



Australian Government

Department of Health

Mental Health Carer Experience Survey

**Guide to the technical specifications of the Carer
Experience Survey for licensed organisations and
organisations seeking a licence to use the instrument**

Endorsed by

**Australian Health Ministers Advisory Council
Mental Health Information Strategy Standing Committee**

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1 PURPOSE – WHAT THIS DOCUMENT AIMS TO DO

This document has been prepared to provide guidance to mental health service organisations planning to introduce the *Carer Experience Survey*. The document:

- provides background information on the survey, covering why and how it was developed, its content and structure, and the current status of development work;
- discusses the main design issues that need to be addressed by organisations considering implementing the survey;
- describes the recommended protocol for using the survey with individual carers;
- outlines the recommended approach to scoring and interpreting survey results; and
- outlines the arrangements in place for organisations to access and obtain approval to use the survey.

2 BACKGROUND TO THE CARER EXPERIENCE SURVEY

2.1 Origin

The *Fourth National Mental Health Plan*¹ (the Fourth Plan) was based upon a vision of a mental health system that enables recovery and ensures that all Australians with a mental illness can access effective and appropriate treatment and community support. The Plan recognised that carers and families should be actively engaged at all levels of policy and service development. They should be fully informed of service options, and anticipated risks and benefits. 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 them, and acknowledgment of their role as a carer.

Initial consultations identified that information on carer experience of service provision was not collected in a systematic way. Therefore, it was decided that there was benefit in a national project to develop a tool to support mental health services to monitor and improve carer experience as part of an evidence-informed quality improvement program.

2.2 The Carer Experience of Service Provision project

The Australian Mental Health Outcomes and Classification Network (AMHOCN) was given the task of undertaking this project. The initial focus of this project was on developing an instrument that could be used to measure carer experience of service provision.

Several principles underpinned the project. Firstly, any measure must be meaningful to carers who will ultimately have to complete it. Secondly, there was recognition that a carer measure should have immediate relevance for services, and should encourage them to consider their current practices to improve carer experience. Thirdly, it was acknowledged that the carer measure would need to focus on the carer experience rather than a carer's view of the consumer's experience. A measure of consumer experience has

¹ Australian Health Ministers, Fourth National Mental Health Plan 2009-14. Canberra: Commonwealth of Australia, 2009
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been separately developed (see the Your Experience of Service (YES) survey)².

A review of the literature was not able to identify a suitable individual-level measure of carer experience which had comprehensively established psychometric properties. Each measure had its relative strengths and weaknesses and no single measure emerged as being immediately appropriate for use with carers of mental health service users. Therefore, AMHOCN developed a carer experience of service provision survey using a co-design approach.

This project was conducted in three stages. The first stage involved a review of policy, literature and existing measures supported by a Technical Advisory Group of carers and representatives of carer organisations. The second stage involved national consultations with carers, consumers and clinicians to develop the content of the survey using a grounded theory approach. Several ad hoc forums were also conducted with carers throughout this project, for example, to test new questions or terminology. The final stage of the research involved a proof of concept trial with 150 carers and a test retest reliability trial with 41 carers.

2.3 Current status of the survey

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

Research is continuing on the development of domains, indexes and a short-form version of the survey.

3 TECHNICAL SPECIFICATIONS OF THE CARER EXPERIENCE SURVEY

The survey released for use incorporates a number of changes that were identified as desirable from the trials of the tool and the psychometric analysis of the data. The amendments included the removal of items that were highly correlated with other items, addition of a question to improve the model and minor changes to language and terminology to improve the meaning of items.

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

3.1 Naming of the survey

The title of this survey was developed with input from carers. It was felt by these carers that the name needed to clearly identify the audience (*carers*) and the topic (*experience*). The term carer is defined in the introduction to the survey, recognising that carers may not identify themselves as carers. Assigning a national name to identify the survey is essential to promote consistent use. A condition of the license arrangements includes the requirement that the title be used in all local versions of the survey. The title may also be abbreviated to *CES*.

² Australian Institute of Health and Welfare, Your Experience of Service survey instrument. Australian Government, 2016
<https://mhsa.aihw.gov.au/committees/mhissc/YES-survey>

3.2 Introductory wording to be added to Carer Experience Survey forms

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

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 using this service, 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 survey 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.

