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**

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

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 purposes\(^6\) (Table 30).

<table>
<thead>
<tr>
<th>Method</th>
<th>Fieldwork cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tablet</td>
<td>47.76</td>
</tr>
<tr>
<td>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</td>
<td></td>
</tr>
<tr>
<td>Face to face interviewing</td>
<td>82.48</td>
</tr>
<tr>
<td>Includes: printing (posters, PIFs, consent forms, brochures, envelopes, 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</td>
<td></td>
</tr>
<tr>
<td>Mail</td>
<td>87.76</td>
</tr>
<tr>
<td>Includes: printing (posters, PIFs, consent forms, brochures, envelopes, etc), mail costs, mail handling, double data entry, data checking, data processing, and production of tables. Excludes: Analysis and reporting</td>
<td></td>
</tr>
<tr>
<td>CATI(^\d)</td>
<td>112.64</td>
</tr>
<tr>
<td>Includes: IQCA interviewers, printing (posters, PIFs, brochures), data checking, data processing, and production of tables. Excludes: training of consumer interviewers, analysis and reporting</td>
<td></td>
</tr>
</tbody>
</table>

\(^\d\) CATI costs assume a completion rate of one interview per hour

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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

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\(^6\) 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 health 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.