delivery protocols to enable staff to effectively identify carers as soon as possible in all episodes of care, and this is recorded and prominently displayed within the consumer's health record.	9. You were identified as a carer of your family member, partner or friend
Partnerships	7.2 The MHS implements and maintains ongoing engagement with carers as partners in the delivery of care as soon as possible in all episodes of care.	1. You understood what you could expect from the mental health service for yourself and your family member, partner or friend 14. Staff worked in a way that supported your relationship with your family member, partner or friend
	7.3 In circumstances where a consumer refuses to nominate their carer(s), the MHS reviews this status at regular intervals during the episode of care in accordance with Commonwealth and state / territory jurisdictional and legislative requirements.	NA
Provision of Information	7.4 The MHS provides carers with a written statement, together with a verbal explanation of their rights and responsibilities in a way that is understandable to them as soon as possible after engaging with the MHS.	2. You were given an explanation of any legal issues that might affect your family member, partner or friend 3. You understood your rights and responsibilities 17. A brochure or other material about your rights and responsibilities 22. Information about taking a support person to meetings or hearings if you wished
Diversity of Carers	7.5 The MHS considers the needs of carers in relation to Aboriginal and Torres Strait Islander persons, culturally and linguistically diverse (CALD) persons, religious / spiritual beliefs, gender, sexual orientation, physical and intellectual disability, age profile and socio-economic status.	4. Your personal values, beliefs and circumstances were taken into consideration 5. You were able to obtain cultural or language support (such as an interpreter) when you needed

Age of Carers	7.6 The MHS considers the special needs of children and aged persons as carers and makes appropriate arrangements for their support.	NA
Confidentiality	7.7 The MHS has documented policies and procedures for clinical practice in accordance with Commonwealth, state / territory privacy legislation and guidelines that address the issue of sharing confidential information with carers.	NA
Consultation	7.8 The MHS ensures information regarding identified carers is accurately recorded in the consumer's health record and reviewed on a regular basis.	NA
	7.9 The MHS provides carers with non-personal information about the consumer's mental health condition, treatment, ongoing care and if applicable, rehabilitation.	10. You were given opportunities to discuss the care, treatment and recovery of your family member, partner or friend (even, if for reasons of confidentiality, you could not be told specific information)
	7.10 The MHS actively seeks information from carers in relation to the consumer's condition during assessment, treatment and ongoing care and records that information in the consumer's health record.	6. You were given the opportunity to provide relevant information about your family member, partner or friend 7. Your opinion as a carer was respected 8. You were involved in decisions affecting your family member, partner or friend 16. You had opportunities to communicate confidentially with the treating doctor if you needed (such as by phone, email or in person)
Exit information	7.11 The MHS actively encourages routine identification of carers in the development of relapse prevention plans.	
	7.12 The MHS engages carers in discharge planning involving crisis management and continuing care prior to discharge from all episodes of care.	11. You were involved in planning for the support, care, treatment and recovery of your family member, partner or friend 13. Staff conveyed hope for the recovery of your family member, partner or friend 15. You were given information about services and strategies available if your family member, partner or friend became unwell again

		21. A number you could call after hours for the service
	7.13 The MHS provides information about and facilitates access to services that maximise the wellbeing of carers.	12. You were given the opportunity to enhance your abilities as a carer 19. Information about carer support services (such as local groups, carer consultants, counsellors)
Participation	7.14 The MHS actively seeks participation of carers in the policy development, planning, delivery and evaluation of services to optimise outcomes for consumers.	18. An explanation of how to make a compliment or complaint about the mental health service 20. Information on opportunities to participate in improving this mental health service
Training	7.15 The MHS provides ongoing training and support to carers who participate in representational and advocacy roles.	NA
	7.16 The MHS provides training to staff to develop skills and competencies for working with carers.	NA
	7.17 The MHS has documented policies and procedures for working with carers.	NA
Outcomes of Experience		23. Your relationship with the person for whom you care 24. Your hopefulness for your future 25. Your overall wellbeing 26. Overall, how would you rate your experience as a carer with this mental health service over the last three months

Appendix C: Sample Mental Health Carer Experience Survey

<SERVICE LOGO>

Mental Health
Carer Experience Survey

This survey is about your experiences, as a carer, with <INSERT SERVICE NAME> **over the last three months**. By completing this survey, you will help the service better understand how to work with carers towards the recovery of mental health consumers. If you care for more than one person, just think of one of these people when completing the questionnaire.

WHO IS A CARER?

Carers can come from many different backgrounds but many never think of themselves as carers. Many feel they are doing what anyone else would in the same situation; looking after their family member, partner or friend. Carers are the family member, partner or friend of someone with a mental illness whose lives are also affected by that illness. Carers provide support and assistance to the person with a mental illness.

GETTING STARTED

Your responses to this questionnaire are anonymous. Your experiences are very important to us so we would like you to provide an answer to each question. But you can leave a question blank if you wish. There is space at the end of the survey for you to provide additional feedback about your experiences.

As a carer with a family member, partner or friend who had contact with this mental health service in the **last three months**, how often did the following occur?

