health

National Mental Health Consumer Experiences of Care Project

FINAL REPORT

Development and Evaluation of a Consumer Experiences of Care Survey Instrument

29 May 2013



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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.

1. 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.

The report details:

- an overview of the project
- a summary of the work undertaken to develop a draft survey tool suitable for testing in a national proof of concept trial
- the methodology developed for testing of the draft survey tool
- the evaluation findings relating to the instrument following the trial
- the recommended refined instrument informed by the evaluation
- recommendations for future development and implementation work informed by the findings.

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

2. Scope, purpose, limitations

The Consumer Experiences of Care project (endorsed by Mental Health Information Strategy Standing Committee-MHISSC) 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

The Victorian Department of Health was contracted by the Department of Health and Ageing (DoHA) to deliver this project. DoHA retains oversight of the project and all its deliverables.

The project focused on the development of an instrument fit for purpose in an adult mental health service. The instrument was not designed to cater for the breadth of mental health populations, such as young people, older people, forensic or child and adolescent consumers. Nor will it be designed to meet the specific needs of culturally and linguistically diverse (CALD) and Aboriginal and Torres Strait Islander (ATSI) communities or measure the views and experiences of mental health clinicians or carers.

The National Mental Health Consumer Experiences of Care project was aimed to inform quality improvement across mental health services through the development of a recovery-oriented consumer experience of care survey tool. The survey tool should be user-friendly, meaningful, minimise burden on consumers completing the survey, support service quality improvement and improve data collection and reporting mechanisms.

Methodology

This project comprised the following phases:

- Planning phase (June-August 2011)
- Phase 1: Development of draft instrument (September 2011-February 2012)
- Phase 2: National multi-site proof of concept trial, (March -November 2012), additional reliability testing (December – April 2013) evaluation and instrument refinement (May 2013).

Progress to Phase 2 was conditional on endorsement of the draft survey tool and proof of concept trial plan by the National Mental Health Information Strategies Standing Committee (MHISSC).

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Project Governance

A national expert advisory group (EAG) was established to oversee the project comprising, jurisdictional representatives, consumer and carer representative and national technical experts (Attachment 1).

The consumer and carer perspective was strongly embedded into the project through:

- A dedicated consumer representative as a member of the project team to facilitate consumer involvement in the project development, planning, delivery and evaluation.
- Inclusion of consumer and carer representatives on the Expert Advisory Group (EAG)
- National consultations and workshops with consumers and carer peak organisations throughout the life of the Project.

A sub group of the EAG met as technical experts to provide assistance in the development of the trial methodology and to review the preliminary evaluation findings.

3 Background

Below is a brief summary of the work undertaken to inform the development of the draft survey tool and proof of concept trial methodology. This encompassed a literature review and a first round of national consultations.

3.1 Instrument development

Literature review

Comprehensive technical and consumer focussed literature reviews were conducted; the technical review explored issues relating to measures of health and mental health consumer experience, questionnaire design, implementation, analysis and reporting, the consumer review explored consumer participation in survey development, and identified consumer focussed priorities for a meaningful measure of experience. The reviews included case studies of several mental health consumer experience measures currently in use in Australia and internationally.

The reviews considered existing tools in terms of meeting project requirements and additional considerations. The following tools were considered in this process:

Measure	Operator
MH -CoPES	NSW
MHSIP/CPoC	QLD, PMHA
Consumer and Care Surveys	Victoria
Consumer and Care Surveys	WA
NHS Patient Survey 2004 (and later iterations)	UK
My Voice, My Life	NZ
Psychiatric Outpatient Experience Questionnaire	Norway

Both reviews highlighted the strengths of existing tools, noted limitations in terms of them meeting this project's requirements, and identified considerations for future tool development (Attachments 2, 3).

National Scoping – policy, practice, consumer perspectives

Following completion of the literature review the project team conducted national consultations with representatives from every Australian State and Territory on issues relating to the design of the survey tool and how it should be used:

- the features of an optimal recovery oriented survey tool including topics and how to ensure privacy and confidentiality
- the best ways to offer a survey to get the most participation possible
- · experience with similar surveys and lessons learned
- what information from consumers needs to be captured and how, to support service quality improvement
- potential challenges in delivering a survey as well as positives and negatives for consumers and services
- how often and in what format the results should be reported to consumers, services and the public
- what is important from a service provider and government perspective.

The project team consulted with:

- consumer peak organisations and consumer groups
- mental health service consumers
- consumer consultants including those with experience offering surveys to consumers
- adult clinical mental health service providers and managers
- quality and performance managers in mental health and broader health care
- government funders and policy makers including those with experience developing and using similar survey tools
- technical experts including the Australian Bureau of Statistics and the Private Mental Health Alliance.

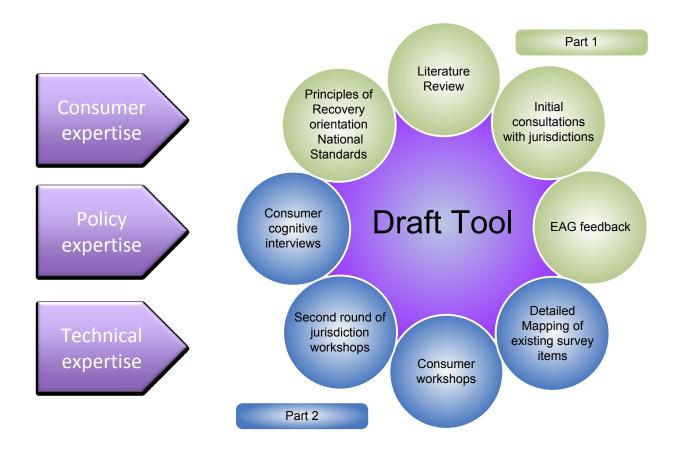
A total of 94 experts were consulted in 35 face to face meetings and teleconferences.

Both reviews highlighted the strengths of existing tools, noted limitations in terms of them meeting this project's requirements, and identified considerations for future tool development.

The National Expert Advisory Group (EAG) reviewed the work undertaken in Part 1 of Phase 1 of the project, and supported that the way forward was to develop a new survey tool, building on the experience of existing tools and findings from the consultations. The new tool should have a strong recovery orientation and be referenced by the six recovery principles and the Supporting Recovery Standard (10.1) from the *National Standards for Mental Health Services* 2010.

The development process of the draft survey tool detailed below consisted of:

- · detailed mapping of existing survey tools
- consumer workshops
- national consultation workshops
- consumer cognitive interviews.



Mapping of existing tools and documents

A mapping exercise was undertaken, working with policy and standards documents and case study examples to canvass the range of domains that are in scope for the instrument, and seen to be relevant to consumers. Mapping of survey domains, as well as further mapping of items against domains, informed the scope and content of early drafts of the questionnaire. This work was further explored through stakeholder and consumer consultations (see below).

Existing experience of care survey tools were mapped across the 6 principles of recovery oriented practice. These principles formed "domains". These domains were noted to have considerable overlap given the intersecting values that were implicit in them. On the advice of the EAG, the additional domains of safety and access were included as key requirements of quality experience of care. Consumer feedback and review of existing survey tools led to the inclusion of physical environment as another domain.

The mapping highlighted that some survey tools were more heavily weighted in certain areas. Some items were infrequently included – such as physical environment. Grouping items into domains allowed for identification of key themes and processes and for identification of higher order concepts captured in existing surveys.

Following a process of refinement and reiteration the following 8 domains of consumer experience ('experience domains') were utilised in the tool's development. Some regrouping of the 6 principles of recovery oriented care occurred as there was clear feedback that the concrete provision of information enabled choice and involvement and that attitudes were implicit in rights and respect. They have considerable overlap with 8 domains of patient centred care as identified in Picker.

Final Domains:

- Individuality
- Choice and involvement
- · Attitudes, rights and respect
- Information
- Partnerships sub domain
- Access
- Safety
- Physical environment

Additionally, the instrument included a number of questions enquired about the effect the service had on the consumer's hopefulness, ability to manage day to day life, well-being and their overall experience. These items mapped to a ninth domain that is referred as the 'outcome domain'.

The domains provided a structure for grouping items and were tested in the evaluation. They were referenced in the development of the final instrument that is presented as the outcome of this project.

Consumer Involvement:

Workshops

3 face to face workshops delivered by the project team were held with groups of consumer representatives in NSW, Vic and SA (with five, eight and six participants respectively).

Via a two and a half hour workshop, using group activities and a structured work book, participants explored items that could be incorporated into the core of a consumer self completed experiences of care tool. The workbook presented the mapping process of items from existing tools by domain and the participants critiqued items in terms of appropriateness to task and consumer acceptability, identifying priority areas for inclusion and areas of irrelevance. They challenged language and concepts, considering items in terms of applicability and importance to consumers in both inpatient and community mental health care.

National Consultations

Based on the workshop findings and with reference to the literature, policy and practice, a draft survey tool was developed for national consultation. This tool intentionally included items that may have been of lesser importance and examples that represented consumer views. It was presented in a manner designed to facilitate discussion and engagement.

2 hour, face to face workshops delivered by the project team, were held in each jurisdiction (Northern Territory participated remotely) designed to test the items and domains developed in an early version of the draft instrument.

Over 100 participants brought technical expertise, policy, practice and consumer experience, well reflecting the range of stakeholder groups required to engage with the draft tool.

Cognitive Interviews

Following the jurisdictions' feedback, the tool underwent further redrafting and further consumer scrutiny via cognitive interviews. Eight structured interviews were held with Victorian public mental health consumers (ranging in age from mid 20's to mid 50's) led by the consumer representative and a trained quantitative evaluator to test the redrafted tool. Consumers had recent (less than 6 months) experience of inpatient or community public mental health care across at least 5 different public mental health services. Consumers were asked to reference their completion of the draft tool in terms of this recent health experience.

Common terms were tested to ensure consistency of understanding and meaning and to identify the need for alternative phrasing or examples

Scales were tested to ensure that the scales were not forced on participants but were intuitive.

Items were validated through probing for consumer identified examples and explanation of the meaning they attributed to the item.

Participants were also asked to critique the survey in terms of acceptability, coverage, duplication, depth and gaps relating to consumer experience in both inpatient and community mental health treatment and care.

Demographic and open ended questions were tested for ease and clarity of completion (Attachment 4).

Governance and Review

The Expert Advisory Group reviewed and refined the draft instrument and the trial methodology to test the instrument. Subsequently the draft instrument and proof of concept trial were presented to and received support from the Safety Quality Partnerships Subcommittee of the Mental Health Standing Committee in March 2012. MHISS also endorsed the draft instrument and proposed proof of concept trial proceeding to obtaining ethics approval in March 2012.

The Draft Instrument

A draft survey tool was developed for testing in public adult inpatient and community mental health settings. A common tool was developed for use across both settings with one item that was specifically designed for inpatient /residential rehabilitation settings. It was hypothesised that a small number of items may be less applicable for consumers who primarily receive home based community treatment and care – this was to be explored in the evaluation and addressed by the inclusion of additional NA options. Trial testing aimed to produce further opportunities to revise items, and as such a greater number of items were included in the draft survey tool for the trial, to allow determinations about the strength of items to be determined psychometrically (Attachment 5).

The survey tool was not tested in the format that will be used in piloting. This is because items may be banked (i.e. grouped) to assist in ease of completion. Questions were not banked according to common themes, in order to test the item rather than the construct that may be shared across a domain of common items. Three open ended questions were included, structured to facilitate narrative feedback on how to improve care experience (negative experience), the best thing about the service (positive experience) and free feedback. A number of limited, non identifying demographic items were included to assist in data analysis in terms of representativeness of the sample and to enable interpretation of the findings across different subpopulations (e.g. gender or age differences in completion issues).

The majority of items in the survey were constructed as statements preceded by a stem statement, e.g. "Thinking about the care you received from this service within the last three months or less what was your experience in the following areas?" The stem clearly references the context of care that the participant is to reflect on, and the time period for consideration (the previous 3 months or less of care). A minimum number of different stems are utilised to increase ease of completion.

Two Likert scales were utilised in the survey: a frequency scale and a performance scale. Both scales are positively weighted and consist of five points. The positive weighting had been recommended

following the technical review of the literature which suggests that health consumers are more likely to positively respond to health experience, and allows for greater discrimination of the responses. A five point scale allows for response discrimination, without placing significant cognitive burden on participants. The frequency scale is commonly utilised to collect experience information as it enables reporting of care occurrences. The performance scale enables reporting of the consumers thoughts about certain care activities. Both scales are semantic only. A minimum number NA options were included to assist in forcing a response – consumers were also able to skip items that were unclear or not applicable.

A master question list mapped all the items utilised in the survey against the eight experience domains developed through the consultation process. A target symbol labels the primary domain that the item is intended to refer to and other domains also captured by the item are noted. The master list notes the anticipated context of care that the items are applicable to, and the type of scale being utilised to capture the differentiated response.

3.2 The Proof of Concept trial

Purpose (and limitations) of the trial

The Proof of Concept trial (PoC) was designed to assess the validity and reliability of the draft instrument itself. While aspects of the instrument delivery will be tested through this trial, it was not intended to assess modes and their effects (such as different ways to offering or complete the tool as these will be subject to later investigation through pilot testing). Specifically it was to allow examination of the following aspects of the instrument:

Validity – both criterion and construct. Construct validity assess whether an item actually measures the construct (or concept) it purports to measure. Criterion validity examines how well one item predicts an outcome (or in our case an overall assessment of experience). Both construct and criterion validity will be examined through post-hoc statistical analyses.

Reliability – the reliability of the instrument will be assessed on two levels. First, the internal consistency of the scales will be assessed through testing with a sample of the general population. This will also allow the attribution of quantitative value to the points on the scales, to inform analyses. Test-retest reliability will be assessed with a target sample of mental health consumers

Response rates – tracking of survey offer will allow response rates to be measured, as well as some insights into refusals to be drawn.

Trained consumer /peer offer – findings from the literature, case study review and consultations have supported the value of consumer offer of the survey. PoC will allow the method of trained consumer offer to be trialled, and evaluation of this approach to inform latter implementation design.

The instrument tested at the PoC had a number of important features that were deliberately included at this point in the development process. These were:

Length – As previously noted, the survey to be tested in the PoC had more items than will be included in the final survey tool, and is therefore slightly longer than the final survey tool will be. This was to allow statistical analyses to inform determinations about item strength and possible revisions to the survey tool.

Order – The order of items in the draft survey tool was randomised to prevent any context effects during PoC trial. This will better allow the criterion validity of items to be assessed. Analyses conducted following the PoC trial will inform the ordering of items (or 'banking' of similar items) on the final survey tool.

Format – Given the considerations around the length and ordering of the draft survey tool, the presentation of the survey tool is formatted to allow for these factors, and as such does not include design considerations that will be important for later iterations of the survey tool (such as keeping the survey tool to a single two-sided A4 page in hard copy).

Method

Ethics

Ethics approval was sought prior to going to PoC to ensure that the PoC adhere to strict ethical standards in both data collection procedures and analysis of the data, and acknowledges the vulnerability of the research population. Human Research Ethics Committee approval from each health service trial site was obtained: six approvals in total.