3.3 Number and sequencing of items

The 37 item survey is structured into four sections:

Section 1 includes the experience items or *independent variables*. The section includes 16 items measured on a five-point frequency scale (never, rarely, sometimes, usually, always) and 6 items measured on a categorical scale (yes, no, don't know, not needed).

Section 2 includes the outcome items or *dependent variables*. Three items are measured on a change scale (a lot worse, a little worse, no change, a little better, a lot better, not needed) and one item measured on a performance scale (poor, fair, good, very good, excellent).

Section 3 includes two open-ended questions to elicit positive and negative experiences with the service.

Section 4 includes demographic items or *explanatory variables*.

Section 5 includes an item to identify the source of any assistance in completing the survey. This can then be used to weight for any effects identified on the data.

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

Table 1: Carer Experience Survey items

Item sequence	Technical reference # ³	Question	Response type	Type of variable	Domain	Short form
Stem: <i>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?</i>						
1	C-1	1. You understood what you could expect from the mental health service for yourself and your family member, partner or friend	Frequency scale	Independent	Providing information and support	TBC
2	C-2	2. You were given an explanation of any legal issues that might affect your family member, partner or friend	Frequency scale	Independent	Providing information and support	TBC
3	C-3	3. You understood your rights and responsibilities	Frequency scale	Independent	Providing information and support	TBC
4	C-4	4. Your personal values, beliefs and circumstances were taken into consideration	Frequency scale	Independent	Valuing individuality	TBC
5	C-5	5. You were able to obtain cultural or language support (such as an interpreter) when you needed	Frequency scale	Independent	Valuing individuality	TBC
6	C-6	6. You were given the opportunity to provide relevant information about your family member, partner or friend	Frequency scale	Independent	Supporting active participation	TBC

³ For technical reference purposes, these items are referred to as C-1 to C-37. These questions should be positioned as the first 33 items with any additional local or service-specific items following. Technical reference numbers assigned to each item of the survey are intended for ‘behind the scenes’ use and not for display on printed or on-screen versions of the survey. It is possible that new questions may be included in future versions of the survey to update the content, capture local issues or new policy directions. To assist in managing this process, the technical reference numbers are designed to allow cross-mapping of items between versions.

Item sequence	Technical reference # ³	Question	Response type	Type of variable	Domain	Short form
7	C-7	7. Your opinion as a carer was respected	Frequency scale	Independent	Showing respect	TBC
8	C-8	8. You were involved in decisions affecting your family member, partner or friend	Frequency scale	Independent	Supporting active participation	TBC
9	C-9	9. You were identified as a carer of your family member, partner or friend	Frequency scale	Independent	Showing respect	TBC
10	C-10	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)	Frequency scale	Independent	Supporting active participation	TBC
11	C-11	11. You were involved in planning for the ongoing care, treatment and recovery of your family member, partner or friend	Frequency scale	Independent	Supporting active participation	TBC
12	C-12	12. You were given the opportunity to enhance your abilities as a carer	Frequency scale	Independent	Valuing individuality	TBC
13	C-13	13. Staff conveyed hope for the recovery of your family member, partner or friend	Frequency scale	Independent	Showing respect	TBC
14	C-14	14. Staff worked in a way that supported your relationship with your family member, partner or friend	Frequency scale	Independent	Valuing individuality	TBC
15	C-15	15. You were given information about services and strategies available if your family member, partner or friend became unwell again	Frequency scale	Independent	Providing information and support	TBC

Item sequence	Technical reference # ³	Question	Response type	Type of variable	Domain	Short form
16	C-16	16. You had opportunities to communicate confidentially with the treating doctor if you needed (such as by phone, email or in person)	Frequency scale	Independent	Supporting active participation	TBC
Stem: <i>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?</i>						
17	C-17	17. A brochure or other material about your rights and responsibilities	Categorical	Independent	Providing information and support	TBC
18	C-18	18. An explanation of how to make a compliment or complaint about the mental health service	Categorical	Independent	Providing information and support	TBC
19	C-19	19. Information about carer support services (such as local groups, carer consultants, counsellors)	Categorical	Independent	Providing information and support	TBC
20	C-20	20. Information on opportunities to participate in improving this mental health service	Categorical	Independent	Providing information and support	TBC
21	C-21	21. A number you could call after hours for the service	Categorical	Independent	Providing information and support	TBC
22	C-22	22. Information about taking a support person to meetings or hearings if you wished	Categorical	Independent	Providing information and support	TBC
Stem: <i>As a result of your experience with this mental health service in the last three months, has your life changed in the following areas?</i>						