Please tick one box for each statement	**Never**	**Rarely**	**Some-times**	**Usually**	**Always**	**Not Needed**
1. You understood what you could expect from the mental health service for yourself and your family member, partner or friend	☐1	☐2	☐3	☐4	☐5	☐9
2. You were given an explanation of any legal issues that might affect your family member, partner or friend	☐1	☐2	☐3	☐4	☐5	☐9
3. You understood your rights and responsibilities	☐1	☐2	☐3	☐4	☐5	☐9
4. Your personal values, beliefs and circumstances were taken into consideration	☐1	☐2	☐3	☐4	☐5	☐9
5. You were able to obtain cultural or language support (such as an interpreter) when you needed	☐1	☐2	☐3	☐4	☐5	☐9
6. You were given the opportunity to provide relevant information about your family member, partner or friend	☐1	☐2	☐3	☐4	☐5	☐9
7. Your opinion as a carer was respected	☐1	☐2	☐3	☐4	☐5	☐9
8. You were involved in decisions affecting your family member, partner or friend	☐1	☐2	☐3	☐4	☐5	☐9
9. You were identified as a carer of your family member, partner or friend	☐1	☐2	☐3	☐4	☐5	☐9
10. You were given opportunities to discuss the care, treatment and recovery of your family member, partner or friend (even, if for reasons of confidentiality, you could not be told specific information)	☐1	☐2	☐3	☐4	☐5	☐9
11. You were involved in planning for the ongoing care, treatment and recovery of your family member, partner or friend	☐1	☐2	☐3	☐4	☐5	☐9

As a carer with a family member, partner or friend who had contact with this mental health service in the **last three months**, how often did the following occur?

Please tick one box for each statement	**Never**	**Rarely**	**Some-times**	**Usually**	**Always**	**Not Needed**
12. You were given the opportunity to enhance your abilities as a carer	☐1	☐2	☐3	☐4	☐5	☐9
13. Staff conveyed hope for the recovery of your family member, partner or friend	☐1	☐2	☐3	☐4	☐5	☐9
14. Staff worked in a way that supported your relationship with your family member, partner or friend	☐1	☐2	☐3	☐4	☐5	☐9
15. You were given information about services and strategies available if your family member, partner or friend became unwell again	☐1	☐2	☐3	☐4	☐5	☐9
16. You had opportunities to communicate confidentially with the treating doctor if you needed (such as by phone, email or in person)	☐1	☐2	☐3	☐4	☐5	☐9

As a carer with a family member, partner or friend who had contact with this mental health service, in the **last three months** have you been given the following?

Please tick one box for each statement	**Yes**	**No**	**Don't know**	**Not needed**
17. A brochure or other material about your rights and responsibilities	☐1	☐2	☐8	☐9
18. An explanation of how to make a compliment or complaint about the mental health service	☐1	☐2	☐8	☐9
19. Information about carer support services (such as local groups, carer consultants, counsellors)	☐1	☐2	☐8	☐9
20. Information on opportunities to participate in improving this mental health service	☐1	☐2	☐8	☐9
21. A number you could call after hours for the service	☐1	☐2	☐8	☐9
22. Information about taking a support person to meetings or hearings if you wished	☐1	☐2	☐8	☐9

As a result of your experience with this mental health service in the **last three months**, has your life changed in the following areas?

Please tick one box for each statement	**A lot worse**	**A little worse**	**No change**	**A little better**	**A lot better**	**Not needed**
23. Your relationship with the person for whom you care	☐1	☐2	☐3	☐4	☐5	☐9
24. Your hopefulness for your future	☐1	☐2	☐3	☐4	☐5	☐9
25. Your overall wellbeing	☐1	☐2	☐3	☐4	☐5	☐9

26. Overall, how would you rate your experience as a carer with this mental health service over the **last three months**?

Poor	**Fair**	**Good**	**Very Good**	**Excellent**	**Don't know**
☐1	☐2	☐3	☐4	☐5	☐8

27. Overall, during the **last three months**, did your family member, partner or friend want you involved in their care?

Never	Rarely	Some-times	Usually	Always	Not Needed
☐1	☐2	☐3	☐4	☐5	☐9

28. My experience with this service would have been better if...

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

DEMOGRAPHICS

Please tick one box for each question

30. What is your gender?

☐1 Male ☐2 Female ☐3 Other

31. What is the main language you speak at home?

☐1 English ☐2 Other

32. What is your age?

☐1 18 - 24 years	☐2 25 to 34 years	☐3 35 to 44 years
☐4 45 to 54 years	☐5 55 to 64 years	☐6 65 to 74 years
☐7 75 years and over		

33. Are you of Aboriginal or Torres Strait Islander descent?

☐1 No ☐2 Yes, Aboriginal ☐3 Yes, Torres Strait Islander ☐4 Yes, both Aboriginal and Torres Strait Islander

34. How long have you been a carer of your family member, partner or friend with a mental illness?

☐1 Up to 6 months	☐2 6 months to 1 year	☐3 1 to 2 years
☐4 2 to 5 years	☐5 5 to 10 years	☐6 Over 10 years

35. What is your relationship to the family member, partner or friend for whom you are a carer?

The person I care for is:

☐1 My spouse / partner (including married, defacto)	☐2 My mother or father (including step and in-law)	☐3 My brother or sister (including step and in-law)
☐4 My son or daughter (including step and in-law)	☐5 A friend	☐6 Other

36. How long has your family member, partner or friend been a client of this mental health service?

☐1 Less than 1 month	☐2 1 to 6 months	☐3 6 months – 1 year
☐4 1 to 5 years	☐5 More than 5 years	

37. Did someone help you complete this survey?

☐1 No	☐2 Yes – family member, partner or friend	☐3 Yes - language or cultural interpreter
☐4 Yes – carer or consumer worker/ peer worker	☐5 Yes - another staff member from the service	☐6 Yes - someone else

Thank you for completing this Survey.

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