Trial sites were selected to represent a range of jurisdictions, to include both metro and regional locations, and to have sufficient consumer flows to allow collection of a minimum n=120 completions from the community setting and n=80 completions from the inpatient setting (sufficient for conducting post-hoc statistical evaluation). Sites involved were also those that expressed support for the PoC and a willingness to engage in the process. Sites were required to submit an expression of interest to participate indicating their willingness to implement trial protocol.

Engagement with sites, agreements

Formal participation agreements were executed by the Victorian Department of Health and participating trial sites, identifying roles and responsibilities across the period of the project. These agreements included the level of support provided by the project team throughout the trial and the site requirements.

Supports provided to participating sites included: funding for services to enhance consumer participation and engagement via employment of a consumer worker, information about what to expect during the trial including the service level results that will be received following the trial, the rights and responsibilities of participating sites, and the provision of engagement materials (such as posters and brochures) that could be displayed on site to help promote the PoC trial to both consumers and staff (detailed further below).

Provision of funding to support a part time consumer worker offering the survey was intended to minimise the burden of participation on trial sites and enhance optimum engagement of consumers in testing the survey.

All trial sites had a site associate researcher who was to provide a conduit to the primary researcher and ensure that any protocol and practice issues were promptly addressed. The project team liaised throughout the trial with the site associate researcher to monitor and respond to any protocol or risk issues.

As per the participation agreement, individual site briefings were conducted by the project team prior to trial commencement with relevant clinical leaders and site managers to confirm the protocol including: the role of the associate researcher, the local screening process, and supervision and ongoing safe practice arrangements for the consumer worker.

Informed consent

Issues of consent are of utmost importance when surveying consumer populations, and there are additional considerations with a vulnerable population such as mental health consumers. Critically, the two issues to be balanced are that of ensuring informed consent is provided, against ensuring consumer justice by offering opportunities to contribute feedback and evaluation of experiences within a service.

The approach method for the PoC included a trained consumer / peer offer (see below). A fundamental aspect of the trained consumer offer focussed on the appropriate provision of both written and verbal information pertaining to consumers rights (including privacy and confidentiality) with regard to the survey and evaluation activities. The right to refuse participation without fear of negative consequences emphasised. Multiple opportunities were made available for opting out of the trial and evaluation activities. To ensure justice was provided with regards to consumers' rights to provide feedback on their experiences, the survey was offered to all consumers at a site (within the frame of the eligibility criteria).

Anonymity of participation and confidentiality of responses were identified as factors that could enhance consumer participation and were embedded in the trial protocol.

Testing two visual modes

Two modes of implementation were tested at PoC: pen and paper completion and electronic completion using tablets. Importantly, they were both visual modes (which minimizes mode effects in the data), and both enabled self-completion of the survey tool. The pen and paper offer included an option for either onsite completion or a secure drop-box return (not accessible by service staff) and an option for pre-paid mail-back return.

Tablets were programmed with survey software to ensure the presentation of the survey closely followed that of the pen and paper version. Both tablets and pen and paper surveys were offered at each site.

Trained consumer /peer offer

The survey was offered face to face by trained consumer consultants / peer workers (consumer workers) at the health service site in public areas. Findings of the case study review and consultations demonstrated increased response rates associated with this delivery mode, as well as alignment with consumer preferences. A limited capacity building program and weekly skill development and support program was offered to the consumer workers on the project's research and evaluation methods.

An important aspect of the trained consumer worker offer included the informed consent process, as well as maintaining the integrity of the self-completion mode once a consumer has commenced completing a survey tool. Consumer workers offering the survey were available to field enquiries, however were instructed to not assist in the completion of a survey tool, to manage any potential social desirability bias.

Consumer workers offering the survey tracked the number of surveys offered, to inform response rates. Tracking did not involve the collection of any identifying data, and was limited to the number, date and time that a survey was offered. Tracking data was not available to service staff. The consumer workers recorded any information offered by consumers who refused participation at the point of offer, to inform understandings of consumers' reasons for not completing the survey.

Site preparation

A number of supports were provided to participating sites including information about what to expect during the trial, service level results, the rights and responsibilities of participating sites, and the provision of engagement materials (such as posters and brochures) that could be displayed on site to help promote the PoC trial to both consumers and staff.

Promotional and support material was available in staff and public areas informing people of the forthcoming trial and displayed throughout the trial collection and evaluation period.

Service level data

Service level data was collected from the sites participating in the PoC to capture consumer population data at a specific point in time during the collection period. Data was sought on demographic fields, specifically:

- Gender
- Age
- Legal Status
- Cultural and Linguistic Diversity
- Aboriginality and Torres Strait Islander.

No other data, such as name, address or any contact details was collected

Sample and Field work period

Six service sites participated: three in a community setting and three in an in-patient setting from four jurisdictions with two sites being in non-metro locations.

The questionnaire was offered in all sites over at least eight consecutive weeks. Consumer workers offering the survey all worked part time in the role – ranging from 1.8 days week – 2.5 days week with

some working set days and times and others being more flexible in availability. Where a consumer worker was absent for at least a week, the survey period was extended by a week. Data collection for mail back surveys continued for one week beyond the fieldwork period.

Site Support

Support for the trial was provided by the project team: with weekly group telephone support provided to consumer workers in relation to their role and any issues that were arising over the collection period. The need for support has been identified by similar initiatives. In addition two days of training was provided to the consumer workers prior to commencement of the trial to ensure that they were appropriately equipped to implement the protocol. Regular liaison occurred between the project team and associate researcher to ensure local protocol issues were addressed, with the service retaining core responsibility for supervision and support of the consumer worker.

Eligibility frame

All consumers registered as receiving care at the service during the fieldwork period were able to be offered the survey, within the frame of the eligibility protocol as follows:

- In-patient settings all consumers who have had a minimum of one-night stay in the service;
- Community settings all consumers who are registered with the service as receiving ongoing
 treatment and care, as defined by having received at least 2 site based contacts where the
 consumer has participated within this episode of care.

The eligibility frame was designed to promote the justice of offering the survey to all consumers, however ensuring that consumers who are offered the survey had a sufficient minimum experience of the service about which they are being asked to provide feedback. Consumers were offered the survey whilst receiving care rather than on exit or post exit or transfer from the service.

In addition to eligibility based on length of experience with the service, there were also some exclusions to eligibility based on wellness to participate (such as those in seclusion or being treated in high dependency care), and English comprehension of those who speak languages other than English.

Risk management

Standards risk management were taken to manage risks associated with the PoC.

These included protocols around the ascertaining of informed consent and the explanation of privacy and confidentiality to consumers. All data collected through the PoC was de-identified. Trial sites reports received aggregate results only.

Post-hoc evaluation interviews included a consent process and all data was de-identified to protect consumers' privacy and confidentiality. A significant events protocol was in place throughout the PoC but did not need to be enacted.

Participation Information and consent forms included information on local 24 mental health crisis telephone numbers should psychological distress arise prior, during or post survey completion as well as usual complaints and information avenues.

Nil adverse events were reported.

Service level results

Local site results were provided to the participating trial sites services and included a summary of the response rates and representativeness of their sample, as scores for each item in the survey as well the open ended feedback.

4. Survey Instrument Evaluation

This chapter provides an overview of the psychometric properties of the *National Consumer Experience of Care (Your Care)* survey. Data has not been analysed by site as the focus of this analysis is on testing the properties of the survey (to allow for improvements to the survey) rather than reporting results from the survey. Each participating site has received a report on the results for their service. As the participating sites represent a self-selected sample there is no expectation that the survey results are generalisable beyond the participating sites. Therefore, survey results have not been reported except where necessary as part of an analysis. All analysis was conducted using SPSS PASW Statistics 18.

Additional qualitative feedback collected as part of the broader evaluation activities relating to the project has been included where relevant.

In reading this chapter please note that:

- Reported sample sizes will vary depending on the number of respondents answering each question and the type of analysis being conducted.
- As the psychological distance between points on Likert scales are being tested to determine the
 properties of the scale, where possible comparison of scores between segments has used
 proportions rather than measures of central tendency.
- 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.

4.1 Response rates

The response rates demonstrate 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.

This section explores the response rates for the survey (Table 1). The survey was returned by 222 respondents (123 inpatient and 99 community). This exceeded the initial target of 200 responses for this analysis.

Table 1: Response rates by service setting

Response Collection Type	Community Site 1	Community Site 2	Community Site 3	Community Sub total	Inpatient Site 4	Inpatient Site 5	Inpatient Site 6	Inpatient Sub total	Total
Service population (A)	208	250	459	917	83	87	91	261	1178
Offered (B)	54	185	96	335	34	41	98	173	508
Refusals (C)	15	100	34	149	1	5	17	23	172
Distributed (D)	39	85	62	186	33	36	81	150	336
All responses received (E)	19	22	58	99	27	29	67	123	222
Responses more than 80% completed (F)	16	21	54	91	25	29	52	106	197
Offered survey response rate(E/B)	35%	12%	60%	30%	79%	71%	68%	71%	44%
Population return rate (E/A)	9%	9%	13%	11%	33%	33%	74%	47%	19%
Population offer rate (B/A)	26%	74%	21%	37%	41%	47%	108%	66%	43%
Offered survey response >80% survey completion (F/B)	30%	11%	56%	27%	74%	71%	53%	61%	39%
Refusal rate (C/B)	28%	54%	35%	44%	3%	12%	17%	13%	34%

4.1.1 Eligible population

The eligible population for this survey was the service population, less those mental health consumers who were unable to participate because of any of the following:

- Their service staff (usually a clinician or case worker) identified that they were too unwell. As
 interviewing was conducted over a period of weeks, these people may have been eligible and
 offered a survey at a later point in time.
- The person lacked sufficient written or verbal English language skills to understand the
 introductory information about the project and consent, or to complete the survey independently.
 This could have been identified by the service staff, or the consumer worker in implementing the
 survey process.
- The person lacked capacity to consent. This could have been identified by the service staff or the consumer worker in implementing the survey process.

As the factors that make a consumer ineligible may change over time and relate to individual characteristics that are not available from services, we have used the service population (A, Table 1) in our estimations of the eligible population (knowing this will be an over-estimation of the eligible population size).

The service population was 1,178 clients (917 community, 261 inpatient). In total, 19% of the population returned a survey (47% for inpatients and 11% for community clients) (E/A, Table 1).

4.1.2. Offer rate

The offer rate is the proportion of the population offered a survey. Overall, 43% of the service population was offered a survey (B/A, Table 1). This is consistent with other surveys of mental health consumers. The offer rate was significantly higher in inpatient than community setting (66% compared to 37%). In community settings, the consumer worker was only able to offer the survey to clients who physically attended the location. As consumer workers worked part time, they may never have had the opportunity to offer the survey to some clients. Services were asked to remove those clients who only received home visits and did not attend a centre from the eligibility list. However, this was not always possible.

4.1.3 Survey completion

Overall, 44% of people offered a survey (E/B, Table 1) agreed to participate and returned a survey (either through an iPad or paper completion). This is consistent with other surveys of mental health consumers. Inpatients had a higher return rate than did community clients (71% compared to 30%).

Clients could return a survey incomplete, through either the iPad or paper forms. Reviewing surveys that were at least 80% complete, provided a completion rate of 39% overall with inpatients still having a higher level of participation than community clients (61% compared to 27%) (F/B, Table 1).

4.1.4 Refusal rate

The refusal rate is the proportion of people offered a survey who refused to participate. This rate is an overestimation of the actual refusal by individuals for several reasons:

- If a person refused a survey at one point in time and completed it at a subsequent time they are still counted as a refusal, as the anonymous nature of the survey does not allow for identification of individual's participation.
- Post survey review of consumer worker diaries and administrative data revealed that ineligible consumers were on occasion counted as refusals (that is, refused a survey by the consumer worker).
- Similarly, people also refused a survey if they had already completed a survey.
- Finally, people may have been offered a survey several times and refused some or all of these approaches potentially allowing one client to be recorded as refusing several times.

Despite these over estimations of actual refusals by individuals, the overall refusal rate was 34% (C/B, Table 1). The refusal rate was higher in community than inpatient settings (44% compared to 13%). This is likely to reflect the larger population size of community settings and the increased possibility of multiple offers and refusals over the surveying period.

4.1.5 Representativeness of the sample

The sample was highly representative of the service population (Table 2). Only two characteristics differed significantly between the population and sample (p>.05). These characteristics were explored in the questions to identify first time service users and people who were <u>not</u> on an involuntary order at some point during the last three months. The first time service users question was not found to affect consumers' ratings of service experience. It is likely the difference in sample and population characteristics was a result of inaccurate self-reporting in the sample. As this question added no value to interpreting ratings of service experience, the value of its inclusion in the survey is questioned.

Legal status (voluntary, involuntary) has been found to be valuable in explaining service experience (see section 0). In comparing the sample with the population characteristics, it seems that when people have been involuntary during the last three months, they are able to accurately report this in the survey. Hence, for involuntary status there is no significant difference between the sample and the population. However, there was a significant difference between the sample and the population in the proportion of people who were voluntary over the last three months. This seems to result from voluntary clients selecting 'unsure' in the survey. This suggests that in analysis 'voluntary' should include 'unsure'. Removing 'unsure' is not recommended as it is likely to force some people to

inaccurately identify as involuntary. The current response pattern suggests that when people have been involuntary at some period over the last three months, they are very clear on their legal status.

Table 2: Comparison of sample demographics to the service population

Gender	Community population n=917	Community sample n=100	Inpatient population n = 260	Inpatient sample n=109	Total population n=1,177	Total sample n=209
Male	61%	52%	45%	47%	57%	49%
Female	39%	48%	55%	52%	43%	50%
Other	-	-	-	1%	-	1%

Language	Community population n=917	Community sample n=100	Inpatient population n = 260	Inpatient sample n=109	Total population n=1,177	Total sample n=209
English	96%	96%	98%	99%	96%	98%
Other	4%	4%	2%	1%	4%	2%

Aboriginal and Torres Strait Islander	Community population n=917	Community sample n=100	Inpatient population n =260	Inpatient sample n=109	Total population n=1,177	Total sample n=209
No	94%	97%	91%	90%	94%	93%
Aboriginal	3%	3%	6%	10%	4%	7%
Torres Strait	0%	-	1%	-	0%	-
Both	0%	1%	0%	-	0%	1%
Not stated	3%	-	2%	-	3%	-

Age	Community population n=917	Community sample n=100	Inpatient population n = 260	Inpatient sample n=109	Total population n=1,177	Total sample n=209
18-24	8%	11%	13%	11%	9%	11%
25-34	23%	29%	26%	31%	23%	30%
35-44	29%	28%	22%	22%	28%	25%
45-54	24%	20%	27%	31%	24%	26%
55-64	15%	10%	10%	4%	14%	7%
65+	2%	2%	2%	1%	2%	2%

First time	Community population n=917	Community sample n=100	Inpatient population n = 260	Inpatient sample n=109	Total population n=1,177	Total sample n=209
Yes	6%	29%	48%	58%	15%	45%
No	94%	71%	52%	42%	85%	55%

Involuntary at some point	Community population n=917	Community sample n=100	Inpatient population n = 260	Inpatient sample n=109	Total population n=1,177	Total sample n=209
Yes	35%	30%	51%	38%	39%	34%
No	64%	56%	49%	42%	61%	48%
Not sure	-	15%	-	21%	-	18%

4.2 Survey method

Inpatients showed a preference for iPad over hard copy surveys. Survey results were found to be consistent irrespective of the method of administration. The exception to this was Q 22. (You had things to do that were meaningful for you) where iPad users were more positive.