Item sequence	Technical reference # ³	Question	Response type	Type of variable	Domain	Short form
23	C-23	23. Your relationship with the person for whom you care	Change scale	Dependent	Making a difference	TBC
24	C-24	24. Your hopefulness for your future	Change scale	Dependent	Making a difference	TBC
25	C-25	25. Your overall wellbeing	Change scale	Dependent	Making a difference	TBC
26	C-26	26. Overall, how would you rate your experience as a carer with this mental health service over the last three months?	Performance scale	Dependent	Making a difference	TBC
27	C-27	27. Overall, during the last three months, did your family member, partner or friend want you involved in their care?	Frequency scale	Explanatory	TBC	TBC
28	C-28	28. My experience with this service would have been better if...	Open-ended	Explanatory	TBC	TBC
29	C-29	29. The best things about this service were...	Open-ended	Explanatory	TBC	TBC
30	C-30	30. What is your gender?	Categorical	Explanatory	TBC	TBC
31	C-31	31. What is the main language you speak at home?	Categorical	Explanatory	TBC	TBC
32	C-32	32. What is your age?	Ordinal	Explanatory	TBC	TBC
33	C-33	33. Are you of Aboriginal or Torres Strait Islander descent?	Categorical	Explanatory	TBC	TBC
34	C-34	34. How long have you been a carer of your family member, partner or friend with a mental illness?	Ordinal	Explanatory	TBC	TBC
35	C-35	35. What is your relationship to the family member, partner or friend for whom you are a carer?	Categorical	Explanatory	TBC	TBC

Item sequence	Technical reference # ³	Question	Response type	Type of variable	Domain	Short form
36	C-36	36. How long has your family member, partner or friend been a client of this mental health service?	Ordinal	Explanatory	TBC	TBC
37	C-37	37. Did someone help you complete this survey?	Categorical	Explanatory	TBC	TBC

3.3.1 Local or service-specific items

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

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

Any additional items added to the survey should be positioned following the first 29 'standard' items. This placement is designed to ensure that any new items added do not affect responses to the first 29 items. For reference purposes, service-specific items are referred to as S-1 to S-n, where n equals the number of items added.

3.3.2 Demographic items

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

3.4 Rating scales used for recording carers' responses to the survey

The Carer Experience Survey uses three five-point Likert-style rating scales for carers to record their response to the individual items:

A frequency scale (never, rarely, sometimes, usually, always) is used for the experience questions (or independent variables) in this survey (C-1 to C-17). This is a positively weighted scale (two negative points and three positive points) to improve the distribution of responses which are known to be positively skewed. With the removal of categorical codes available for some items measured on this scale (i.e. don't know and not applicable) this is an interval scale.

A change scale (a lot worse, a little worse, no change, a little better, a lot better) is linked to questions about the contribution of the service to the outcomes experienced by the carer. This scale is used for the three items (items C-23 to C-25). With the removal of categorical codes available for some items measured on this scale (i.e. don't know and not applicable) this is an interval scale.

A performance scale (poor, fair, good, very good, excellent) is used for the main independent variable, overall experience (C-26). Again, this is a positively weighted scale (two negative points and three positive points) used to 'normalise' the distribution of responses which are known to be positively skewed. This scale has interval properties.

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

used to generate a score that allows the survey data to be analysed quantitatively.

3.5 Development of a carer experience index

To produce an aggregate score, total score or index, the semantic values used in the survey must be converted into numeric values. While further work will be required to develop an empirically derived overall index the following approach is outlined as an interim solution. As this is an interim approach, caution should be taken in the interpretation of results

Step 1: Assign numeric values to consumer ratings

Numeric values can be assigned to semantic ratings as outlined in table 2

Table 2: Assigning numeric values to the Frequency and Performance scales

Value	Numeric value to be assigned				
	1	2	3	4	5
Frequency scale	Never	Rarely	Some-times	Usually	Always
Change scale	A lot worse	A little worse	No change	A little better	A lot better
Performance scale	Poor	Fair	Good	Very Good	Excellent
Performance Information	No				Yes

Step 2: Sum the total scores for the Experience Items

Total sum of numerically assigned values (1 to 5) for each of the Experience items (items C – 1 to C – 22). Note that items C- 23 to C - 26 report on the outcomes of experience and do not contribute to the total score but can be reported as a domain of the measure (section 3.6).

