

Indigenous Adult Mental Health Outcomes Project

***In the Cairns Network
Far North Queensland***

Final Draft

December 10, 2006

Published on line

2018

Melissa Haswell, Rachael Wargent, Ernest Hunter
Australian Integrated Mental Health Initiative (AIMhi)
North Queensland Indigenous Stream
North Queensland Health Equalities Promotion Unit
University of Queensland and Queensland Health
Cairns, Queensland

Foreword

This project used multi-faceted, collaborative approaches to enhance; then monitor, the systematic collection of standardised clinician-rated Outcomes information with Indigenous adult consumers across the Far North Queensland mental health network. While the project was led by University of Queensland researchers, valuable input was provided by Indigenous and non-Indigenous researchers, health information and service managers, trainers, clinicians and stakeholders including remote area consumers and carers in Queensland, as well as experts from Melbourne, Sydney and New Zealand. It is hoped that the research questions, study design, methods used and the reflections presented in this report have captured the diversity of views and issues raised by these valued collaborators.

Given that the focus here is on Indigenous Mental Health Outcomes, it was essential that discourse at all stages of the project privileged the views of Australian Indigenous people. In later stages, input was also provided by members of the Maori Monitoring and Implementation Group of the Mental Health – Standardised Measures of Assessment and Recovery Team (MH-SMART), who are addressing similar issues in New Zealand. Through such processes, the researchers aimed to highlight shared Indigenous perspectives about ways that Indigenous mental health could be better understood, assessed and addressed. Mental health information has a particularly high risk of cross-cultural inaccuracy as it relies on exceptional communication and understanding. Hence Indigenous input into its collection, analysis and interpretation is essential. The findings of this report add quantitative support to this perspective and there is ample literature and policy directing this approach (Queensland Mental Health Policy Statement: Aboriginal and Torres Strait Islander People, 1996, Aboriginal & Torres Strait Islander Research Agenda Working Group, 2003, NHMRC, 2003).

Above all, this report aims to assist Australia to collect and interpret as accurate and useful information on Mental Health Outcomes of Indigenous consumers to guide informed action towards improvement. The researchers acknowledge the limitations of this project's findings and interpretations and welcome feedback, which may be sent to the Project Leader, melissa_haswell@qut.edu.au.

Acknowledgements

The study was conducted by researchers of Australian Integrated Mental Health Initiative (AIMhi) Indigenous Stream, North Queensland Health Equalities Promotion Unit (NQHEPU), School of Population Health, University of Queensland. The team consisted of Melissa Haswell, Ernest Hunter, Rachael Wargent, Tom Ogwang, Brenda Hall and Reuben Walker, with contributions from the many collaborators and Steering Group members listed below. Special acknowledgement is made to Michelle Tonkin-Smith who provided a detailed editing of the final report.

Funding for this initiative was provided by Mental Health, Queensland Health through the Information Systems and Management Unit. Significant in kind contributions were also provided through Australian Integrated Mental Health Initiative (AIMhi) Indigenous Stream and the Northern Area Health Service, Queensland Health, which funded associated projects that informed this study and enabled a detailed editing of this report.

Steering Group Representation and Members:

The Steering Group was chaired by Dr. Melissa Haswell and included representation from the key stakeholder organisations listed below. Its members were:

Expert Consultants, Mental Health Outcomes Research

- Clinical Associate Professor Alan Rosen, School of Psychological Medicine, Sydney Univ
- Professor Tom Trauer, Department of Psychiatry, University of Melbourne

Queensland Health – Corporate Office, Brisbane

- Ruth Catchpoole, Team Leader, Information Systems and Management Unit
- Luke Hatzipetrou, Team Leader, Zonal Outcomes Team
- Dean Lewin, Principal Project Officer, Information Systems and Management Unit

Queensland Health – Cairns Health District and Northern Area

- Mercy Baird, Indigenous Mental Health Coordinator, Cairns Integrated Mental Health
- Andrew Brownlie, Nursing Director, Mental Health Unit, Cairns Base Hospital
- Tony Swain, Acting Team Leader, Mental Health for the Northern Area Health Service
- Kathy Stapley, formerly Zonal Outcomes Coordinator, Cairns Network

Wuchopperen Health Service

- Leanne Knowles, Executive Officer, and Greg Pratt, Male Counsellor, Social Health