People were offered the opportunity to complete the survey either by iPad or paper. While two-thirds of respondents completed the survey by paper (67%) there were notable differences by service setting (Table 3). Inpatients were over three times more likely to use an iPad to submit a survey (26%) than were community service users (8%).

Choice of offering of survey media was reported to reflect consumer worker preferences.

Table 3: Survey method preferences for different settings

Method	Community (n=99)	Inpatient (n=123)	Total (n=222)
iPad (n=74)	8%	26%	33%
Paper (n=148)	37%	30%	67%
Total (n=222)	45%	55%	100%

Results were analysed using Chi-Square to identify if either the setting (inpatient or community service) or survey method (iPad or paper) had any effect on the frequency distribution of rating questions. The analysis revealed few effects (Table 4).

In relation to service setting, five questions were found to yield significant differences (p<.05) suggesting the ability of these questions to discriminate between different experiences by service setting. These questions were:

- 6. You were able to get in contact with this service when you needed.
- 7. You had access to your treating doctor or psychiatrist when you needed.
- 9. The facilities and environment met your needs (such as cleanliness, private space, reception area, furniture, common areas, etc).
- 20. Your privacy was respected.
- 23. Access to peer support (such as information about peer workers, referral to consumer programs, advocates, etc).

In relation to the method of administration, just one question was found to yield a significant difference (p<.05) in results:

22. You had things to do that were meaningful for you.

As iPad users were far more positive in their rating of this question than paper users, it is quite possible that the use of an iPad had a direct impact on the ratings provided. No other questions showed a significant difference in responses based on method of administration. This validates the decision to use two visual modes to reduce the impact of administration on results while testing the construct of the survey.

Table 4: Impact of setting and method on responses to rating questions

KEY ■ = Significant difference in rating (Chi-Square <.05), ■ = No significant difference in rating (Chi-Square >.05)

Questions n=195 to 209	Setting (inpatient vs. community	Method (iPad vs. paper)
You had opportunities for your family and carers to be involved in your treatment and care if you wanted	×	×
Your opinions about the involvement of family or friends in your care were respected	×	×
3. You felt safe to ask questions, provide feedback or make a complaint if you wanted	×	×
4. Staff made an effort to see you when you wanted	×	×
5. You were able to get in contact with this service when you needed	✓	×
6. You had access to your treating doctor or psychiatrist when you needed	✓	×
7. You had access to a range of other professional services if you needed (such as dietary advice, talking therapies, skill development, etc)	×	×
8. You felt welcome at this service	×	×
9. The facilities and environment met your needs (such as cleanliness, private space, reception area, furniture, common areas, etc)	✓	×
10. You were able to do the things that were important to you while using this service (such as have family and friends visit, make phone calls, have a cup of tea or coffee, etc)	×	×
11. Staff caring for you took the time to get to know you as a person	×	×
12. Your individuality and values were respected (such as your culture, faith or gender identity, etc)	×	×
13. You were listened to in all aspects of your care and treatment	×	×
14. You were involved in planning your future care	×	×
15. You had opportunities to discuss your progress with the staff caring for you	×	×
16. Staff showed respect for how you were feeling	×	×
17. Staff worked as a team in your care and treatment (for example, you got consistent information and didn't have to repeat yourself to different staff)	×	×
18. Staff ensured you understood the effects of your treatment options (including any medication, talking therapies, etc)	×	×
19. You felt safe using this service	×	×
20. Your privacy was respected	✓	×
21. Staff showed hopefulness for your future	×	×
22. You had things to do that were meaningful for you*	NA	✓
23. Access to peer support (such as information about peer workers, referral to consumer programs, advocates, etc)	✓	×
 Convenience of the location for you (such as close to family and friends, transport, parking, community services you use, etc) 	×	×
25. Explanation of your rights and responsibilities	×	×
26. Information given to you about this service (such as how the service works, which staff will be working with you, how to make a complaint, etc)	×	×
27. Development of a care plan with you that considered all of your needs (such as health, living situation, age, etc)	×	×
28. Overall, how would you rate your experience of care with this service in the last 3 months?	×	×
29. The effect the service had on your ability to manage your day to day life	×	×
30. The effect the service had on your hopefulness for the future 31. The effect the service had on your overall well-being	× ~	×
31. The effect the service had on your overall well-being	×	Х

^{*}Q22 was only asked of the inpatient sample

4.3 Missing data for closed questions

While the proportion of data missing increases in relation to the number of questions asked, this cannot automatically be assumed to be a fatigue response. An alternative scenario is that the more questions asked, the more likely the respondent is to be interrupted, particularly where surveys are completed before appointments or structured activities. Review of standard deviations scores shows minimal change in the variability of responses, suggesting that fatigue does not affect the quality of the data that is provided.

Completion of each question in the survey was voluntary. The proportion of data that is missing gives some indication of how easy clients found the survey to complete and the relevancy of questions. There was a total combination of 7770 possible responses to closed questions (experience, overall and demographic questions) (Table 5). Overall, 9% of possible responses were missing. The proportion of missing data was higher for iPad completion (15%) than paper (6%) which may reflect a level of interest in the technology rather than the survey. Similarly, the proportion of missing data was higher for inpatients (12%) than community clients (3%).

Table 5: Missing data (sample level)

Missing Data Category	Total sample (n=222)	Inpatient (n=123)	Community (n=99)	iPad (n=74)	Paper (n=148)
Missing responses	704	500	204	387	317
Possible responses	7770	4305	7140	2590	5180
% data missing	9%	12%	3%	15%	6%

The proportion of missing data by question ranged from 13% to 5% (Table 6). Generally, less data was missing from experience questions (9%) than either overall or demographic questions (both 13%). It is important to note that the experience questions constitute the first 22 questions, and this difference may reflect fatigue and order effects.

The missing data was further examined based on the position of questions in the survey (Figure 1). It is clear that later questions have a higher rate of missing data than earlier questions.

Figure 1: Missing data based on question position in survey (with linear trend line)

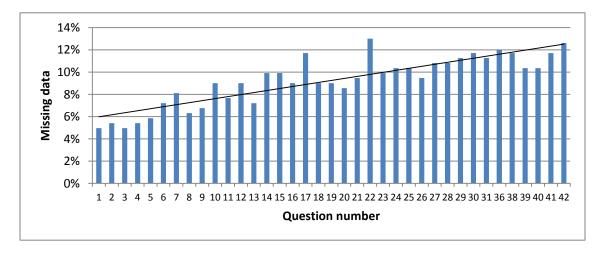


Table 6: Missing data (by question)

Question	Total (n=222)	Inpatient (n=123)	Community (n=99)	iPad (n=74)	Paper (n=148)
Q22. You had things to do that were meaningful for you	13%	13%	-	16%	11%
Q42. At any point during the last 3 months were you receiving involuntary treatment?	13%	14%	11%	19%	9%
Q36. What is your gender?	12%	15%	9%	22%	7%
Q17. Staff worked as a team in your care and treatment	12%	15%	8%	15%	10%
Q30. The effect the service had on your hopefulness for the future	12%	14%	9%	16%	9%
Q38. Are you of Aboriginal or Torres Strait Island origin?	12%	14%	9%	20%	7%
Q41. How long have you been receiving care from this service on this occasion?	12%	12%	11%	20%	7%
Q29. The effect the service had on your ability to manage your day to day life	11%	14%	8%	16%	9%
Q31. The effect the service had on your overall well-being	11%	14%	8%	16%	9%
Q27. Development of a care plan with you that considered all of your needs	11%	15%	6%	18%	7%
Q28. Overall, how would you rate your experience of care with this service in the last 3 months?	11%	15%	6%	18%	7%
Q24. Convenience of the location for you	10%	14%	6%	19%	6%
Q25. Explanation of your rights and responsibilities	10%	12%	8%	15%	8%
Q39. What is your age?	10%	11%	9%	18%	7%
Q40. Is this the first time you have been a consumer of this service?	10%	11%	9%	18%	7%
Q14. You were involved in planning your future care	10%	13%	6%	16%	7%
Q15. You had opportunities to discuss your progress with the staff caring for you	10%	13%	6%	16%	7%
Q23. Access to peer support	10%	13%	6%	15%	7%
Q21. Staff showed hopefulness for your future	9%	12%	6%	15%	7%
Q26. Information given to you about this service	9%	12%	6%	15%	7%
Q10. You were able to do the things that were important to you while using this service	9%	10%	8%	14%	7%
Q12. Your individuality and values were respected	9%	11%	6%	14%	7%
Q16. Staff showed respect for how you were feeling	9%	12%	5%	15%	6%
Q18. Staff ensured you understood the effects of your treatment options	9%	12%	5%	15%	6%
Q19. You felt safe using this service	9%	12%	5%	15%	6%
Q20. Your privacy was respected	9%	11%	5%	15%	5%
Q7. You had access to a range of other professional services if you needed	8%	11%	4%	16%	4%
Q11. Staff caring for you took the time to get to know you as a person	8%	11%	3%	15%	4%
Q6. You had access to your treating doctor or psychiatrist when you needed	7%	11%	3%	16%	3%
Q13. You were listened to in all aspects of your care and treatment	7%	11%	3%	14%	4%
Q9. The facilities and environment met your needs	7%	10%	3%	12%	4%
Q8. You felt welcome at this service	6%	9%	3%	12%	3%
Q5. You were able to get in contact with this service when you needed	6%	9%	2%	12%	3%
Q2. Your opinions about the involvement of family or friends in your care were respected	5%	7%	3%	8%	4%
Q4. Staff made an effort to see you when you wanted	5%	7%	3%	9%	3%
Q1. You had opportunities for your family and carers to be involved in your treatment and care if you wanted	5%	7%	3%	8%	3%
Q3. You felt safe to ask questions, provide feedback or make a complaint if you wanted	5%	7%	2%	9%	3%

Qualitative feedback from consumer workers revealed that some respondents returned incomplete surveys due to factors such as being called in to an appointment or activity. So a longer survey has an opportunity cost - the more questions the higher the likelihood of interruption, particularly when surveys are completed before appointments. We also know that some respondents verbally reported the survey was too long. Observations reported by consumer workers of completion time ranged from 10 30 minutes. We would expect, if missing data results from fatigue, rather than interruption, that the standard deviations of mean scores would increase with the question load. That is, there would be more variability in answers later in the survey. However, plotting of standard deviation scores (Figure 2) shows that there is minimal increase in standard deviation as a function of question number.

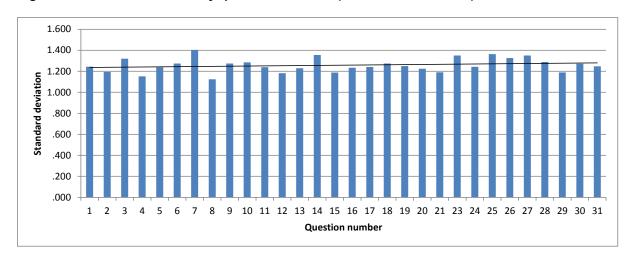


Figure 2: Standard deviation by question number* (with linear trend line)

4.4 Rating scales

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.

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.

The analysis suggests that the scales can be assigned numeric properties. As these properties are very close to equal distance, future research should explore the impact of using the score from the lpsos general population online poll with equal distance values (for example, reviewing changes in rank order or questions or services).

^{*} As Question 22 was only asked of inpatients it has been removed from this analysis as the smaller sample size affects the variability in the data.

This section examines the performance of the rating scales in the Proof of Concept Trial. The *Experiences of Care Survey* includes two rating scales:

A frequency scale for questions 1 to 22 – *Never, Rarely Sometimes, Usually, Always*A performance scales for questions 23 to 31 – *Poor, Fair, Good, Very Good, Excellent*As previous research demonstrated that consumer ratings of mental health services are positively skewed, both rating scales used in the survey were also positively skewed (three positive points, two negative points) to move the data towards a normal distribution. Two tests of normality were used to analysis the distribution of the data, skewness and kurtosis. These analyses have been conducted for the total sample, inpatients and community service users.

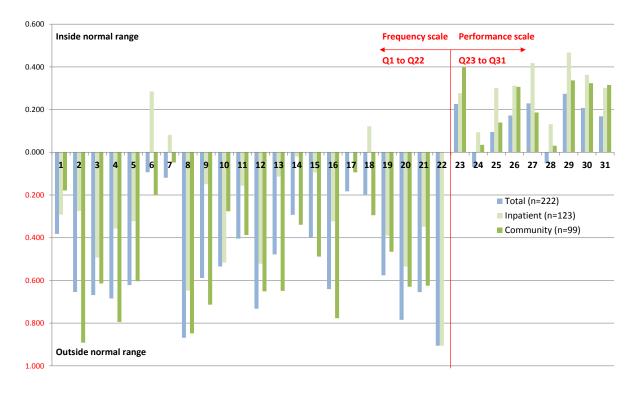
4.4.1 Skewness

Skewness is a measure of the asymmetry of a distribution from the mean. For a normal distribution the skewness is 0.

The analysis found that responses on the frequency scale were skewed towards positive results (Data Appendix A1). This demonstrates that the services in the sample were considered high performing by their clients. Responses on the performance scale were generally within the normal distribution, demonstrating that the outcome and recovery questions measured on this scale are harder to achieve. Specifically, the number of questions skewed by sample was (Figure 3):

- 24 total sample
- 18 inpatient sample
- 21 community sample.

Figure 3: Skewness by question



4.4.2 Kurtosis

Kurtosis is a measure of the shape of the distribution to determine the level of volatility. For a normal distribution the kurtosis is 0.

The analysis (Appendix A1) found that the frequency questions generally fell within the normal range, though there were a few exceptions for different samples (Figure 4). However, for inpatients responses on the performance scale generally fell outside of the normal range.

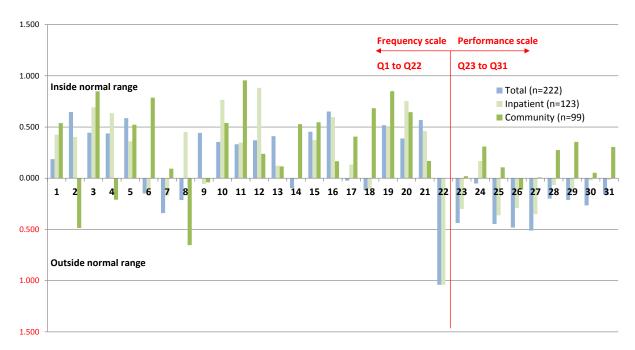


Figure 4: Kurtosis by question

To identify the impact of kurtosis for the performance scale, the shape of normal probability plots of residuals from the linear regression models were reviewed. The shape revealed a linear relationship (rather than this S shape associated with kurtosis) (Data Appendix A2).