“Don’t Know” is assigned a value of 8 which does not contribute to total score

“Not Needed” is assigned a value of 9 which does not contribute to the total score

NB Missing responses, Don’t Know and Not Needed are treated as system missing and not included in the calculations.

Step 3 convert the total experience score to a standard score based on maximum possible score

This third and final step involves converting the total score to a standardised score that takes excludes missing data and items recorded by the consumer as ‘Not Applicable’ or Don’t Know.

$$\text{Total standardised score for experience items (\%)} = \frac{100 \times \text{Total score for consumer's responses}}{\text{Maximum score of valid responses (excludes missing values, "Not needed", "Don't know")}}$$

Another way of calculating a total score is to weight the items as shown in these table above, then construct a mean of eligible items (excluding missing data, Don't Know and Not applicable as system missing). The mean will be between 1 and 5. This mean is then multiplied by 20 to get a score out of 100

3.6 Domains covered by the Carer Experience Survey questions

The domains are consistent across the suite of experience measures Carers Experience Survey (CES)⁴, Your Experience of Service (YES), Your Experience of Service, Community Managed Organisations (YES CMO). The domain names were developed through a consumer and carer consultation process.

The domain structure of the YES covers 6 broad areas:

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

Making a difference

This domain describes how the service contributed to outcomes for individuals. It includes social and emotional wellbeing and physical health.

Providing information and support

This domain describes how the service works for the individual. It includes resources such as written information, a care plan, and access to peer support.

Valuing individuality

This domain describes how the service meets individual's needs. It includes sensitivity to culture, gender and faith and the importance of personal values and beliefs.

Supporting active participation

This domain describes how the service provides opportunities for engagement, choice and involvement in the process of service delivery.

Showing respect

The domain describes how the service provides the individual with a welcoming environment where they are recognised, valued and treated with dignity.

Ensuring safety and fairness

This domain describes how services provide individual's with a physically and emotionally safety environment.

However, only 5 of these 6 domains are covered by the Carer Experience Survey as outlined in Table 6 below.

Table 6 shows how each of the 26 experience items and the 4 outcome items mapped to the domains.

Domains covered by 25 items ⁵	Survey questions that primarily map to the domain	Number of items primarily mapped to this domain	Score Range
Making a difference	C 23. C 24. C 25. C 26.	4	4 - 20
Providing information and support	C 1. C2. C 3. C 15. C 17. C 18. C 19. C 20. C 21. C 22	10	10 - 50
Valuing individuality	C 4. C 5. C 12. C 14.	4	4 - 20
Supporting active participation	C 6. C 8. C 10. C 11. C 16	5	5 - 25
Showing respect	C 7. C 9 C 13.	3	3 - 15
Ensuring safety and fairness	N/A	N/A	

Domain scores are calculated

$$\text{Total standardised score for experience items} = \frac{100 \times \text{Total score for consumer's responses for that domain}}{\text{Maximum score of valid responses (excludes missing values, "Not needed", "Don't know")}}$$

Another way of calculating a total score is to weight the items as shown in these table above, then construct a mean of eligible items (excluding missing data, Don't Know and Not applicable as system missing). The mean will be between 1 and 5. This mean is then multiplied by 20 to get a score out of 100

3.7 Reporting other attributes of the Carers Experience Survey

Involvement as carer

Question 27 does not contribute to the total score but is important for interpretation of the results. This is simply reported as the proportion of valid responses in each category.

Demographics

⁵ Note that item 27 does not contribute to the total score
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Demographics are simply reported as the proportion of valid responses in each category.

3.8 Short form version of the Carer Experience Survey (SF-CES)

The short-form version of the Carer Experience Survey will be developed after the first round of implementation when there is sufficient sample size available to support this work.