Apunipima Cape York Health Council

AIMhi Project Chief Investigators of the Indigenous Stream

- Dr Melissa Haswell, Senior Lecturer Public Health (Mental Health), Head of the North Queensland Health Equalities Promotion Unit, Cairns Office, Univ of Queensland
- Professor Ernest Hunter, Consultant Psychiatrist, Remote Area Mental Health, Queensland Health & Adjunct Professor, Univ of Queensland
- Dr Tricia Nagel, Consultant Psychiatrist of the Top End Mental Health Service, NT Health and Senior Lecturer, Menzies School of Health Research, Darwin

Royal Flying Doctors Service

- Robert Williams and Brod Osborne, Psychologists

With additional input from and thanks to the following groups and individuals:

- Consumers and Carers in the Cape York region who shared their time and insight with us and with their clinicians.
- Clinicians in the Cairns Network who provided Outcomes information.
- Colleagues from the Maori Monitoring & Review Group, MH-SMART: Materoa Mar, Te Pare Meihana, Ana Sokratov, Dr Te Kani Kingi, Michele Levy, Dr Sylvia Van Altvorst.
- Participants of the Wuchopperen Workshops in 2003, 2005, 2006, and the 15 Indigenous Health Workers attending the Health Worker Forums who shared their views & ideas.
- Yvonne Wilkinson & Anthony Weller (previous Mental Health, Northern Area Health Service) for enabling support & Michelle Tonkin-Smith (Queensland Health) for editing.
- Trudi Sebasio (Principal Project Officer, Queensland Health), Kevin Freele, Diana Bissett, Talita Wheeler and Cairns Base Hospital Benchmarking Unit (Cairns District), Ruth Fagan (Gurriny Yealamucka Health Service, Yarrabah), Dr Radhika Santhanam (University of Queensland), Assoc Prof Komla Tsey (James Cook University) for support and advice.

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Executive Summary

This project, conducted by the Australian Integrated Mental Health Initiative – Indigenous Stream in Far North Queensland, explored an issue of crucial importance to the state and national Mental Health Outcomes initiative: namely, ‘will Outcomes measures contribute to the improvement of mental health among Aboriginal and Torres Strait Islander Australians?’ It is well known that Indigenous Australians are the most highly disadvantaged group in the nation and they experience an overwhelmingly greater burden of both mental and physical ill health compared to the mainstream. Thus the improvement of mental health care for this group is a national priority.

Australia has been applauded in many international documents for its well planned and implemented systems and training processes to achieve a sound mechanism for measuring Mental Health Outcomes and for reporting on and using the information to feed back into policy and practice. Queensland has taken on an additional responsibility for specifically exploring the reliability, validity and utility of these measures among consumers of culturally diverse groups, including Aboriginal and Torres Strait Islander people. This project, the Indigenous Mental Health Outcomes project, complements that of Queensland’s Transcultural Mental Health Centre in exploring complex issues that impact on the use and appropriateness of mainstream tools in transcultural contexts. As there are few Aboriginal and Torres Strait Islander mental health nurses and psychologists, the vast majority of Outcomes assessments made with Indigenous consumers are completed by transculturally.

This project, supported by the discussions held with key Indigenous and non-Indigenous stakeholders in an initial consultation workshop, started from a premise that there was sufficient justification for an evaluated trial of two of the Mental Health Outcomes scales, namely the Health of the Nations Outcomes Scale (HoNOS) and Life Skills Profile (LSP), with Indigenous adult consumers. Its aim was to modify, then assess the validity, reliability and usefulness of HoNOS and LSP with Indigenous adult (aged 18 to 64) mental health consumers in the Cairns Network of Far North Queensland.

The initial consultation workshop was also used as an opportunity to collectively identify potential pitfalls in the use of the measures and to formulate a pro-active strategy for avoiding the pitfalls and enhancing the validity of the data as much as possible. Over the next few months, a document was developed in consultation with the project’s Steering Group that presented:

- Four guiding principles to assist clinicians in completing outcomes assessments with Indigenous consumers. Briefly these involved having additional informants (family member/carer **and** local practitioner, Principle One), not underrating problems associated with levels of social disadvantage (Principle Two) or unacceptable behaviours (Principle Three) even if they are common in the community and not rating social and culturally acceptable behaviours, experiences and beliefs associated with funerals, religious or traditional activities as symptoms of illness (Principle Four);
- Instructions on how the principles should be applied when rating HoNOS and LSP items;
- Scenarios with instructions for potential use in training and support activities for clinicians;
- Advice on an Indigenous identification screen and a set of additional questions to be added onto the Outcomes Information System (OIS) that clinicians were required to complete when the consumer being assessed was identified as Indigenous.