4.4.3 Rating scales with Not Applicable option

The survey included eight experience questions with a *Not Applicable* option. This option was included on rating questions that might not be relevant to all respondents to allow people a way of moving through the survey. It is important to note that respondents could also leave questions blank if they wished. The questions with a *Not Applicable* option were:

- 1. You had opportunities for your family and carers to be involved in your treatment and care if you wanted
- 2. Your opinions about the involvement of family or friends in your care were respected.
- 3. You felt safe to ask questions, provide feedback or make a complaint if you wanted.
- 4. Staff made an effort to see you when you wanted.
- 5. You were able to get in contact with this service when you needed.
- 6. You had access to your treating doctor or psychiatrist when you needed.
- 7. You had access to a range of other professional services if you needed (such as dietary advice, talking therapies, skill development, etc).
- 23. Access to peer support (such as information about peer workers, referral to consumer programs, advocates, etc).

The proportion of missing data in for these questions was reviewed to see if the availability of a *Not Applicable* option reduced the proportion of results that were missing (Figure 1). The rate of missing data reflected the questions' position in the survey.

The pattern of *Not Applicable* responses was reviewed against the proportion of missing data to see if there was a relationship (Figure 5). For example, an inverse relationship would suggest that the two options are interchangeable. This was not found to be the case. There was no discernible pattern between the proportion of missing data and *Not Applicable* responses.

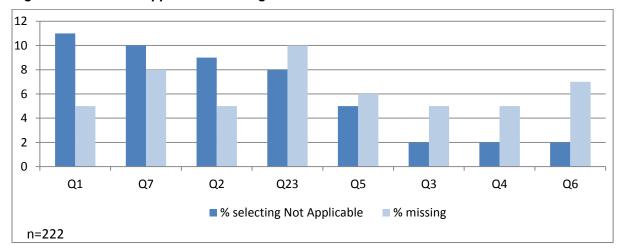


Figure 5: Use of Not Applicable in rating scales

Three questions had few responses (2%) to the *Not Applicable* option:

- 3. You felt safe to ask questions, provide feedback or make a complaint if you wanted.
- 4. Staff made an effort to see you when you wanted.
- 6. You had access to your treating doctor or psychiatrist when you needed.

4.4.4 Distance between points on scales

Two semantic scales were tested for this trial:

- A frequency scale (Never, Rarely, Sometimes, Usually, Always)
- A performance scale (Poor, Fair Good, Very Good, Excellent)

In order to be able to produce aggregate scores, the semantic scales must be converted into numeric values. The psychometric properties of these scales are largely unknown (and not tested on a population of mental health consumers).

At the end of the iPad survey, consumers were asked to indicate how close or far apart the three inside points of the scales (eg, Rarely, Sometimes, Usually) were from one another and the two extreme points (eg. Never, Always).

Consumers used a slider rule to adjust the three inside points of each scale as they saw fit. The mean actual distance was measured between all points to provide the mean psychological distances between the points of each scale.

The task proved difficult for consumers to complete. The level of participation was low (27 for the frequency scale and 17 for the performance scale). While the results were consistent with those found

by Rohrman¹ reported in the literature (Table 7), the Rohrman study did not present scales in sets but tested the intrinsic value of individual words divorced of context. So this study may not be directly comparable.

To provide additional information on the properties of the scales in context, in April 2013 Ipsos conducted an online survey of 1,024 Australians. The same method employed in the iPad trial was employed, with the exception that the three movable points were aligned left (that is, in a neutral position).

When filtered to respondents that adjusted the scale and removing outliers, the results showed that respondents considered the points on the frequency scale to be very close to equal distance apart (Table 7). This is despite only being giving an example of a skewed scale in the introduction to the test.

Table 7: Numeric values of the frequency scale

Sources of data	Never	Rarely	Some-times	Usually	Always
Rohrman (2007) n=100	0	1.3	3.6	7.4 *	10
NCEoC PoC (extremes and non-users of the scale removed (n=26)	0	1.4	4.4	6.9	10
Ipsos online poll n=887	0	2.1	5.0	7.7	10

^{*} Rohrman tested *Frequently* not *Usually*

For the performance scale, the results are consistent with prior research and demonstrate no difference between the general population and mental health consumers (Table 8). Fair, Good and Very Good each sit slightly above an equal distance position.

Table 8: Numeric values of the performance scale

Sources of data	Poor	Fair	Good	Very Good	Excellent
Rohrman (2007), n=100	1.5	5.2	7.2	8.5	10
Proactive Insight (2002) ² , n=417	2.0	4.8	6.8	n.a.	9.0
Proactive Insight (1996) ³ , n= unknown	2.5	5.0	7.0	n.a.	9.1
NCEoC PoC, n=17	0	3.0	5.5	8.0	10
Ipsos online poll n=876	0	2.7	5.4	7.9	10

¹ Rohrman Bernd Verbal qualifiers for rating scales: Sociolinguistic considerations and psychometric data, University of Melbourne, Jan 2007

² Proactive Insight, Scale research report, 2002, Unpublished

³ Proactive Insight, 1996, reported in Proactive Insight, 2002, Unpublished

4.5 Test retest reliability

Overall, the analysis demonstrates that some items are more reliable, or perhaps less influenced by change, than others.

Two approaches to retest reliability were conducted for this survey. Firstly, for the first week of fieldwork, community mental health service users who completed a survey were asked if they wished to participate in a retest survey to measure the reliability of the survey. Participants were given one week to return the second survey.

Twenty people agreed to participate in the retest survey and 10 people actually returned a completed survey, giving a response rate of 50%.

With just ten completed returns the sample size was too small to provide a real estimate of the reliability of the survey. However, based on the few surveys available, the surveys show strong correlations between test and re-test for Q5 (.86), Q6 (.76), Q7 (.85), Q9 (.74), Q13 (.65), Q15 (.81), Q19 (.745), Q24 (.85), Q28 (.74) at $p \le 0.1$.

Secondly, in an effort to provide a larger sample of consumers ethical approval was gained to conduct a mail survey with consumers from a community mental health service. To protect consumers' privacy, the service mailed out 217 invitations and consent forms to eligible consumers. Consumers wishing to participate in the study then completed the consent form and received the first survey from lpsos. Once the first survey was received a second survey was posted to consumers. Consumers received a small payment in recognition of their time and effort in completing the survey. The population response rate through to the second survey was 9% (Table 9).

Table 9: Retest survey response rates

Item	n= 217
Eligible population (A)	217
Consent Forms completed (B)	36
Survey 1 completions (C)	29
Survey 2 completions (D)	19
Opt-in rate (A/B)	17%
Survey 1 response rate (A/C)	13%
Survey 2 response rate (A/D)	9%

As the analysis demonstrated that both scales used have internal properties, Pearson correlation was to measure reliability.

The second survey included a question to identify if consumers had any experiences since they completed the first survey that might have influenced their responses to survey two. Nearly two thirds (62%) had experienced one or more of the following:

- 55% Had contact with someone from their mental health service
- 45% Had contact with another health professional
- 28% Had their medication or treatment changed
- 31% Had a life change (such as housing, employment, finances, relationship, leisure, etc)

Given the significant number of respondents who reported an event between the two surveys, and the potential impact of this on the correlation observed between the test and re-test surveys, moderate levels of correlations were accepted.

Of the 30 questions, 15 were found to be correlated using Pearson's correlation.

Table 10: Correlations between items on the test and retest surveys

Question	Correlation r>.5
Q1	NS
Q2	.445
Q3	.149
Q4	.553
Q5	.729
Q6	.717
Q7	.708
Q8	.283
Q9	.621
Q10	.439
Q11	NS
Q12	NS
Q13	.549
Q14	.543
Q15	.619
Q16	NS
Q17	NS
Q18	.408
Q19	.684
Q20	.580
Q21	NS
Q22	NS
Q23	.739
Q24	.612
Q25	.489
Q26	.623
Q27	NS
Q28	.636
Q29	.584
Q30	.567

NS = not significant

Green shading = correlation >.51

Of the 30 questions, using Pearson's correlation:

- Eight did not have correlations significantly different from zero
- Sixteen had correlations that met the threshold for reliability (r >.51 for moderate correlation)
- Six questions did not have a minimum level of reliability

The seven questions with lower levels of reliability included many topics that might have been influenced by the events consumers reported occurring between completion of the test and retest surveys, such as recontact with the service. It is likely that the variability in results reflects changes in consumers' experience. It is noteworthy that the outcome questions, which measure longer term concepts, were more likely to be reliable than the experience questions.

Statistical testing of the correlation values (using z' transformations) at 95% confidence level showed that repeated test-retest reliability studies of 11 of the 30 statements would hardly ever return a strong correlation result (r > .70) (see Data Appendix A3).

As there are not strong levels of correlation for all statements, this will affect the ability of those statements to detect a change in consumers' perceived experience of care in longitudinal surveys. The minimum detectable change at 95% confidence level (MDC 95) can be used to highlight differences the statements' ability to detect change in service performance.

4.6 Internal consistency

In constructing the initial survey, to ensure coverage of issues questions were mapped to eight experience domains identified through a review of policy and initial consultations with consumers, carers and professional stakeholders in mental health (Table 11).

Table 11: Policy map of experience questions

Que	stion	Individuality	Choice and involvement	Attitudes, rights, respect	Information	Partnerships	Access	Safety	Physical environment
1.	You had opportunities for your family and carers to be involved in your treatment and care if you wanted		•	•		•			
2.	Your opinions about the involvement of family or friends in your care were respected	•	•	•		•			
3.	You felt safe to ask questions, provide feedback or make a complaint if you wanted		•	•	•			•	
4.	Staff made an effort to see you when you wanted		•	0			•		
5.	You were able to get in contact with this service when you needed	•			•	•	•		
6.	You had access to your treating doctor or psychiatrist when you needed		•		•	•	•		
7.	You had access to a range of other professional services if you needed (such as dietary advice, talking therapies, skill development, etc)	•	•			•	•		
8.	You felt welcome at this service	•		0				•	
9.	The facilities and environment met your needs (such as cleanliness, private space, reception area, furniture, common areas, etc)	•					•	•	•
10.	You were able to do the things that were important to you while using this service (such as have family and friends visit, make phone calls, have a cup of tea or coffee, etc)	0	•	•					•
11.	Staff caring for you took the time to get to know you as a person	•	•	•					
12.	Your individuality and values were respected (such as your culture, faith or gender identity, etc)	•	•	•					•
13.	You were listened to in all aspects of your care and treatment	•	•	•					
14.	You were involved in planning your future care	•	•			•	•		
15.	You had opportunities to discuss your progress with the staff caring for you	•	•	•					
16.	Staff showed respect for how you were feeling	•		0					
17.	Staff worked as a team in your care and treatment (for example, you got consistent information and didn't have to repeat yourself to different staff)		•	•		•	•		
18.	Staff ensured you understood the effects of your treatment options (including any medication, talking therapies, etc)		•	•	•			•	
19.	You felt safe using this service	•		•	•	•	•	•	•
20.	Your privacy was respected	•	•	0		•			•
21.	Staff showed hopefulness for your future			•					
22.	You had things to do that were meaningful for you	0	•	•		•			
23.	Access to peer support (such as information about peer workers, referral to consumer programs, advocates, etc)		•		•	•	•		
24.	Convenience of the location for you (such as close to family and friends, transport, parking, community services you use, etc)	•				•	•		•
25.	Explanation of your rights and responsibilities		•	0	•			•	
26.	Information given to you about this service (such as how the service works, which staff will be working with you, how to make a complaint, etc)		•	•	•			•	•
27.	Development of a care plan with you that considered all of your needs (such as health, living situation, age, etc)	•	•			•	•		

Internal consistency for each of the eight experience domains was evaluated using Cronbach Alpha. All alpha values but one (partnerships) demonstrated good internal consistency (Table 12).

Table 11 Key

- Primary domain
- Secondary domain

Table 12: Alpha values for experience domains

Experience domain	Alpha value
Individuality	.81
Choice and involvement	.85
Attitudes, rights and responsibilities	.89
Information	.72
Partnerships	.44
Access	.80
Safety	.75
Physical environment	n.a. (single
	question)

4.7 Construct validity

On the full sample, five domains were identified that were more internally consistent than the eight experience domains initially developed. The community and inpatient PCAs explain more variance than the PCA for the full sample. However, the difference is marginal and the models very similar. Across the PCA analyses, access, information and individuality are common themes. Privacy and safety are also commonly linked. The construct domains should be further explored in the Pilot to determine the implications of different constructs for reporting (to services and government).

Construct validity requires the presence of both convergent and discriminant validity. Examining discriminant validity between any two rating questions relies on bivariate correlations as well as the reliability estimate of each question. Hence, given that the re-test did not yield a sufficient number of surveys, discriminant validity cannot be reported. This section will focus on convergent validity which measures whether constructs that should theoretically be related actually are related.

4.7.1 PCA full sample

To examine convergent validity (identifying the eight designated domains from the pattern of ratings), a principle component analysis (PCA) was conducted on the entire data set.

The initial PCA provided two metrics indicating that the set of ratings is suitable for structure detection:

- KMO measure of sampling adequacy: .96
- Bartlett test of sphericity (Chi2 = 3487, 231 df, p < 0.001)

The eight domains do not emerge as factors from the data and only three factors emerge (accounting for 68% of total variance) (Table 13).

Table 13: PCS eigenvalues (full sample)

Initial Eigenvalues

Domains	Total	% of Variance	Cumulative %
1	12.375	56.252	56.252
2	1.514	6.880	63.131
3	1.034	4.700	67.831

These three domains related to: individuality, information, access (Data Appendix A4). Domain 1 had 13 items. These were subject to a further PCA which yielded two factors. So the final factor analysis on the full sample projected five domains. These domains were found to have a strong relationship with the theorized eight experience domains (Table 14).

Table 14: Comparison of experience and PCS domains (full sample)

Experience domain	PCA domain
Individuality	Respect and listening
Choice and involvement	Respect and listening
Attitudes, rights and responsibilities	Respect and listening
Information	Information
Partnerships	-
Access	Access
Safety	Privacy and safety
Physical environment	Facilities and the
	environment

It is not surprising that no domain was found to relate to the concept of partnerships as the Cronbach Alpha demonstrated poor internal consistency for these questions (Section 1.10).

The internal consistency analysis repeated on the five PCS domains identified delivers more consistent scores than the eight experience domains (Table 15).

Table 15: Internal consistency of PCS domains (full sample)

Domain	Alpha value
Respect and listening	.93
Privacy and safety	.90
Information	.88
Access	.86
facilities and environment	n.a. (single question)

4.7.2 PCA inpatient sample

To determine if the overall model is consistent for the different populations of consumers (inpatient and community), PCAs were conducted on each subgroup.

The initial inpatient PCA provided two metrics indicating that the set of ratings is suitable for structure detection:

- KMO measure of sampling adequacy: .94
- Bartlett test of sphericity (Chi2 = 2598, 351 df, p < 0.001.

Again, the eight experience domains do not emerge as factors. Four factors were found to account for 71% of the variance (Table 16). The solution was rotated to maximise differences in correlation across factors (Data Appendix A6)

Table 16: PCS eigenvalues (inpatients)

	ni	ti	al	Ei	ge	nv	al	lu	es
-		•			5	4	**	·	C D

Domains	Total	% of Variance	Cumulative %
1	15.312	56.713	56.713
2	1.694	6.272	62.985
3	1.298	4.808	67.793
4	.958	3.549	71.342

A PCA was conducted on the first factor, with 14 items, to produce two domains. The final five domains were:

- Individuality
- Privacy and safety
- Information
- Access
- Meaningful activities.

4.7.3 PCA community sample

The PCA was conducted on the sub-set of community patients (but without Q22 as this was only asked of inpatients).