3.9 Issues for organisations to consider before implementing the Carer Experience Survey

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

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

3.9.1 Carer identification

Before embarking on the survey project, it is important that services ensure that they are able to identify carers – *both those that visit the service as well as those who do not* (due to location, work, family life or other barriers). It is important from a statistical and advocacy point of view that all carers have an equal opportunity of being offered a survey. In the proof of concept trial it was identified that some services were not able to offer the Carer Experience Survey as they could not identify carers in a systematic way. This was usually due to carer (or next of kin) details being recorded on paper-based files rather than entered into an electronic database.

If the Carer Experience Survey is only offered to carers who visit a facility or who attended an appointment this will introduce systematic bias into the data and the results will not be representative of the population of carers.

3.9.2 Scope of services to be covered

Organisations need to consider which services under their management are in scope for implementing the Carer Experience Survey. In determining scope and eligibility, organisations need to be mindful that the release version of the survey is based on a national project that aimed to develop a tool for monitoring carers' experience across clinical mental health services. Organisations considering implementing the Carer Experience Survey will need to assess the suitability of the survey within their own environments and decide whether it is fit for the purposes intended.

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

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

3.9.3 Approach to sampling carers

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

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

- The Carer Experience Survey can be implemented on an ongoing basis where all carers are routinely offered the survey at pre-determined points in the service provision cycle (for example, all carers are offered the survey after the consumer has received 3 months of care, or at regular reviews, at discharge of the consumer or annually for ongoing relationships);
- Alternatively, the Carer Experience Survey could be implemented on a comprehensive annual census basis, where all carers of consumers seen over a given period (e.g. the last three months) are offered the survey. Annual administration allows sufficient time to identify improvements, implement changes and for those changes to be experienced by carers; or
- Implement the survey on a selected sample basis, where only a defined proportion of all carers are offered a survey (for example, one in every 10 carers are randomly selected to participate). A cautionary note to add here is that, typically, many carers are keen to share their experiences of surveys. Sampling or screening based on carer characteristics or a random selection process may appear as exclusionary to those carers who are not invited to participate.

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

- ensures carers can be identified;
- ensures that carers completing the survey are representative of the total population of carers associated with the organisation;
- is sustainable over the longer term (to enable changes over time to be monitored);
- provides minimal response burden on the carer; and
- ensures the data can be readily aggregated and used within the organisation.

3.9.4 When to offer the survey

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

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

3.9.5 Mode of administration

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

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

3.9.6 Adding content to the survey

The Carer Experience Survey allows for organisations to add items to the survey content from time to time that are designed to address local issues of interest. As noted earlier (section 3.3.1), these items should be positioned at the end of the rating items (after C-29) so that responses to core items are not affected by the presentation of the new items. Ideally, any additional items should use the same response scales that are used in the 'standard' items and be kept to a minimum (recommended maximum of five additional items).

3.9.7 Consent issues

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

3.9.8 Maximising response rates

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

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

- establishing suitable governance arrangements that provide a central point for coordination and monitoring the progress of the survey;
- ensuring any people offering the survey are fully trained in the local survey protocols, research ethics and techniques to avoid influencing the results;
- monitoring the implementation of the Carer Experience Survey by different teams and giving them feedback;
- inclusion of carer and peer workers (where available) in all aspects of the survey planning, promotion and implementation to promote ownership and ensure that the approach taken is responsive of local carer views;
- establishing organisation-wide processes to promote the survey through staff briefings and educational material;
- preparation of brochure and promotional material to raise awareness of the survey and its aims with carers; and

- routinely making available the aggregated survey results to all stakeholder groups at regular periods.

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

3.9.9 Managing risk

At times carers may add responses to surveys that raise significant issues that have legal or safety implications. For example, a carer may report a staff member engaged in illegal activity, or make a serious complaint. Organisations should establish appropriate governance arrangements to manage and respond to such occurrences. The information sheet prepared for carers should also emphasise that the survey is not for lodging complaints or raising allegations, and alert carers to the existing complaint mechanisms in place.

3.10 Recommended protocol for using the Carer Experience Survey with individual carers

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

How should carers be invited to complete the survey?

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

Different methods of survey administration have different strengths and weaknesses:

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

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

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

Should a fact sheet be prepared for carers?

