

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).

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.

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.

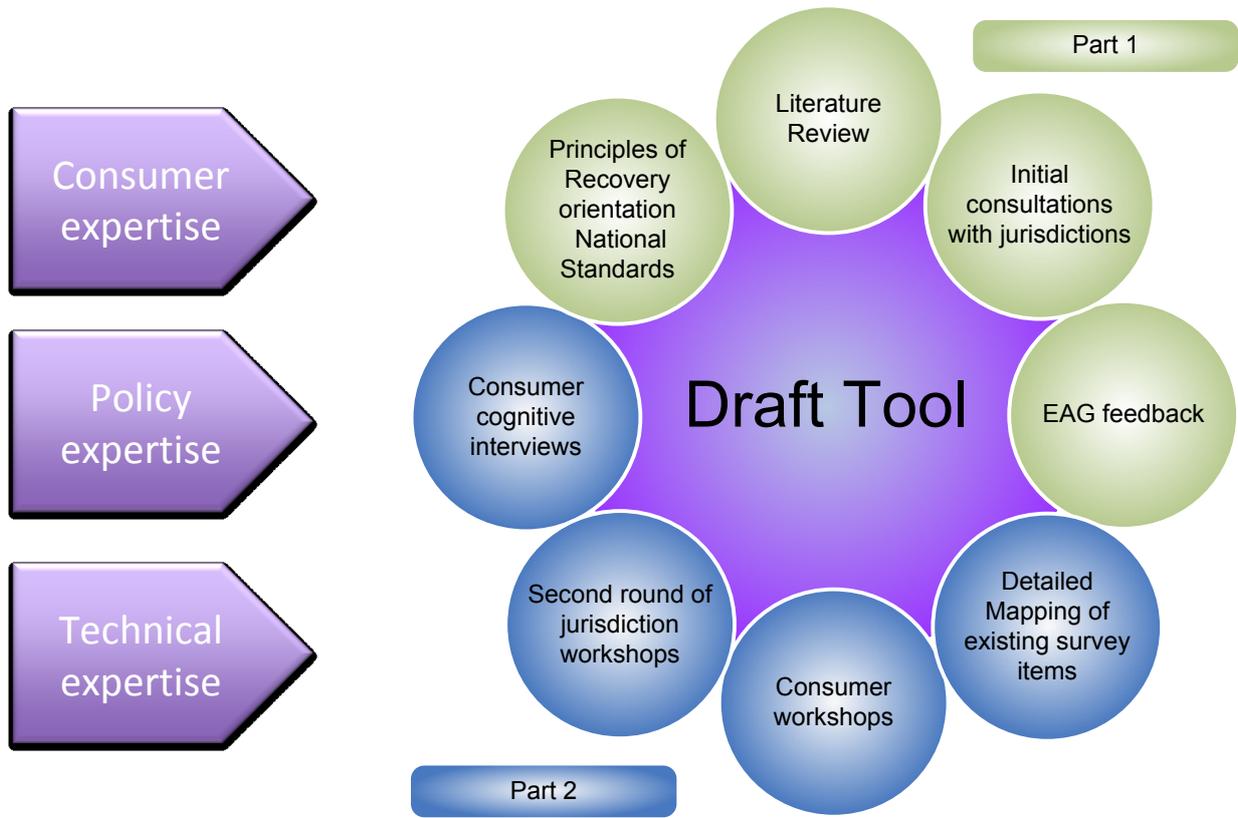
A total of 94 experts were consulted in 35 face to face meetings and teleconferences.

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.