The initial PCA provided two metrics indicating that the set of ratings is suitable for structure detection:

- KMO measure of sampling adequacy: .91
- Bartlett test of sphericity (Chi2 = 1671, 325 df, p < 0.001.

The designated eight domains do not emerge as separate factors, five domains emerge (Table 17).

Table 17: PCS eigenvalues (community)

Initial Eigenvalues

Domains	Total	% of Variance	Cumulative %
1	12.231	47.042	47.042
2	1.698	6.531	53.573
3	1.434	5.514	59.087
4	1.320	5.075	64.162
5	1.009	3.879	68.041

The five domains were rotated to maximize differences in correlation across factors (Appendix 6). Factors emerged around the following topics:

- Respect and care
- Access
- Information
- Privacy and safety
- Individuality

4.8 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.

Criterion-related validity analysis examines validity by linking measures external to the survey to survey measures. However, given the anonymous character of the survey, external measures are not available in this survey.

Criterion-related validity analysis was conducted instead by using outcome questions as dependent variables of consumer experience of care:

- Q28. Overall, how would you rate your experience of care with this service in the last 3 months?
- Q29. The effect the service had on your ability to manage your day to day life.
- Q30. The effect the service had on your hopefulness for the future.
- Q31. The effect the service had on your overall well-being.

The four outcome questions were found to be highly correlated (r>.7)⁴. (Data Appendix A8).

The relationship between the outcome variables and consumer experiences of care was tested on two polar opposites:

- What facets of consumer experience of care separate people with a negative experience (Poor or Fair) vs a relatively positive one (Good).
- What facets of consumer experience of care separate people with a strong positive experience (Very Good or Excellent) vs a relatively positive one (Good).

Binary logit regression was used to identify which facets of consumer experience of care link to positive or negative outcome, based on each outcome variable.

The binary logit re-classified between 70% and 90% of each defined group of consumers (negative experience as Poor or Fair, Positive as Good, and strongly positive as Very Good or Excellent) (Table 18).

Table 18: Binary logit regression models

Negative to	positive					Positiv	e to	strongly pos	sitive	e			
Q28. Overall experience		Predicted Q28 Low side- binary Percentage			vera	ıll experienc	Δ	Predic Q28 binary	High	side-	Percenta		
		.00	1.00		Correct	9				.00	1.00		Correct
Low side-	.00	39	12		76.5		High	.00		37	14		72.5
binary	1.00	14	38		73.1	side- binary		1.00		11	89		89.0
Overall Per	centage				74.8	Overall	l Per	centage					83.4
Q29. Abilit	y to manage	Predic Q29 binary		side						Predic Q29 binary	High	side-	
day-to-day	ine	.00	1.00		Percenta Correct	day-to	-day	life	iage	.00	1.00		Percenta Correct
Low side-	.00	49	13		79.0	High s	side-	.00		43	19		69.4
binary	1.00	18	50		73.5	binary		1.00		15	58		79.5
Overall Per	centage				76.2	Overall	l Per	centage					74.8
		Predic				O30 H	lono	fulness for tl		Predic			
Q30. Hope future	fulness for the	Q30 binary	Low	side-	Percenta	future	lope	iuilless loi ti		binary		side-	Percenta
		.00	1.00		Correct		oide	00		.00	1.00		Correct
Low side-	.00	50	15		76.9	High s binary	siae-			39	26		60.0
binary	1.00	15	46		75.4			1.00		18	59		76.6
Overall Per	centage				76.2	Overall	l Per	centage					69.0

In relation to the specific questions identified as key drivers in each model (Figure 6) there was very strong symmetry in the drivers of negative and positive experience. This validates the use of a linear model across the entire spectrum of experience (that is, there is a direct and predictable relationship between experience and outcome questions).

⁴ As Q31 had r>.9 correlation to two other outcome variables it was removed from the analysis.

Figure 6: Summary of drivers

Experience driving overall experience past 3M (Q28)

Driving negative experience

- Q8: You felt welcome at the service
- Q9: The facilities and environment met your needs
- Q23: Access to peer support
- Q25: Explanation of your rights and responsibilities
- Q27:Development of a care plan with you

Driving strong positive experience

- Q8: You felt welcome at the service
- Q21: Staff showed hopefulness for your future
- Q23: Access to peer support
- Q24: Convenience of the location
- Q27:Development of a care plan with you

Experience driving ability to manage day-to-day (Q29)

Driving negative experience

- Q16: Staff showed respect for how you were feeling
- Q17: Staff worked as a team in your care and treatment (for example, you got consistent information and you didn't have to repeat yourself to different staff)
- Q20: Your privacy was respected
- Q23: Access to peer support
- Q24: Convenience of the location

Driving strong positive experience

- Q6: You had access to your treating Dr or psych when you needed
- Q15: Your had opportunities to discuss your progress with the staff caring for you
- Q17: Staff worked as a team in your care and treatment
- Q18: You felt safe using this service
- Q24: Convenience of the location

Experience driving hopefulness for the future (Q30)

Driving negative experience

- Q10: You were able to do the things that were important to you
- Q21: Staff showed hopefulness for your future
- Q23: Access to peer support
- Q26: Information given to you about this service

Driving strong positive experience

- Q9: The facilities and environment met your needs
- Q12: Your individuality and values were respected
- Q13: You were listened to in all aspects of your care and treatment
- Q23: Access to peer support
- Q24: Convenience of the location

4.9 Experience questions

The value of several questions to the survey was low. Of these questions, three were found to be unique (Q2, Q7, and Q10) and it is recommended they should be kept in the survey. The remaining questions that contributed little to the analysis (Q3, Q5, Q11, Q14, Q22) were found to be highly correlated to other questions in the survey. Their content and continuing need to be included in the survey should be reviewed against the qualitative feedback from consumers and others.

This section provides a summary of a series of analyses that were conducted to determine the value of each experience question to the overall survey (Table 19).

The accompanying table brings together a summary of analysis by questions to allow review of each question. The analysis and coding used in this table are as follows:

- Logit regression was conducted using outcome questions (Q28 to Q30) as dependent variables.
 Logit regression identifies those experience questions (Q1 to Q27) that significantly impact on either a positive or negative overall experience. If a question was found to be a significant driver to any of these three questions it is shaded green. See Section 1.8 for more details.
- Multiple regression was conducted using overall questions (Q28 to Q31) as dependent
 variables. Multiple regression identifies the contribution experience questions (Q1 to Q27) make
 as part of an array in explaining the variance in the dependent variable. If a question was found to
 be a significant driver to any of these four dependent questions it is shaded green. See Section
 1.11 for more details.
- Principal components analysis was conducted to test the ability to develop factors within the data. It was identified that the data was most suited to separate models for inpatient and community samples. The purpose of this test was not to test factors, but to identify those questions that make a contribution to the establishment of factors in the data. This was established by removing items and observing the effect this had on the change in the predictability of the factor. The higher the alpha score the more valuable the question is to the factor identity. Questions with a higher alpha score are coded in green. See Section 1.7.1 for more information.
- Reliability was measured using Pearson's correlation. As 62% of consumers reported an
 experience between completing the two surveys that could affect their ratings, low levels of
 reliability were accepted (r>.51).
- The proportion of missing data for each item is also included in the table. While we know that the
 proportion of data missing increases as a function of the length of the survey, it does also provide
 a level of importance of the question to clients and ease of completion. See Section 5.3.3 for
 more information.

All of these factors were then considered through a clerical review to rate the overall contribution the question makes to the survey (based on the statistical analysis only).

Table 19: Summary of item analysis

Key: \blacksquare = Question inclusion is of value to the analysis; \blacksquare Question exclusion is value to the analysis; Uncoloured = Question made no contribution to the analysis; x = Not included in the analysis

Question	Logit Regression	Multiple Regression	Change in Alpha value (In-patient)#	Change in Alpha value (Community)#	Person's Correlation	% missing	Contribution to survey
Q26. Information given to you about this service			4	5		9%	High
Q6. You had access to your treating doctor or psychiatrist when you needed			3	7		7%	High
Q27. Development of a care plan with you that considered all of your needs			3	3		11%	High
Q23. Access to peer support			1	2		10%	High
Q12. Your individuality and values were respected			1	9		9%	High
Q16. Staff showed respect for how you were feeling			1	2		9%	High
Q21. Staff showed hopefulness for your future			1	2		9%	High
Q13. You were listened to in all aspects of your care and treatment			1	2		7%	High
Q15. You had opportunities to discuss your progress with the staff caring for you			1	1		10%	High
Q8. You felt welcome at this service			0	1		6%	High
Q17. Staff worked as a team in your care and treatment			0	0		12%	High
Q24. Convenience of the location for you			-1	0		10%	High
Q18. Staff ensured you understood the effects of your treatment options		0	Χ	Χ		9%	High
Q25. Explanation of your rights and responsibilities		0	3	4		10%	High
Q9. The facilities and environment met your needs		0	-4	Χ		7%	High
Q19. You felt safe using this service	0		14	Χ		9%	High
Q20. Your privacy was respected	0	0	7	6		9%	High
Q1. You had opportunities for your family and carers to be involved in your treatment and care if you wanted	0	0	3	7		5%	High
Q4. Staff made an effort to see you when you wanted			1	7		5%	High
Q22. You had things to do that were meaningful for you*			NA	NA		13%	Low
Q2. Your opinions about the involvement of family or friends in your care were respected			3	Х		5%	Low
Q5. You were able to get in contact with this service when you needed			3	4		6%	Low
Q7. You had access to a range of other professional services if you needed			2	-1		8%	Low
Q3. You felt safe to ask questions, provide feedback or make a complaint if you wanted			1	Х		5%	Low
Q11. Staff caring for you took the time to get to know you as a person			1	2		8%	Low
Q14. You were involved in planning your future care			0	3		10%	Low
Q10. You were able to do the things that were important to you while using this service			0	3		9%	Low

[#] Alpha value with all relevant statements minus alpha value without statement

Correlation coefficients for each of these eight experience questions with low utility to the survey were then reviewed to establish the extent to which each of these questions make a unique contribution to the content of the survey (Table 20).

The correlations revealed that three questions are not extremely correlated (r>.600) with any other question:

- Q2. Your opinions about the involvement of family or friends in your care were respected
- Q7. You had access to a range of other professional services if you needed (such as dietary advice, talking therapies, skill development, etc)
- Q10. You were able to do the things that were important to you while using this service (such as have family and friends visit, make phone calls, have a cup of tea or coffee, etc)

Table 20: Correlations with low utility questions

Low utility to analysis	Correlated questions (r >.600)
Q2. Your opinions about the involvement of family or friends in your care were respected	Nil
Q7. You had access to a range of other professional services if you needed (such as dietary advice, talking therapies, skill development, etc)	Nil
Q10. You were able to do the things that were important to you while using this service (such as have family and friends visit, make phone calls, have a cup of tea or coffee, etc)	Nil
Q22. You had things to do that were meaningful for you*	Q14. You were involved in planning your future care Q18. Staff ensured you understood the effects of your treatment options (including any medication, talking therapies, etc) Q19. You felt safe using this service Q20. Your privacy was respected
Q5. You were able to get in contact with this service when you needed	Q4. Staff made an effort to see you when you wanted Q6. You had access to your treating doctor or psychiatrist when you needed
Q3. You felt safe to ask questions, provide feedback or make a complaint if you wanted	Q16. Staff showed respect for how you were feeling
Q11. Staff caring for you took the time to get to know you as a person	Q8. You felt welcome at this service Q12. Your individuality and values were respected (such as your culture, faith or gender identity, etc) Q13. You were listened to in all aspects of your care and treatment Q15. You had opportunities to discuss your progress with the staff caring for you Q16. Staff showed respect for how you were feeling Q21. Staff showed hopefulness for your future
Q14. You were involved in planning your future care	Q8. You felt welcome at this service Q13. You were listened to in all aspects of your care and treatment Q15. You had opportunities to discuss your progress with the staff caring for you Q18. Staff ensured you understood the effects of your treatment Q21. Staff showed hopefulness for your future Q22. You had things to do that were meaningful for you

4.10 Open-ended questions

The findings suggest that putting the negative question first in the survey worked well and respondents were clearly able to separate their negative and positive feedback reducing the need for recoding between open ended questions. The reduced response rate to open ended questions by iPad users suggests the need for better training with consumers who are new users of iPads.

Three open-ended questions were included in the survey. These questions were:

- Q34. My experiences would have been better if...
- Q35. The best things about this service were...?
- Q43. Please provide any additional comments you would like to make about this service.

Questions 34 and 35 have been analysed in this section. The third question (Q43) was included to ensure clients had opportunities to make additional comments to services that fell outside of the topics of the survey. A qualitative review of the results found that the responses to this question duplicated comments to the earlier open-ended questions. This review also found that generally the results to the Q34 and Q35 reflected the direction of the question (negative or positive).

For both open-ended questions, inpatients were less likely to respond than community clients (63% compared to 68%) but wrote more when they did (80.62 words compared to 69.90 words) (Table 21).

Table 21: Average word and character counts for open-ended questions

Table 21a: Question 34

Q34 My experiences with this service would have been better if	% answered question	Words	Characters (no spaces)	Average words per respondent	Average characters per respondent
Inpatients (n=76)	62%	1655	7674	21.78	100.97
Community (n=64)	65%	1211	5581	18.92	87.20
iPad (n=43)	58%	943	4338	21.93	100.88
Paper (n=97)	66%	1923	8917	19.82	91.93
Total	63%	2866	13255	20.47	94.68

Table 21b: Question 35

Q35 The best things about this service were	% answered question	Words	Characters (no spaces)	Average words per respondent	Average characters per respondent
Inpatients (n=79)	64%	995	4822	12.59	61.04
Community (n=71)	72%	770	3855	10.85	48.80
iPad (n=45)	61%	605	2806	13.44	62.36
Paper (n=105)	71%	1160	5871	11.05	55.91
Total (n=150)	68%	1765	8677	11.77	57.85

Table 21c: Question 34 and 35 combined

Questions combined (Q34 + Q35)	% answered question	Words	Characters (no spaces)	Average words per respondent	Average characters per respondent
Inpatients (n=155)	63%	2650	12496	17.10	80.62
Community n=135)	68%	1981	9436	14.67	69.90
iPad (n=88)	59%	1548	7144	17.59	81.18
Paper (n=202)	68%	3083	14788	15.26	73.21
Total (n=290)	65%	4631	21932	15.97	75.63

Respondents from all samples wrote more for the negative question (Q34) than for the positive question (Q35). While respondents were more likely to provide open-ended feedback on the paper survey than the iPad (68% compared to 59%), they wrote more on the iPad than on paper (81.18 words compared to 73.21 words).

4.11 Outcome questions

Overall, Q28 and Q29 performed better and were more unique than Q30 or Q31. These latter two questions could be removed from the survey unless there is a policy imperative for their inclusion.

The survey included four outcome questions used as dependent variables to test the importance of experience questions. These outcome questions also include aspects of recovery. The four questions in the survey were:

- Q28. Overall, how would you rate your experience of care with this service in the last 3 months?
- Q29. The effect the service had on your ability to manage your day to day life.
- Q30. The effect the service had on your hopefulness for the future.
- Q31. The effect the service had on your overall well-being.