Good practice dictates that a summary statement of the aims the survey be prepared for all carers invited to participate which also addresses the basic issues of confidentiality, the voluntary nature of participation, and where to seek any additional information.

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

What should be said to the carer?

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

Begin by stating that:

“I’d like to invite you to complete a survey that asks important questions about your experience with this service over the last three months. By completing this survey, you will help the service better understand how to work with carers.

If you care for more than one person who uses this service, just think of one of these people when completing the survey.

Your responses to this survey 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.”

If someone is not sure if they are a carer, say:

“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.”

It is likely that some carers will ask more detailed questions about the survey and the use of the results. It is important that the person offering the survey be familiar with the aims, and in a position to answer any questions asked.

Can assistance be provided?

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

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

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

Should some carers be excluded?

As noted earlier, the Carer Experience Survey was specifically built for use in mental health services. However, use of the survey across the sector will provide valuable evidence about any future improvements to tool.

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

Is formal consent required?

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

3.11 Using and interpreting survey results

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

3.11.1 Individual item analysis

The most basic use of the survey data is to undertake analysis at the individual item level. This involves examining aggregate responses to each item, usually based on simple frequencies and percentages. For questions measured on the five-point scales, this can involve summing top-two and bottom-two responses as shown on Table 3. For this type of presentation 'don't know' and 'not applicable' should be reported separately so that percentages are comparable between items.

Table 3: Example of how the Carer Experience Survey can be used for individual item analysis

Item	Question	Percent carers responding 'excellent' or 'very good'	Percent carers responding 'poor' or 'fair'
------	----------	--	--

C-1	You understood what you could expect from the mental health service for yourself and your family member, partner or friend	55%	35%
C-3	You understood your rights and responsibilities	65%	20%

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

Assigning numeric values to carer responses to individual survey items will facilitate item-level analysis. The item values for the scales were demonstrated in the Proof of Concept study to have sufficient numeric properties to allow scores to be assigned to responses. Table 4 shows the scores assigned to the three scales used in this survey.

Table 4: Assigning numeric values to the Frequency and Performance scales

Scale	Numeric value to be assigned				
	1	2	3	4	5
Frequency scale	Never	Rarely	Some-times	Usually	Always
Change scale	A lot worse	A little worse	No change	A little better	A lot better
Performance scale	Poor	Fair	Good	Very Good	Excellent

3.12 Additional consideration of the scope of the Carer Experience Survey

3.12.1 Using the survey with Aboriginal and Torres Strait Islander carers

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

3.12.2 Using the survey with people from a CALD background

Similarly, the Carer Experience Survey has not been tested specifically for CALD populations. However, Culturally and Linguistically Diverse carers should not be excluded and any feedback received will inform further targeted investigation into the appropriateness of the survey tool.

3.12.3 Using the survey with young carers

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

3.12.4 Community Managed Organisation (CMO) support services

The survey was designed specifically for carers of consumers accessing public sector clinical mental health services. While not specifically tested for the CMO sector, the content may be relevant for other settings. As

noted, additional questions can be added to capture information that might have particular relevance to an organisation.

4 FURTHER INFORMATION

The Carer Experience Survey and further information is available at: <http://www.amhocrn.org/special-projects/mental-health-carer-experience-survey>

APPENDIX A: CARER EXPERIENCE SURVEY

A copy of the Mental Health Carer Experience Survey is provided in this Appendix. Those wishing to obtain a copy of the Survey for use should go to the AMHOCN website at <http://www.amhocn.org/special-projects/mental-health-carer-experience-survey>, provide some information about intended use and accept the Terms and Conditions.