This document informed the development of an Extended Training Module delivered to all clinicians in the Cairns Mental Health Network (five districts in Far North Queensland) as part of a full day outcomes training. Additional computer screens and questions were also added onto the OIS. Background, HoNOS and LSP data concerning Indigenous consumers that was collected into the System was de-identified and provided to the researchers for analysis. Two interim reports were submitted to assist in implementation processes.

This final report provides a detailed analysis of the 12-month period for July 2004 to June 2005. In order to assess concurrent validity of the scales, patterns observed in hospitalisation data for the Cairns Network over the same period are compared with patterns seen in Outcomes data. Qualitative data collected from consumers and carers from remote Cape York communities was used to explore content validity of HoNOS and LSP items.

The most significant findings of this work include:

- Similar levels of internal consistency of the subscales of both HoNOS and LSP applied with Indigenous consumers as that observed in non-Indigenous populations.
- A reasonable level of agreement between items on these two scales with indicators of wellness and illness identified by Indigenous consumers and carers in in-depth interviews, indicating content validity of both measures.
- A low frequency of involvement of family member/carer and/or local practitioner in assessments leading to outcomes completion, hence low adherence to Principle One.
- Demonstration of significant linkages between clinician-assessed levels of engagement achieved with consumers, families and local practitioners, ease of rating and validity of the assessment in reflecting the consumers' mental health problems.
- Markedly higher scores across most HoNOS and LSP items collected in occasions with family/carer and/or local practitioner involvement compared to occasions without involvement; this was independent of the degree of consumer engagement recorded by clinicians.
- Consistently higher HoNOS total, subscale and item scores among Indigenous adult consumers in the hospital compared to the community setting and among those with psychotic compared to substance abuse or affective disorders.
- A higher frequency of severe problems with hallucinations and delusions (HoNOS item 6) for Outcomes occasions completed upon inpatient admission with younger compared to older consumers; this is consistent with their longer lengths of stay.
- Higher scores in community collection occasions for Indigenous consumers under age 30 compared to those aged 30 and over in total, subscale and many individual items, but only where family/carer or local practitioner informants were included. This is consistent with both higher hospital admission rates and longer lengths of stay observed among younger, compared to older consumers.
- Consistency in average severity of scores for HoNOS and LSP across health districts and hospitalisation usage, with Cairns having the greatest increases in hospitalisations and the highest HoNOS and LSP scores among districts.
- Startling increases in the average scores of HoNOS items 4, 10, 11 and 12 (problems with cognition, activities of daily living, living conditions and occupation and activity) from collection occasions within the 12 month period that were specifically observed

among consumers under age 30. These increases captured by Mental Health Outcomes data were observed simultaneously with a marked increase in admissions, average length of stay and occupied bed days over the previous two years of this same consumer group.

In conclusion, this study, using a range of approaches, has produced a set of guiding principles to enhance Outcomes assessment and presented a considerable body of data that support the importance of these principles in enhancing the reliability and validity of HoNOS and LSP-16 with Indigenous consumers in the Cairns Network. The project also captured an unexpectedly powerful opportunity to demonstrate the utility of the data to inform responses to a very serious situation of increasing hospitalisation among young Indigenous consumers.

Nevertheless, improvements to both the principles and the process of application, use and interpretation of Outcomes data are needed to ensure that the data continues to improve and support better outcomes. Based on the results of this project and with the aim of guiding further improvement, the following recommendations have been made by the researchers:

1 To continue the use of HoNOS and LSP with Indigenous consumers, together with the four Principles, as tools that have the capacity to capture important information for the consumer, carer and clinician and reflect many of their expectations of assistance from mental health care providers.

2 To continue the training and support to clinicians to continually enhance their skills in applying the Principles when rating Indigenous consumers. These principles, since they assist in enabling the clinician to understand the complexity and severity of the consumers' mental state and illness, should be applied to all assessments.

3 To develop and validate consumer-rated tools that capture the more fundamental and culturally determined aspects of Indigenous mental health that HoNOS and LSP do not attempt to measure. Such tools should adopt a positive direction to support a 'working from strengths' approach.

4 To interpret ratings made without adherence to Principle One cautiously, as such assessments may under-estimate the severity of problems experienced by the Indigenous consumer. To continue to allow identification of these occasions, it is recommended that clinicians continue to routinely indicate the presence or absence of additional informants in their assessments as a routine component of Mental Health Outcomes completion.