To determine the relative value of each outcome question to the survey, several factors were considered, including missing data, correlation and contribution to regression models.

In relation to missing data, the proportion of data missing for each question was equivalent (ranging from 11% to 12%).

Correlation between the questions revealed that they are all significantly and highly correlated. Questions 30 and 31 were the highest correlated (Table 22).

Table 22: Correlation matrix (outcome questions)

Question	Q28	Q29	Q30	Q31
Q28. Overall, how would you rate your experience of care with this service in the last 3 months?	1	.726	.772	.818
Q29. The effect the service had on your ability to manage your day to day life	.726	1	.759	.769
Q30. The effect the service had on your hopefulness for the future	.772	.759	1	.854
Q31. The effect the service had on your overall well-being	.818	.769	.854	1

Base = 193 – 198, Overall questions: All results are sig (p<.000)

In regression modelling with experience questions, Q28 and Q29 both had higher adjusted r-square scores meaning they explain a greater proportion of the variance in the data (Table 23).

Table 23: Regression model summaries

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
Q28. Overall, how would you rate your experience of care with this service in the last 3 months?	.862	.743	.705	.6908
Q29. The effect the service had on your ability to manage your day to day life	.830	.689	.643	.6985
Q30. The effect the service had on your hopefulness for the future	.781	.610	.552	.8336
Q31. The effect the service had on your overall well-being	.798	.636	.582	.7920

4.12 Demographics questions

This analysis questions the value of asking clients if they are first time users of the service as their response made no difference to their ratings on experience or outcome questions.

The frequency distributions for rating questions (experience and outcome questions) were analysed against the demographics questions using Chi-Square to identify significant differences in rating by demographic characteristics (Table 24). This information can be used to review the value of each demographic question to the survey as it demonstrates the capacity of demographics to explain the ratings provided by consumers. That is, it identifies consumer groups that have difference experiences so that quality improvement programs can better target service improvements.

Table 24: Impact of demographic questions on rating questions

KEY ■ = Significant difference (Chi-Square <.05), ■ = No significant difference (Chi-Square >.05)

You had opportunities for your family and carers to be involved in your treatment and care if you wanted Your opinions about the involvement of family or friends in your care were respected You felt safe to ask questions, provide feedback or make a complaint if you wanted Staff made an effort to see you when you wanted You were able to get in contact with this service when you needed You had access to your treating doctor or psychiatrist when you needed You had access to a range of other professional services if you needed You felt welcome at this service The facilities and environment met your needs You were able to do the things that were important to you while using this	x x x x x x x	* * * *	* *	*	✓
respected You felt safe to ask questions, provide feedback or make a complaint if you wanted Staff made an effort to see you when you wanted You were able to get in contact with this service when you needed You had access to your treating doctor or psychiatrist when you needed You had access to a range of other professional services if you needed You felt welcome at this service The facilities and environment met your needs You were able to do the things that were important to you while using this	x x	×		✓	✓
wanted Staff made an effort to see you when you wanted You were able to get in contact with this service when you needed You had access to your treating doctor or psychiatrist when you needed You had access to a range of other professional services if you needed You felt welcome at this service The facilities and environment met your needs You were able to do the things that were important to you while using this	×		×		
You were able to get in contact with this service when you needed You had access to your treating doctor or psychiatrist when you needed You had access to a range of other professional services if you needed You felt welcome at this service The facilities and environment met your needs You were able to do the things that were important to you while using this	×	ж		✓	×
You had access to your treating doctor or psychiatrist when you needed You had access to a range of other professional services if you needed You felt welcome at this service The facilities and environment met your needs You were able to do the things that were important to you while using this			×	ж	ж
You had access to a range of other professional services if you needed You felt welcome at this service The facilities and environment met your needs You were able to do the things that were important to you while using this	×	×	*	×	×
You felt welcome at this service The facilities and environment met your needs You were able to do the things that were important to you while using this		×	3C	ж	ж
The facilities and environment met your needs	×	\checkmark	×	ж	×
You were able to do the things that were important to you while using this	✓	×	×	x	×
You were able to do the things that were important to you while using this	✓	×	3C	✓	×
service	✓	×	×	✓	×
Staff caring for you took the time to get to know you as a person	×	×	×	×	×
Your individuality and values were respected	✓ _	×	×	×	\checkmark
You were listened to in all aspects of your care and treatment	✓	×	×	\checkmark	×
You were involved in planning your future care	×	×	×	×	✓
You had opportunities to discuss your progress with the staff caring for you	×	×	×	\checkmark	×
Staff showed respect for how you were feeling	\checkmark	×	×	×	✓
Staff worked as a team in your care and treatment	×	×	×	✓	×
Staff ensured you understood the effects of your treatment options	×	×	×	×	✓
You felt safe using this service	×	×	×	×	×
Your privacy was respected * *	×	✓	×	×	✓
Staff showed hopefulness for your future	×	×	×	×	✓
You had things to do that were meaningful for you	ж	×	×	ж	×
Access to peer support	×	×	×	×	×
Convenience of the location for you	×	×	×	×	*
Explanation of your rights and responsibilities	×	×	×	×	×
Information given to you about this service	×	×	×	×	×
Development of a care plan with you that considered all of your needs	×	×	×	×	×
Overall, how would you rate your experience of care with this service in the last 3 months?	×	×	×	×	×
The effect the service had on your ability to manage your day to day life	×	\checkmark	×	×	×
The effect the service had on your hopefulness for the future		×	×	×	ж
The effect the service had on your overall well-being	×				

In summary, across the 31 questions, the demographic characteristics of respondents made a significant difference (<.05) to their answers on 30 occasions:

- Status made a significant difference to eight questions (Q42)
- Length of care made a significant difference to seven questions (Q41)
- Indigenous status made a significant difference to six questions (Q38)
- Age made a significant difference to five questions (Q39)
- Gender made a significant difference to four questions
- First time service consumer made a significant difference to no questions (Q40)
- Main language made a significant difference to no questions (Q37)

As the survey was conducted in English only it is not surprising that language was not found to have a significant impact on any questions.

4.13 Conclusions

The National Consumer Experience of Care survey instrument as used in the Proof of Concept Trials in late 2012, demonstrated sound psychometric properties:

Response rates: The response rates demonstrate 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.

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.

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 is 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.

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 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 should 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 should be deleted.

5. Survey administration

This section provides a brief commentary on findings from the implementation of the trial. Whilst the primary focus of the evaluation was the evaluation of the draft survey tool, understanding broader survey administration issues was considered important in interpreting the psychometric analysis of the tool and in informing considerations for future implementation.

Post survey interviews were conducted by Ipsos and VMIAC with consumers who had completed the survey, and staff from participating sites, to understand their experience of the survey and its administration. In addition each consumer worker completed a brief report on their experience of the trial.

Method

Post survey interviews were conducted face-to-face on site by a senior member of the research team. One consumer interview was conducted by telephone. Generally, staff were interviewed in small groups (two to 10 people) and consumers were interviewed on their own or with a carer. Staff interviewed included receptionists, carer consultants, clinicians, case managers, psychiatrists, quality managers and unit managers.

In total, post survey interviews were conducted with 69 people (Table 25):

- Seven consumers from two sites
- 62 staff from six sites

Table 25: Number of interviews by site

Setting	Site	Consumers	Staff	Total
ity	1	5	12	17
Community	2		9	9
Com	3	2	11	13
	4		13	13
tient	5		9	9
Inpatient	6		8	8
		7	62	69

Consumer interviews were of 5 to 20 minute duration and staff interviews were of 15 to 45 minute for some of the group interviews.

Participation in the interview process was voluntary. All participants were explained the purpose of the interview and provided consent prior to their participation. The level of consent (verbal or written) varied depending on the local ethical requirements.

Promotional material

Promotional materials were provided to each site, including posters, brochures and a signed dropbox. The brochures were generally on display with the drop box (in reception for community sites and communal areas of inpatient sites), as well as on information stands and coffee tables. The posters were on display in a range of areas including waiting rooms, notice boards, kitchen, toilets and other areas staff and consumers may visit.

There was not strong recall of the brochures and other marketing materials. In several cases, consumers actively looked for the posters in the waiting room while being interviewed and were still unable to locate them.

"I can't see a poster. Where is it?" Consumer, community site

Similarly, most staff were not aware of the posters and did not reference them when talking about sources of information for the survey. No consumers interviewed recalled seeing the posters for the survey before being offered a survey by the consumer worker. This suggests that awareness may be built over time.

"I didn't notice anything like the posters until I came back for the next visit to the centre [after completing the survey]." Consumer, community site

The drop box was more identifiable by staff and consumers with both groups aware of its location. When consumers and staff were aware of the promotional materials they universally praised their quality.

"It was nice that the box and the brochures looked professional...that added to the credibility. It looked slick and like we meant it." Staff, community site

Awareness of the survey process

While the research team briefed staff on site about the survey process prior to commencement of surveying and provided copies of the survey, brochure and a summary information sheet, staff had very different levels of awareness of the survey process. Particularly in community sites, many staff felt unaware of the survey content and had not considered how answering the questions may affect their consumers.

"I didn't really think about the effect on my clients, but they are in the community. It's a survey. I don't know that I need to really vet them that way. Not my clients, anyway." Staff, community site

"Instructions in writing about what it meant for staff would have been helpful". Staff, community site

Where consumer workers attended morning meetings and/or staff meetings, they provided an ongoing source of information to staff about the project.

"[Consumer worker] came to a few meetings to talk about the project. Also she came and did an in-service talk. It was clear enough. We knew what was going on." Staff, inpatient site

As a new project, consumers were not aware of the survey until briefed by the consumer worker. All consumers were very positive of the introduction provided by the consumer worker.

"It was a straightforward thing... [consumer worker] explained what I had to do. She gave me a good explanation." Staff, community site

Consumers understood the consent process, options for completion and how to return the survey.

"I have done some survey work myself and research. I thought they were good questions to ask. It was good to take it home and do it when I had the spare time. It was good to have that option of posting it back in my own time." Consumer, community site

Identifying consumers

In inpatient sites, the consumer workers generally attended morning meetings and/or handovers and were therefore aware of recent admissions and discharges, and able to ask the staff if any consumers should not be approached that day. Consumer workers in inpatient sites were also able to view unit documentation that showed planned admissions and discharges.

The approach to identifying consumers was different between community settings depending on the local management of consumer appointments. Where there was a centralised system, the consumer workers were able to access a list of appointments for each day they were on site. However, in other cases, where clinicians directly managed their own appointments, consumer workers were able to access a list of the entire patient population for the site. This provided little practical information.

"We do a list everyday anyway...it's part of the normal process. [The consumer worker] could just take a copy and start." Staff, community site

The best time to interview consumers, particularly for community settings was something that generally took a week or two to establish so that there were sufficient consumers likely to be available to warrant the attendance of the consumer worker. A relationship with the reception staff was often crucial in establishing the best times to offer the survey (that considered both the number of patients attending and likely waiting for appointments).

Identifying consumers too unwell to participate

The methods for identifying consumers too unwell to participate in the survey varied between sites and in part reflected the administrative structures of the service. Where consumer workers attended morning meetings or handovers, consumers too unwell to participate would be identified.

For community sites, the process was generally less structured than inpatient sites. In some cases there was an assumption that consumers would be well enough to participate (assuming they passed the capacity component of the consent process). In these cases, in the absence of formal processes to identify consumers who were unwell, staff appeared to become less engaged with the survey, and reported not considering the impact of participating in the survey on their consumers. In several cases these staff were not aware of the process to nominate a consumer as too unwell to participate. This group of staff reported having forgotten the content of the survey so were unlikely to be aware of any potential triggers for their consumers. While it is important to note that without exception these staff commented that they did not have concerns about their consumers participating in a survey, they did feel that they could have been better engaged with the process after the initial introduction by the research team.

"I don't remember what was in the survey. I know I saw an early draft...but I would not know if filling it out would send off any of my guys. Didn't even think about it until now. Now you've got me thinking." Staff, community site

"We knew [consumer worker] had it in hand so we didn't need to worry about it." Staff, community site

"I like to think if I did have concerns about a client doing the survey I would have figured out what to do about it, but I don't know off the top off my head." Staff, community site

Consumer worker role

Consumers interviewed unanimously reported that the consumer offer made a big difference to their participation in the survey. The presence of the consumer worker was seen as encouraging and providing a 'warm welcome' to community sites.

"Just having a friendly face here [in the waiting room] to greet you. Such a difference!" Consumer, community site

"I know [the consumer worker]. I trust her. She's one of us! It's nice to see consumers working for the centre. I might get a job too!" Consumer, Community site

Site staff also acknowledged the value of a consumer offer.

"It's more relevant to other consumers to have another consumer offering it [the survey]." Staff, community site

"[The consumer worker] was like the face of the organisation for that time. I think it was a great idea...I think she would have got more honest feedback." Staff, community site

However, some staff expressed concern that the use of the consumer worker limited consumers' opportunities to participate in the survey, as surveys were only available when the consumer worker was on site.

"Lots of missed opportunities." Staff, community site

"[Consumer worker] is not here every day. People leave unexpectedly all the time." Staff, inpatient site

"If people leave unexpectedly, and they do all the time, they don't get a survey." Staff, inpatient site

The way consumer workers were integrated into the site seemed to reflect the culture and previous experiences of the site in working with consumers. In most cases, the consumer worker was considered part of the staff team and participated in staff meetings, briefings and handovers. This was particularly the case where consumer workers had previous professional involvement with the site. In one case, staff wondered whether consumers would be aware that the consumer worker was actually a consumer, given how closely the staff team worked together and shared roles.

"[Consumer worker] is part of the team. No one on the floor would know how her role was any different to any other staff member." Staff, inpatient site

However, there were other cases where the consumer worker was not seen as part of the staff team. This generally occurred where the role of a consumer worker was new to the site.

"[The consumer worker] couldn't attend [staff] meeting where we talk about other patients, that wouldn't be right...same with the offices. There is confidential material around." Staff, community site

The selection and training of the consumer worker was seen as critical, particularly training on the separation of advocacy and research roles. There was one case where staff felt further training would have been beneficial for the consumer worker.

Impact of the approach on site

Staff generally felt that the approach worked well and had little or no impact on local resources.

"Very positive process. Plenty of information...good support if there were any concerns." Staff, community site

"I thought it was a great opportunity for consumers to have a say...I didn't have any concerns about it." Staff, community site

"To have it all go on and not be an extra burden on us was a really positive thing". Staff, community site

Where staff had previously not worked closely with consumer workers, they reflected positively on the opportunity. Several staff commented that it showed a cultural maturity on behalf the organisation and hoped it reflected a continued commitment to active engagement with mental health consumers in positive roles.

"It really makes you see consumers in a different way." Staff, community site

"I had been here for nine months before I met a consumer consultant...." Staff, community site

"The consumer worker got on with staff really well....there was increased interaction with staff. Increased contact with consumers generally which seemed to be very positive." Staff, community site

Staff often mentioned the importance of having a consumer worker with 'the right personality' to fit the site and feel confident to approach consumers, particularly where they may not be familiar with the consumers of the site. Several staff expressed concern about consumer workers' well-being when there were no consumers to interview.