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	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁹
2. You were given an explanation of any legal issues that might affect your family member, partner or friend	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁹
3. You understood your rights and responsibilities	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁹
4. Your personal values, beliefs and circumstances were taken into consideration	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁹
5. You were able to obtain cultural or language support (such as an interpreter) when you needed	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁹
6. You were given the opportunity to provide relevant information about your family member, partner or friend	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁹

7. Your opinion as a carer was respected	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> 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
8. You were involved in decisions affecting your family member, partner or friend	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁹
9. You were identified as a carer of your family member, partner or friend	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> 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)	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁹
11. You were involved in planning for the ongoing care, treatment and recovery of your family member, partner or friend	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> 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	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁹
13. Staff conveyed hope for the recovery of your family member, partner or friend	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁹
14. Staff worked in a way that supported your relationship with your family member, partner or friend	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁹
15. You were given information about services and strategies available if your family member, partner or friend became unwell again	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁹
16. You had opportunities to communicate confidentially with the treating doctor if you needed (such as by phone, email or in person)	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> 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	<input type="checkbox"/> ⁵	<input type="checkbox"/> ¹	<input type="checkbox"/> ⁸	<input type="checkbox"/> ⁹
18. An explanation of how to make a compliment or complaint about the mental health service	<input type="checkbox"/> ⁵	<input type="checkbox"/> ¹	<input type="checkbox"/> ⁸	<input type="checkbox"/> ⁹
19. Information about carer support services (such as local groups, carer consultants, counsellors)	<input type="checkbox"/> ⁵	<input type="checkbox"/> ¹	<input type="checkbox"/> ⁸	<input type="checkbox"/> ⁹
20. Information on opportunities to participate in improving this mental health service	<input type="checkbox"/> ⁵	<input type="checkbox"/> ¹	<input type="checkbox"/> ⁸	<input type="checkbox"/> ⁹
21. A number you could call after hours for the service	<input type="checkbox"/> ⁵	<input type="checkbox"/> ¹	<input type="checkbox"/> ⁸	<input type="checkbox"/> ⁹
22. Information about taking a support person to meetings or hearings if you wished	<input type="checkbox"/> ⁵	<input type="checkbox"/> ¹	<input type="checkbox"/> ⁸	<input type="checkbox"/> 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	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁹
24. Your hopefulness for your future	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> ⁹
25. Your overall wellbeing	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> 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
<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> 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
<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵	<input type="checkbox"/> 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?

- | | | |
|--|--|---|
| <input type="checkbox"/> ¹ Up to 6 months | <input type="checkbox"/> ² 6 months to 1 year | <input type="checkbox"/> ³ 1 to 2 years |
| <input type="checkbox"/> ⁴ 2 to 5 years | <input type="checkbox"/> ⁵ 5 to 10 years | <input type="checkbox"/> 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:

- | | | |
|---|--|---|
| <input type="checkbox"/> ¹ My spouse / partner
(including married,
de facto) | <input type="checkbox"/> ² My mother or father
(including step and in-
law) | <input type="checkbox"/> ³ My brother or sister
(including step and in-
law) |
| <input type="checkbox"/> ⁴ My son or daughter
(including step and in-
law) | <input type="checkbox"/> ⁵ A friend | <input type="checkbox"/> ⁶ Other |

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

- | | | |
|---|---|---|
| <input type="checkbox"/> ¹ Less than 1 month | <input type="checkbox"/> ² 1 to 6 months | <input type="checkbox"/> ³ 6 months – 1 year |
| <input type="checkbox"/> ⁴ 1 to 5 years | <input type="checkbox"/> ⁵ More than 5 years | |

37. Did someone help you complete this survey?

- | | | |
|--|--|---|
| <input type="checkbox"/> ¹ No | <input type="checkbox"/> ² Yes – family member,
partner or friend | <input type="checkbox"/> ³ Yes - language or
cultural interpreter |
| <input type="checkbox"/> ⁴ Yes – carer or consumer
worker/ peer worker | <input type="checkbox"/> ⁵ Yes - another staff
member from the service | <input type="checkbox"/> 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

APPENDIX B: SUGGESTED WORDING FOR CARER INFORMATION SHEETS

Services wishing to implement the Mental Health Carer Experience Survey might consider use of the following information sheet.

Carer Experience Survey

1. What is the Carer Experience Survey?

National policy initiatives, including the *Fourth National Mental Health Plan*⁶ (the Fourth Plan) recognised that carers and families should be actively engaged at all levels of policy and service development. They should be fully informed of service options, anticipated risks and benefits. 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 their role as a carer. Initial consultations identified that information on carer experience of service provision was not collected in a systematic way. Therefore, the Carer Experience Survey was developed to support mental health services to monitor and improve carer experience as part of an evidence-informed quality improvement program.

