

Executive Summary

This report details the development of the national Consumer Experiences of Care survey instrument funded by the Department of Health and Ageing and delivered by the Victorian Department of Health.

This report presents a refined survey instrument developed by the project team with extensive consumer involvement through a process of literature review, consultation, development of draft instrument, small national proof of concept trial, evaluation and instrument refinement.

This instrument is suitable for further field development through a structured first wave implementation.

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

A national expert advisory group (EAG) was established to oversee the project comprising, a consumer and carer representative, jurisdictional representatives and national experts and met on four occasions.

The Consumer Experiences of Care project (endorsed by Mental Health Information Strategy Standing Committee-MHISSC, previously the Mental Health Information Strategy Subcommittee-MHISS) aims to give effect to the commitments in the Fourth National Mental Health Plan (2009-2014) to strengthen the focus of the mental health sector on measures of consumer experiences of care.

The objectives of the project are to:

1. Develop a draft instrument that:

- Incorporates evidence from existing experiences of care measures
- Measures the recovery orientation of care from a consumer perspective based on the recently revised National Standards for Mental Health Services
- Measures the degree to which consumers see themselves as being involved and engaged in their care
- Informs service-level quality improvement.

2. Undertake a national targeted proof of concept trial and refine the draft instrument.

What are Mental Health Experiences of Care?

A person's report on the extent of certain care events, processes and outcomes relating to defined periods of care and their thoughts and responses about this experience.

Care includes all services and interventions provided to a person with a mental health problem by a health service such as: support, activities, therapies and treatment.

Survey Instrument Development and Trial

The project concept was endorsed by MHISS in 2010 and commenced in June 2011.

Literature reviews and national consultations were undertaken to scope the instrument requirements. Following review of these findings, the EAG endorsed development of a new instrument informed by existing measures that captured the principles of recovery as described in the National Standards for Mental Health Services 2010.

The draft instrument informed by a theoretical policy framework, was developed following consumer workshops, national consultations, expert review and cognitive interviews.

In March 2012, MHISS approved the draft survey instrument and testing of the instrument through a trial. The national proof of concept trial was designed to optimise the collection of enough responses for analysis of the draft survey instrument. Based on activity data and preliminary response rate information, six sites: three in-patient, three community settings in four jurisdictions were selected to participate.

A model to test the draft instrument: *Your Care Survey*, utilising a face to face offer of the survey by consumer workers was developed and approved by site ethics committees. This approach aimed to obtain optimal consumer response rates in the proof of concept trial in order to effectively test the robustness of the draft instrument and:

- enhance consumer participation in the experience of care tool development
- enhance effective engagement with proof of concept sites
- identify strategies which enhance consumer engagement in service evaluation and quality improvement.

To enhance goodwill and strengthen the successful experience of services participating in the proof of concept trial, funding was provided to each trial site. This was to resource the employment of part time consumer consultant for the duration of the project. These workers were employed 0.4 to 0.6 full-time equivalent for the project trial period.

A training and capacity building program was developed to ensure that the consumer workers were appropriately skilled and supported to: effectively implement the consumer experiences of care pilot at their trial site, conduct a simple evaluation of the trial from a consumer worker perspective and to identify approaches to utilise the local findings from the survey to inform service improvement.

The trial was conducted over a 16 week period in late 2012 which comprised 3 weeks preparation, 8 weeks surveying and 5 weeks evaluation.

Two modes of implementation were tested in the trial: pen and paper completion and electronic completion using tablets (iPADs). Importantly, they were both visual modes.

An additional trial to test reliability of the survey instrument was undertaken in February 2013. Consumers of a community mental health site were invited via letter to participate in a mail survey and complete 2 paper surveys within a short period of time. Participants received a small reimbursement for their time.

A psychometric analysis of the survey instrument was undertaken. In addition qualitative feedback was received from each of the trial sites through site consumer worker reports, staff interviews and consumer interviews. This feedback primarily related to implementation issues.

Evaluation findings

The draft Consumer Experiences of Care (Your Care) survey as used in the Proof of Concept Trials in late 2012, demonstrated sound psychometric properties

The survey was constructed in four sections. These are referred to in some of the analysis.

- Questions 1 to 27 are referred to as experience questions (independent items).
- Questions 28 to 31 are referred to as outcome questions (dependent items).
- Questions 34 to 35 are open-ended questions (free text).
- Questions 36 to 42 are demographic questions.