"[The consumer worker] sat in the waiting room for hours on end like a shag on a rock...it was embarrassing." Staff, community site

While staff generally reported that there was no extra workload as a result of the survey, the exception to this was around the use and storage of the iPads. Particularly where the consumer worker was new to the use of the iPad there was a need for some local support initially, in addition to the training provided by the project team. Some staff also reported that the secure storage of the iPads in staff offices did cause some difficulties, particularly when staff were not available to retrieve iPads when needed by the consumer worker.

"I was supporting [the consumer worker]... especially the IT [sic] stuff with the iPads, but the benefits outweighed the burden. She did really well." Staff, community site

"I can honestly say that I didn't hear anything bad about it [the research] and believe the staff would have been knocking on my door! None of the clinicians said anything about it in a negative way." Staff, community site

Organisational support for consumer workers

Some staff were unsure they could support the consumer worker's role in offering the survey. They did not want to influence their consumers to participate but felt they could have improved the response rate if they had reminded their consumers about the survey.

"Were we supposed to talk to our clients about the survey? I thought only the consumer worker was allowed to mention it but I'm not sure." Staff, inpatient site

Staff not used to working with consumer workers suggested that consumer workers should be supported through their mental health case worker, rather than the professional structure of the organisation.

"If [consumer worker] needed support I guess she would go to her case worker." Staff, community site

"If I had questions I would go to [consumer worker's case worker]." Staff, community site

This also raised the issue of the potential for a conflict of interest where consumer workers were current consumers of the mental health service and suggests a need for greater staff training.

Alternative approaches

Staff also suggested other approaches to the administration of the survey to improve efficiency or reach more of their consumers, once the research phase was over. These commonly involved allowing clinical staff to give the survey to their consumers, or allowing receptionists to hand out the survey in community settings.

"We are all interchangeable [consumer worker and other staff]. I don't see why any staff member couldn't have given out the survey." Staff, inpatient site

"Why can't the receptionist hand out the survey? Patients have to give them their Medicare card and check-in anyway." Staff, community site

It was also suggested in discussions with one inpatient site that surveying during an admission may affect the quality of the data. However, most staff felt that consumers, including during an inpatient admission, were able to provide valuable and timely feedback about their experience.

"You get different information while people are in the unit compared to outside...you have to question the applicability of the data. Could be clouded. Some sort of consideration needs to be taken...mood can change." Staff, inpatient site

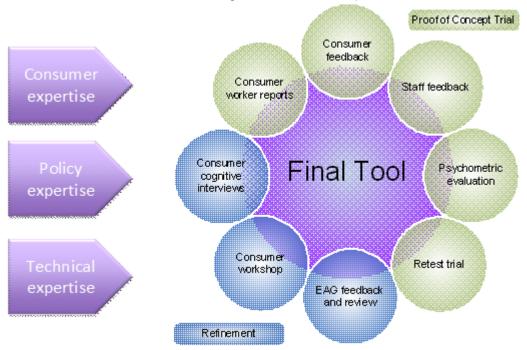
"Consumer feedback is valuable...even when they're unwell it's about their perception of what happens. If it's possible to do anything about it, we will." Staff, inpatient site

Conclusion

Consumers found the survey was easy to complete and the questions were seen as meaningful and relevant to their experience. While the posters and brochures provided to sites were seen as professional and well produced, they did not appear to generate awareness of the survey largely due to the high volume of existing materials on display at sites. Consumer workers were seen as excellent advocates for the survey and congratulated by consumers and staff for providing an example of how consumers can be actively engaged in the mental health workforce and support consumer participation in service improvement. For some staff this was the first time they had worked with mental health consumer workers. The way consumer workers were supported and integrated into the workforce at each site reflected the broader culture and experience of the health service with consumer workers. While there were some differences between sites in administrative arrangements for consumer workers to access client lists and appointment details, the process seemed to work well. Staff generally reported that implementing the survey process at the site was straightforward and required few local resources.

6. Survey Instrument Refinement

The EAG adopted a number of changes to the survey following review of the psychometric testing and the findings from the qualitative evaluation activities with consumer workers, consumers and staff, as outlined in this section. These changes were not unanticipated.



Questions were considered in terms of deletion and or revision.

Deletion of questions

We know from consumer feedback during the PoC trial that while the survey completion results were not adversely affected by the number of questions, consumers would have preferred the survey to be shorter and that a number of consumers reported not wanting to participate in the PoC because of perceived burden. There are also time and cost advantages of a shorter survey.

Questions were analysed to identify the contribution they made to the overall survey⁵ (see Table 19 which lists question item performance in rank order and Table 24 which lists impact of demographics on questions). As a result of this review six questions were deleted.

As part of the consideration to delete these questions, the impact on domain coverage (using the policy map of questions constructed at the commencement of the project) was also considered (see Table 11). As shown in the accompanying table, all experience domains retained target question coverage following survey revision.

⁵ While Q2 (Your opinions about the involvement of family or friends in your care were respected) was identified as of lower contribution to the survey statistically, it was retained unaltered as this question forms part of a group of questions about family and friends involvement, was unique and was important to both consumers and their carers.

Table 26: Impact of deleted questions on experience domains

Policy mapping of questions to Domains	Individuality	Choice and involvement	Attitudes, rights and respect	Information	Partnerships	Access	Safety	Physical environment	Outcome and	Overall
Initial number of target questions per domain	5	5	6	2	2	5	2	1	3	1
Deletions per domain	(2)	(1)	-	-	-	(2)	-	-	-	-
Revised number of questions per domain	3	4	6	2	2	3	2	1	3	1

(see also Attachment 6 for experience domain coverage of refined questions)

The rationale for each question's deletion is provided in the accompanying table.

Table 27: Deletion of questions

Initial questions	Discussion
Q5. You were able to get in contact with this service when you needed (Domain: Access)	This question was highly correlated to questions related to seeing staff when you wanted and access to your treating doctor (Q4 and Q6). Consumer feedback had identified that consumers considered the staff to be the core aspect of the service. As consumers were currently accessing the service when completing the survey, the question of unmet need in terms of service entry or timely assessment may require an alternative audience and may be better targeted through specific surveys
Q7. You had access to a range of other professional services if you needed (Domain: Access)	This question was not highly correlated to any other questions. In development this question had been described as including services from allied health to complementary therapists. On review, many of the issues intended to be covered by this question were seen as being covered in the Q27: development of a care plan that considers all of your needs.
Q10. You were able to do the things that were important to you while using this service (Domain: Individuality)	While not highly correlated with other questions, it was considered that the intent of this question was similar to that of Q22 around meaningful activities. Q22 was referred for further development through cognitive interviewing.
Q11. Staff caring for you took the time to get to know you as a person (Domain: Individuality)	This question was highly correlated with six other questions that covered the concept of individuality and respect. It was considered that this topic was well covered through these existing questions.
Q14. You were involved in planning your future care (Domain: Choice and involvement)	This question was highly correlated to six others, including questions related to opportunities to discuss progress (Q15) and being listened to in all aspects of care and treatment (Q13). The original intention of the question had been to explore discharge planning. Earlier versions of this question had performed poorly in cognitive testing. Poor performance of the question may have related to the timing of survey administration which was prior to service exit rather than at service exit. Other aspects of this question were felt to be covered in the Q27 about the development of a holistic care plan. Discharge planning may be better targeted through specific surveys.

Initial questions	Discussion
Q40. Is this the first time you have been a consumer of this service? (Domain: Demographics)	This demographic question was found to have no significant impact on how consumers rated experience questions. It was also found that consumers in the survey were three times more likely to identify themselves as first time users than found in service population figures. The discrepancy was higher for community consumers. This question lacked face validity and relevance to the consumer experience. First time users may be better targeted through specific surveys.

Changes to question wording

Utilising the evaluation framework previously noted, three questions were found to be under performing. These were questions that had been identified as of high importance to consumers during the survey development phase. Structured cognitive interviews facilitated by a consumer and technical researcher, were held with 8 Victorian mental health consumers to test any proposed question changes in a similar manner to that utilised in the survey development. Changes made to each question are outlined in the accompanying table.

Table 28: Changes to question wording

Initial questions	Discussion	Changed to
Q3. You felt safe to ask questions, provide feedback or make a complaint if you wanted	This question did not test well, and was noted to be unduly complex. It was felt the question had strayed from the original intent of freedom from reprisals if making a complaint.	You believe that you would receive fair treatment if you made a complaint
Q18. Staff ensured you understood the effects of your treatment options (including any medication, talking therapies, etc)	This question fell just short of the threshold for review. However, due to its importance to consumers (and relative underperformance) it was decided to do further cognitive interviewing to improve the question and its utility to the survey.	Staff discussed the effects of your medication and other treatments with you
Q22. You had things to do that were meaningful for you*	This question was only offered in the inpatient settings. It contributed little to the survey overall despite covering an important concept: relief from boredom. In the PoC many consumers reiterated the importance of activities in both the positive and negative open ended feedback	There were activities you could do that suited you

Question ordering

The order of questions, and how they are grouped or banked, has an impact on the ratings provided. It is therefore important that questions are maintained in fixed order once the survey is finalised and that additional questions that may be included from time to time (for example, service specific questions) are presented after the rating questions. Ideally, new questions should use the same scales as existing questions or clearly explain and highlight the change in scale to consumers.

In discussions with the EAG it was decided that, a logical order should be applied to the survey to assist consumers' ease of survey completion and that questions should be grouped around the consumer journey through a mental health service. To understand how consumers see this journey and the questions that would be relevant to each stage, a focus group was held with 15 NSW mental health consumers. During this focus group, consumers identified the major stages of the consumer journey (as themes for banking questions) and then ordered the questions within each bank to produce the final survey structure.

In open-ended questions, it will remain important that negative questions precede positive questions so consumers are able to express their poor experiences before moving on to note positive experiences. This was effective in the PoC.

Question numbering

It is likely that new questions will be included in the survey from time to time to update the content, capture local issues or new policy directions. To assist in managing this process each section of the survey has been labelled with a letter. This will allow new questions to be added to the end of a group without effecting the numbering of subsequent questions. It will also help identify the purpose of each question. The following labels have been used:

- E-1 to E-2 = Experience questions
- O-1 to O-4 = Outcome questions
- S-1 to S-n = Service questions
- F-1 to F-2 = Open ended or free test guestions
- D-1 to D-7 = Demographic questions

New question

Through the PoC trial, consumers reinforced the importance of the opportunity for assistance to complete the survey to ensure that people of different levels of English literacy, cognitive impairment, etc, are able to provide their experience to the service. A question for assisted administration has been included at the ended of the survey (which was tested in the consumer focus group) so that the potential impact of assistance on the results can be controlled.

7. CONCLUSION & NEXT STEPS

The Mental Health Consumer Experiences of Care Survey instrument has been developed as a tool to inform local service improvement referenced by the recovery principles of the 2010 National Standards for Mental Health Services and was trialled in adult public mental health services in four jurisdictions in six settings spanning acute inpatient and site based community settings.

It has been developed with extensive consumer involvement spanning project design, implementation and evaluation through: literature reviews, consumer consultations, consumer workshops, consumer cognitive interviews, trial site engagement, training of consumer workers, qualitative evaluation activities and instrument refinement activities. This process of embedding lived experience expertise reflects implementation of the recovery principles around which the survey instrument is shaped.

Trial findings corroborate the instrument's psychometric robustness and consumer acceptability. The refined survey instrument clearly addresses areas of policy and practice concern to consumers, service providers and policy makers identified at the project's inception, namely a commitment to the implementation of recovery oriented care. It is simple and brief and spans a breadth of concepts that will meaningfully inform service improvement (Annex 1).

The evaluation findings also noted that the trial's small sample size (n=222) has limitations and further development work with a larger population sample will enable the development of reporting capabilities (such as the development of indices). In addition, work is required to assess the utility and acceptability of the instrument in the broader context of service mental health provision (across service settings and age span) as well as to determine effective modes of implementation.

The shape and form of the next steps of instrument development will depend on:

- Opportunities and resources available to support further implementation and evaluation
- Scale and nature of further implementation
- Policy priorities of tool implementation.

This section provides an overview of some of the considerations for further testing and development of the survey and its implementation.

SURVEY DEVELOPMENT

Controlling for confounding effects

For comparative benchmarking and tracking performance over time, it is important to control for factors other than service performance that may affect survey responses. These factors are known to include consumer characteristics (e.g. age and gender) and service characteristics (e.g. size, location, service type). While other factors such as diagnosis and treatment may also affect the results, this information is unlikely to be available due to ethical and privacy reasons. As controlling for these confounding factors is done after surveying, the need for controls can be explored through either a pilot or first wave of surveying.

Domains

The trial demonstrated that domains exist in the data, however, the sample size (n=222) was not sufficient to fully develop these domains statistically. Many health surveys are not presented or analysed in domains. Presenting questions in domains has been reported by respondents to be

easier to complete, although banking questions into domains also increases the similarity of the responses in the bank.

Domains can be constructed in several ways depending on how they will be used. Deductive domains are based on logical classification, whereas inductive domains are developed primarily from an analysis of the data. Deductive domains may be used to cluster questions and for reporting and tracking against performance indicators, policy objectives, organisational process, etc. This survey's development process was informed by deductive domains generated from the recovery principles in the National Standards for Mental Health Services 2010.

Potentially, deductive domains could be developed that span a suit of surveys such as the Consumer Experience of Care, Life in the Community and The Carer Experience surveys as part of the coordination and presentation of data for quality improvement. Maintaining common questions across these surveys assists in this process. Currently there is some overlap in the outcome questions between all three surveys (see below) and it is recommended this is continued.

Table 29: Outcome Questions in Public Mental Health Surveys

Consumer Experience of Care	Life in the Community	The Carer Experience
28. Overall, how would you rate your experience of care with this service in the last 3 months?		
29. The effect the service had on your ability to manage your day to day life	22. Your ability to achieve the things that are important to you	
30. The effect the service had on your hopefulness for the future	20. Your hopefulness for the future	26. Your hopefulness for the future
31. The effect the service had on your overall well-being	21. Your happiness with your life	27. Your overall well-being
		25. Your relationship with the person for whom you care

Alternatively, inductive domains may be developed through statistical assignment of items based on techniques such as Principal Component Analysis. In this case, domains may differ based on service type. It would also be unlikely that the same domains would be generated across the Consumer Experience of Care, Life in the Community and The Carer Experience survey.

As survey responses are susceptible to order effects, the new question order proposed for the final survey may generate some variation in the inductive domains already flagged through the trial. As the survey will not be presented in domains, testing of inductive domains can be conducted after the first wave of surveying.

Domains are sometimes used to develop short form surveys, for example, through identification of key drivers of domains. Less desirable is the use of overall questions to summarise domains. These questions cannot be used in isolation (such as a short form survey) as they are preconditioned by the embedded bank of questions.

Scale values for reporting results

Using the general population data, we now have reliable estimates for the value of the points on each scale. These values do not depart significantly from a linear numeric assignment (1, 2, 3, 4, 5). The next administration of the survey, whether through pilot or the first wave of surveying, should test the impact of using these two different methods of assigning values to the codes. If the results do not impact on service or item rank order, the simplest model should be used.