More information about the development of the Carer Experience Survey can be found at <http://www.amhocn.org/special-projects/mental-health-carer-experience-survey>

2. Are my answers confidential?

All individual survey responses are confidential. Furthermore, the information you provide is anonymous – we do not collect any identifying information on the survey.

3. Where can I get help to complete the questionnaire?

If you need help to complete the survey you may contact a family member, partner or friend. Alternatively, the carer consultant, peer worker, interpreter or other staff at the service may be able to offer you support.

4. What choice do I have about completing the survey?

The decision to complete the Carer Experience Survey is entirely yours. Whatever you decide, your decision will not affect the treatment or support received by you or your family member, partner or friend.

The survey is not marked in any way to identify you and the information you provide is anonymous.

5. What do I do with my survey when I have finished?

The service that has given you a copy of the Carer Experience Survey to complete will provide you with details about returning it to them. (Wording depending on how survey is being offered)

6. What will happen to my completed results?

Services across Australia will use the Carer Experience Survey to provide more collaborative care and support to you and your family member, partner or friend. The survey will be used to identify the strengths and weakness of carer experience and offer directions to services in their quality improvement and performance monitoring projects. (Wording depending on how survey is being offered)

(Insert relevant details for your organisation or state and territory)

⁶ Australian Health Ministers, Fourth National Mental Health Plan 2009-14. Canberra: Commonwealth of Australia, 2009
Ver 1.0

APPENDIX C: TERMS AND CONDITIONS FOR USE

The following Terms and Conditions apply to use of the Mental Health Carer Experience Survey. These Terms and Conditions are available on the AMHOCN website at <http://www.amhocn.org/special-projects/mental-health-carer-experience-survey> and must be agreed to before services can download and use the Survey.

Terms and Conditions for the non-commercial use of the Mental Health Carer Experience Survey (MH CES)

1. By downloading this version of the Mental Health Carer Experience Survey (MH CES) you agree that you will not use the MH CES for any commercial purposes.
2. By downloading this version of the Mental Health Carer Experience Survey (MH CES) you agree that you will not alter the MH CES without express permission. This means that no changes can be made to:
 - a. the wording of individual items;
 - b. the name of the survey, in particular the heading 'Mental Health Carer Experience Survey (MH CES)' must be retained;
 - c. the ordering of items; or
 - d. the response options to each item.

Any requests to alter the MH CES must be directed to the Australian Mental Health Outcomes and Classification Network (AMHOCN).

3. By downloading this version of the Mental Health Carer Experience Survey (MH CES) you do not have the right to create Adapted Material. **Adapted Material** means Material that is:
 - a. derived from or based upon the MH CES;
 - b. translated or adapted from the MH CES; or
 - c. any alteration, enhancement, improvement, arrangement, transformation or other modification of the MH CES,

but does not include the results or changes permitted under item 5 of these Terms and Conditions.

4. By downloading this version of the Mental Health Carer Experience Survey (MH CES), you can:
 - a. add a local or jurisdictional logo or other form of agency identification;
 - b. add items that are of interest to you under an identifiable 'additional questions heading'; and
 - c. make technical and formatting changes that are necessitated by the choice of medium chosen to administer the MH CES.
5. If using the Mental Health Carer Experience Survey (MH CES), you must include an acknowledgment with the Material by adding the following words to each instance of use of the MH CES:

"© 2016 Commonwealth of Australia for and on behalf of the Australian Mental Health Outcomes and Classification Network"

6. By downloading this version of the Mental Health Carer Experience Survey (MH CES), you agree:
 - a. to maintain communication; and
 - b. to share experiences regarding use of the MH CES with AMHOCN.

7. By downloading this version of the Mental Health Carer Experience Survey (MH CES), you agree to promptly provide AMHOCN with copies of any published material (e.g. journal articles) prepared from use of the MH CES.

8. By downloading this version of the Mental Health Carer Experience Survey (MH CES), you agree to ensure that the officers and employees of your organisation, who will be using the MH CES, are made aware of these Terms and Conditions.

9. By downloading this version of the Mental Health Carer Experience Survey (MH CES), you do not have the right to approve further use of the MH CES to a third party.

10. By downloading this version of the Mental Health Carer Experience Survey (MH CES), you accept all risk and consequences resulting from the use of the MH CES.