Response rates: The survey was returned by 222 respondents (123 inpatient and 99 community). The response rates demonstrated that consumers had a high level of participation in the survey, comparing favourably to other similar surveys of mental health consumers in Australia. The sample was found to be representative of the population of consumers from which it was drawn.

Consumer feedback corroborated that the survey was easy to complete and the questions were meaningful. Consumer participation was reportedly reduced due to the impact of the research and consent overlay. Survey offering was impacted by the availability of the consumer workers (particularly at community sites) and that face to face survey offering was solely centre based which excluded community consumers who were receiving home based care.

Survey administration method: There was minimal interaction between the survey administration method and survey results, with the exception of Q22 where iPad users gave higher ratings to the activities available in inpatient settings. It may be that the iPad was seen as an activity or that people who selected iPads were more likely to seek other activities in their environment.

Choice of survey media may have been influenced by consumer worker technology preferences; in addition some consumers appeared to struggle with the tablet technology as a result of fine motor difficulties.

Survey length: The proportion of data missing increased in relation to the number of questions asked. As the variance in the data provided did not increase as a function of questions order, the increase in missing data may demonstrate that the more questions asked, the more likely the respondent is to be interrupted, particularly where surveys are completed before appointments or structured activities. There was no indication of a need to dramatically reduce the survey length.

Rating scales: Generally the rating scales performed well. The use of positively loaded scales helped reduce positive skew in the data with most questions normally distributed. As the scale response options were already positively weighted, no changes to the scales are recommended. Where skewness is problematic for analysis, transformations can be used.

While the distribution of inpatient scores on the performance scales demonstrated some characteristics of kurtosis, this was not found to impact on analyses.

Not Applicable: The availability of Not Applicable for a subset of questions worked well. The availability of Not Applicable did not affect the proportion of questions left blank, suggesting that the option filled a different need.

Distance between points on the scales: The analysis suggests that the scales are interval scales and can be assigned numeric properties.

Reliability: Reliability was measured through two test- retest surveys with community mental health consumers: firstly with respondents in the main study and secondly via a separate group of consumers using a different community mental health service. This analysis found that two thirds of consumers had an event between the completion of the test and retest surveys (such as contact with the mental health service, changes in medication or change in personal circumstances). This may account for the moderate levels of correlation found between the test and retest surveys.

Construct validity: The sample and subsample (by service setting) produced domains that matched the theoretical model used to develop the questionnaire and explained more of the variance in the data than the initial theoretical model.

Criterion-related validity: Consumer experience of care is the antecedent to outcome ratings. That is, there is a strong relationship between consumer ratings of care experience and care outcomes. The outcome questions are functioning as intended.

Experience questions: Most experience questions work well. However, a small number were found to be of low value and were recommended to be deleted or modified through cognitive interviews.

Outcome questions: While all outcome questions performed well, overall, Q28 and Q29 performed better and were more unique than Q30 or Q31.

Demographics questions: The analysis demonstrated that all but two demographic questions were important in understanding consumers' answers to experience questions. One question relating to ethnicity was retained as potentially relevant if the survey is available to a more diverse group of consumers while a question aiming to identify first time service consumers was recommended to be deleted.

The Refined Survey Instrument

The EAG adopted a number of changes to the draft survey based on the above findings, qualitative feedback and additional consumer cognitive interviews. Six poorly performing items were deleted and three questions were modified. All changes were referenced against the theoretical policy framework informed by the recovery principles in the 2010 National Standards for Mental Health Services to ensure adequate question coverage of the target domains. An additional question on assisted completion was included.

The refined survey structure, reflecting a consumer journey was developed following a further consumer workshop. The recommended survey structure includes capacity for additional questions should these be required (Annex 1).

Conclusion

This refined instrument, developed with extensive consumer involvement spanning project design, implementation and evaluation is suitable for broader field implementation. It presents with psychometric properties which support further investment. The scope and form of these next steps will depend on policy priorities and resource availability.

Further field work with a larger sample is required particularly to enable the development of mechanisms to support benchmarking and tracking of performance through the:

- Determination of utility of inductive vs deductive domains
- Testing of scale values
- Development of indices
- Testing of the utility of the instrument across different service settings and service types
- Controlling for confounding factors (e.g. service characteristics).

Through this work the merit of a short form survey, and /or the inclusion of additional survey items can be explored. In addition, decisions regarding implementation (including the mode of administration), will need to consider management of consent, database management and the role of consumer workers within the survey process. Embedding consumer expertise throughout these next stages will be critical in ensuring the Consumer Experiences of Care survey instrument is recovery focussed and truly informs service improvement.