Development of Indices

For benchmarking and tracking service performance over time there is merit in development of an overall index of performance. The PoC psychometric analysis demonstrated that the survey lends itself well to regression analysis. Using regression analysis to weight performance scores is the preferred method of developing an index as it incorporates performance and importance of the item to consumers in the measure. Sometimes, outcome or overall experience questions can act as a close approximation for a constructed index and do not require complex analysis. The relationship between the constructed index and outcome questions should be explored against the intended use of such an index (such as ranking services) to identify the simplest effective approach. This could be done with the data from a pilot or the first wave of surveying.

Indices can also be identified to track areas of performance, other than overall performance. These indices could be tracking of a single question that relates to a policy priority or constructed variables that relate to domain performance.

The selection and construction of indices will be driven by the need for each index.

Short form survey

On occasion there is merit in the development of short form surveys. This may be accomplished by selection of questions that drive domains or outcome variables. In this case, while the survey has around 30 items, there was no evidence of cognitive burden in the psychometric analysis. In addition, the volatility of consumer experience identified through the retest analysis also suggests that surveying on smaller samples or more frequently may not reflect change in the service but other experiences for the consumer. Furthermore, it is also important to remember that short form and long form surveys are not automatically comparable as the answers to individual questions are affected by the order and context of questions. One possible solution to this is to administer the short form questions first in both short and long form surveys. However, for the current survey, there seems little merit in the development of a short form survey.

Inclusion of additional items

As previously noted, it is likely that services or jurisdictions will want to include additional items in the survey from time to time that reflect their local environment. These questions should be positioned at the end of rating questions so that responses to these questions are not affected by the presentation of the new questions. The refined survey has been structured to accommodate this requirement.

Ideally, new questions should use the same scales that are in the main survey. Depending on the source and use of the additional questions, this may not be possible. In any event, the formatting of the questions and their introductory text should be used to clearly draw consumers' attention to the change in scale.

National work to define core common hospital patient experience questions has led to the development of a suite of questions (derived from validated patient experience surveys) that may be incorporated into existing hospital experience measurement activities. These items have not been

developed for use with mental health consumers nor tested with this group of people; however there is policy interest in alignment of health experience measurement. Potential inclusion of a number of relevant items (depending on the service setting) from this suite, will allow for inclusion of mental health consumer experiences in this sample. All of these questions utilise different scales and there is some overlap of the concepts captured in the common patient experience questions and in the mental health survey.

In the current survey, one item has been developed for inpatient use only. All other items have been developed to be applicable across the trial service settings which included inpatient and centre-based community care. In reviewing the survey for application to other types of services, it is worthwhile considering the need for additional questions that address any service-type specific experiences or outcomes. These questions should use the same scales as the main survey and be presented immediately after the experience questions to ensure comparability of existing questions across services. Similarly, the existing questions should be reviewed for relevance prior to administration. Post survey monitoring of missing data and data distribution for each question by service type will also identify items that are not suited to the audience.

IMPLEMENTATION ISSUES

Need for a pilot

As discussed above, a pilot is only needed if further work is intended that would alter the survey presented to consumers. Given the extensive development process of the survey, and that there has been a decision to structure the questions into consumer journey rather than bank in domains, it is unlikely that a formal pilot will be required. In this case, a managed implementation processes should be used for the first wave of surveying to test the administration protocols (for example, scripting on the iPads and CATI, interviewing training, management of eligibility guidelines, etc). This usually involves early surveying at 10% of facilities in each method before implementing the remaining fieldwork as part of a risk management plan.

Survey timing

The survey has been designed to be administered during the service experience, prior to discharge. It is important that the survey is administered once the consumer has had sufficient time to experience the service. This time will vary depending on the nature of the service and length of admission.

Survey frequency

The survey was developed with the expectation of annual administration at a point in time with all eligible current consumers. The length of fieldwork should reflect the amount of time required to reach the desired sample size for a given service. Annual administration allows sufficient time to identify improvements, implement changes and for those changes to be experienced by consumers.

Survey method

From the national consultations, it was clear that jurisdictions and services were interested in iPad/ Tablet, Face to Face interviewing, Mail surveys and Computer Assisted Telephone Interviewing (CATI). Further research should test these different forms of survey administration to determine if the method affects the responses so that data can be weighted to provide services with a comparative benchmark.

While mail, face to face and electronic forms of administration are all visual forms of administration and likely to perform consistently (as found in the PoC trial where mail and tablet responses were

compared) telephone interviewing is quite different in form (auditory), does not allow respondents to scan ahead to get a feel for the questions or scope of the survey, and has the added issue of potential effects from interacting with an interviewer. Therefore, at a minimum the impact of telephone interviewing on responses needs to be investigated if this method is to be used to develop a weighting method (if found to be needed). As this will not affect the construct of the survey, method testing could be done in a pilot or the first wave of surveying.

The preferred method will reflect issues such as local approaches to the management of consent, database management, access to consumers (for example, whether facility based or outreach), support from consumer representatives and networks, and organisational support and culture. Indicative direct costs have been developed for comparative purposes⁶ (Table 30).

Table 30:

Method	Fieldwork cost
Tablet Includes: printing (posters, PIFs, consent forms, brochures), programming the survey, uploading the data, data checking, data processing, and production of tables. Excludes: equipment cost, offer of iPad to consumers, analysis and reporting	47.76
Face to face interviewing Includes: printing (posters, PIFs, consent forms, brochures, envelops, etc),mail costs, mail handling, double data entry, data checking, data processing, and production of tables. Excludes: interviewers (assumed use of current peer workforce), interviewer training and management, analysis and reporting	82.48
Mail Includes: printing (posters, PIFs, consent forms, brochures, envelops, etc), mail costs, mail handling, double data entry, data checking, data processing, and production of tables. Excludes: Analysis and reporting	87.76
CATI [*] Includes: IQCA interviewers, printing (posters, PIFs, brochures), data checking, data processing, and production of tables. Excludes: training of consumer interviewers, analysis and reporting	112.64

^{^.} CATI costs assume a completion rate of one interview per hour

Consumer engagement and participation

Consumer engagement was a cornerstone of the survey development and testing and was embedded in the PoC trial. This approach demonstrated both successful contributions to the research design, consumer participation in the PoC, as well as in broader workforce matters such as through the enhancement of consumers role in quality improvement and as role models for recovery.

Incorporation of consumer expertise in future implementation approaches will ensure this commitment continues. The ways consumers can be involved in future administration of the survey needs to be considered for example:

- As interviewers in CATI surveys
- As distributors of surveys for self-completion face-to-face
- As the contact person for more information for mail surveys
- As communicators with consumer and carer networks and support groups promoting engagement in the survey

⁶ Costs are based on a population size of N=300 and completed surveys of n=50

In addition, consumer engagement in the quality improvement cycle through interpreting and communicating the findings of survey results and in the developing service improvement responses has been an important component of creating credibility with consumers in existing experience measurement surveys.

Quality Improvement

The survey has been developed with the aim of informing service improvement: for this to be effected implementation should be placed within a quality improvement framework. Such a framework that embeds consumers as a key party in the process reflects existing mental health and heath quality standards and evidence. Feedback from providers has also noted the value of resources that assist services to understand their findings and provide guidance on ways to proceed with relevant local service improvement based on survey findings.

Ethical considerations

Ethical approval was required for the testing of the survey in the trial. Guidance will need to be sought as to whether ethical approval will be required for the next stages of implementation depending on whether implementation is considered research or service improvement. If the next stages of development are controlled implementation it is probable that this could be defined as service improvement.

Protocol

There was support across stakeholder groups for access to benchmark and tracking data to guide local service improvement priorities and understand relative service performance. Achieving these aims requires the development and coordination of the data collection methods and centralised data management processes to ensure the comparability of data. This central coordination can also be used to protect the confidentiality of service results (if required) while still supporting the aggregation of data to create large enough samples to undertake the statistical analysis as previously identified, to inform approaches to the development of reporting frameworks and comparative benchmarks.

ANNEX 1: REFINED CONSUMER EXPERIENCES OF CARE SURVEY – Proposed final instrument questions showing item sequence, content category, item wording and response options

Question sequence number ¹	Content category ²	Item technical reference number ³	Item wording	Rating scale (Response options) ⁴				
Stem for it	Stem for items E-1 to E-17: Thinking about the care you have received from this service within the last 3 months or less, what was your experience in the following areas:							
			• • • • • • • • • • • • • • • • • • •					
			BANK 1 (STARTING OUT) ⁵					
1	Experience	E-1	You felt welcome at this service	Frequency				
2	Experience	E-2	Staff showed respect for how you were feeling	Frequency				
3	Experience	E-3	You felt safe using this service	Frequency				
4	Experience	E-4	Your privacy was respected	Frequency				
5	Experience	E-5	Staff showed hopefulness for your future	Frequency				
6	Experience	E-6	Your individuality and values were respected (such as your culture, faith or gender identity, etc)	Frequency				
			BANK 2 (WORKING TOGETHER) ⁵					
7	Experience	E-7	Staff made an effort to see you when you wanted	Frequency *				
8	Experience	E-8	You had access to your treating doctor or psychiatrist when you needed	Frequency *				
9	Experience	E-9	You believe that you would receive fair treatment if you made a complaint	Frequency *				
10	Experience	E-10	Your opinions about the involvement of family or friends in your care were respected	Frequency *				
11	Experience	E-11	The facilities and environment met your needs (such as cleanliness, private space, reception area, furniture, common areas, etc)	Frequency				
	BANK 3 (TREATMENT AND CARE) ⁵							
12	Experience	E-12	You were listened to in all aspects of your care and treatment	Frequency				

Question sequence number ¹	Content category ²	Item technical reference number ³	Item wording	Rating scale (Response options) ⁴	
13	Experience	E-13	Staff worked as a team in your care and treatment (for example, you got consistent information and didn't have to repeat yourself to different staff)		
14	Experience	E-14	Staff discussed the effects of your medication and other treatments with you	Frequency	
15	Experience	E-15	You had opportunities to discuss your progress with the staff caring for you	Frequency	
16	Experience	E-16 ⁶	There were activities you could do that suited you	Frequency *	
17	Experience	E-17	You had opportunities for your family and carers to be involved in your treatment and care if you wanted	Frequency *	
Stem for ite	ems E-18 to E-22: T	hinking abou	t the care you received from this service within the last 3 months of less, please rate the foll service	lowing aspects of this	
18	Experience	E-18	Information given to you about this service (such as how the service works, which staff will be working with you, how to make a complaint, etc)	Performance	
19	Experience	E-19	Explanation of your rights and responsibilities	Performance	
20	Experience	E-20	Access to peer support (such as information about peer workers, referral to consumer programs, advocates, etc)	Performance *	
21	Experience	E-21	Development of a care plan with you that considered all of your needs (such as health, living situation, age, etc)	Performance	
22	Experience	E-22	Convenience of the location for you (such as close to family and friends, transport, parking, community services you use, etc)	Performance	
	Stem for items	O-1 to O-4: A	As a result of your experience with the service in the last 3 months or less please rate the following	lowing	
23	Outcome	0-1	The effect the service had on your hopefulness for the future	Performance	
24	Outcome	0-2	The effect the service had on your ability to manage your day to day life	Performance	
25	Outcome	0-3	The effect the service had on your overall well-being	Performance	
26	Outcome	0-4	Overall, how would you rate your experience of care with this service in the last 3 months? Perform		

Question sequence number ¹	Content category ²	Item technical reference number ³	Item wording	Rating scale (Response options) ⁴	
			OPTIONAL ADDITIONAL SERVICE-SPECIFIC QUESTIONS		
Additional items can be added here	S	S-1	Specific wording and number of any additional questions to be determined by the service organisation in accordance with local requirements	Recommended to use either Frequency or Performance	
to suit local service needs. The number of additional items is referred to as 'n' below.	S	S-n	Specific wording and number of any additional questions to be determined by the service organisation in accordance with local requirements	Recommended to use either Frequency or Performance	
OPEN ENDED QUESTIONS					
27+n	F	F-1	My experience would have been better if	Free text	
28+n	F	F-2	The best things about this service were	Free text	

DEMOGRAPHIC QUESTIONS

Introductory wording for items D-1 to D-7: This section asks for some information about you. The information helps us to know if we are missing out on feedback from some groups of people. It also tells us if some groups of people have a better or worse experience than others.

Knowing this helps us focus our efforts to improve services. No information used in this section will be used to identify you.

Question sequence number ¹	Content category ²	Item technical reference number ³	Item wording	Rating scale (Response options) ⁴
29+n	Demographics	D-1	What is your gender?	1 Male, 2 Female, 3 Other
30+n	Demographics	D-2	What is the main language you speak at home?	1 English, 2 Other (Please write in)

DEMOGRAPHIC QUESTIONS

Introductory wording for items D-1 to D-7: This section asks for some information about you. The information helps us to know if we are missing out on feedback from some groups of people. It also tells us if some groups of people have a better or worse experience than others. Knowing this helps us focus our efforts to improve services. No information used in this section will be used to identify you.

Question sequence number ¹	Content category ²	Item technical reference number ³	Item wording		Rating scale (Response options) ⁴
31+n	Demographics	D-3	Are you of Aboriginal or Torres Strait Island	1	No,
02*	2 668. 666		origin?	2	Yes, Aboriginal,
				3	Yes, Torres Strait Islander,
				4	Yes, Aboriginal and Torres Strait Islander
32+n	Demographics	D-4	What is your age?	1	16 to 24 years
			,	2	25 to 34 years
				3	35 to 44 years
				4	45 to 54 years
				5	55 to 64 years,
				6	65 years and over
33+n	Demographics	D-5	How long have you been receiving care from	1	Less than 1 week
			this service on this occasion?	2	1 to 2 weeks
				3	3 to 4 weeks,
				4	1 to 3 months,
				5	4 to 6 months
				6	More than 6 months
34+n	Demographics	D-6	At any point during the last 3 months were you receiving	1	Yes, involuntary patient / on a
			involuntary treatment (such as an		community treatment order
			involuntary patient or on a community treatment order)	2	No, I was always a voluntary patient
			under Mental Health Legislation?	3	Not sure
35+n	Demographics	D-7	Did someone help you complete this survey?	1	No
				2	Yes – family or friend
				3	Yes – language or cultural interpreter
				4	Yes – consumer worker or peer worker
				5	Yes – another staff member from the
					service
				6	Yes – someone else

Key to Table notes

1. Question sequence number

This column identifies the proposed questions sequence numbering in the revised survey instrument.

2. Content category

This column groups the items into like categories.

3. Item technical reference number

These numbers are intended for technical reference only for future cross-mapping between potential survey versions. The alphanumeric numbering system combines the item content category (the alpha) and the sequence number of the item within the category (the numeric).

4. Rating scale (Response options)

Frequency scale:

1 Never, 2 Rarely, 3 Sometimes, 4 Usually, 5 Always.

Items marked with asterisk (*) also include the response option of 'Not applicable'.

Performance scale:

1 Poor, 2 Fair, 3 Good, 4 Very good, 5 Excellent. Items marked with asterisk (*) also include the response option of 'Not applicable'. Items marked with asterisk (*) also include the response option of 'Not applicable'

5. Bank

This describes the underlying rationale for grouping and sequencing (or 'banking') of items. It is not intended that these bank descriptions be displayed on printed survey forms.

6. Item E-16 - "There were activities you could do that suited you"

This item was only used in the inpatient version of the survey used in the Proof of Concept trial. It is not considered applicable outside inpatient and residential settings.