5 To ensure that clinicians are made fully aware of the importance of working in collaboration with family/carers and a local practitioner, preferably an Indigenous mental health worker, in all mental health assessments that guide diagnosis, care planning and outcomes assessment (including initial and outcomes assessments) that they complete with Indigenous consumers **regardless of the degree of engagement or understanding they feel they have with the consumer.**

6 To support more research on the relationship between involvement of informants and HoNOS and LSP scores for consumers from similar and different cultural backgrounds as their clinicians using a design which can clarify cause and effect associations.

7 To adjust Principle Four to instruct clinicians to ensure that consumers' beliefs, experiences and behaviours are consistent in form, intensity and duration with accepted local norms before considering them as culturally valid, and hence excluded, from rating in items 2 (self harm) and 6 (hallucinations and delusions). The modification should also guide clinicians to include mental health problems that result from such experiences in their ratings, even if the experience itself is determined to be within social and cultural norms and not a symptom of mental illness.

8 To provide continued encouragement and support of district management and clinicians to increase the level of coverage according to the Outcomes Initiative protocols. In the inpatient setting, this particularly includes routine occasions at discharge as well as admission; in the community setting this means increasing coverage of all consumers at the recommended intervals for standard reviews.

9 To adjust Principle One to explicitly state that while recognising the right of the consumer to refuse involvement of additional informants in their assessment and care, clinicians and services should continually reflect on how opportunities for meaningful involvement of consumers, families, carers and Health Workers can be increased.

10 To provide opportunities for clinicians to become better prepared and supported to work with consumers, families and Indigenous Health Workers in completing Outcomes ratings. Making this a key component of training and professional development may increase clinicians' confidence and skill in working with multiple informants.

11 To encourage services to adopt a positive and pro-active approach to achieving successful collaboration with Indigenous Health and Mental Health Workers who can in turn empower consumers and families to actively guide the mental health assessment and care pathways.

12 To ensure that population level analysis and dissemination of Outcomes data be completed in a timely and locally relevant manner to maximise its use, not only between clinicians and consumers, but also in informing service planning to increase responsiveness to the varied and changing needs of the consumer population.

13 To disseminate this project's findings to key stakeholders of other regions, and encourage a collaborative approach inclusive of local Indigenous stakeholders to play a leading role in achieving the use of the guiding principles, the enhanced training and tools, and the resulting data within their locations.

14 To ensure that the following considerations are made when conducting comparisons between Indigenous and non-Indigenous Mental Health Outcomes Data: recognition of the heterogeneity of Indigenous Australian peoples (thus avoiding overgeneralisation), recognition of differences within and between regions, use of appropriate age-stratification reflecting age-related trends in Indigenous mental health indicators and documenting the presence or absence of additional informants in assessments.

Summary of Methods, Key Findings and Recommendations

An Action-oriented Framework

This project accessed views, guidance and data from a range of stakeholders in Mental Health Outcomes and Indigenous Mental Health, as well as from the wider literature. The project's action-orientation was a major strength, as it assisted the implementation of Mental Health Outcomes training and collection, and conversely, was enhanced by the improved Mental Health Outcomes collection. The project's methods were also consistent with broader policies urging Indigenous health researchers to adopt action and outcomes-oriented approaches to promote health, including mental health, equality.

Aim, Background and Process

The aim of this project was to modify, then assess the validity, reliability and usefulness of the Health of the Nations Outcomes Scale and the Life Skills Profile with Indigenous adult (aged 18 to 64) mental health consumers in the Cairns Network of Far North Queensland.

The project arose from concerns, amongst leaders of Queensland's Mental Health Outcomes Initiative, Indigenous mental health stakeholders and mental health clinicians and researchers, about the use of mainstream mental health assessment tools with Indigenous consumers. A pre-project workshop was held at Wuchopperen Community-controlled Health Service in 2003 to discuss these issues as they apply to measuring Mental Health Outcomes of adult consumers (aged 18 to 64 years). The Wuchopperen group was assisted by relevant documents, notably "Tell the Story" (Gulash et al., 1999). "Tell the Story" highlights problems that occur when mental health assessments with Indigenous consumers are conducted by non-Indigenous clinicians using standardised tools and without additional social and cultural guidance. The group shared this concern and focused their attention on specific issues likely to affect the accuracy of clinician-rated Health of the Nations Outcomes Scale (HoNOS) and the Life Skills Profile (LSP) when applied without guidance from Indigenous family members and local practitioners. These included under-rating due to general barriers to open communication, misinterpretation of verbal and body language across cultural boundaries, desensitisation to severe disadvantage when it is experienced by the whole community, perceived acceptance of culturally unacceptable behaviours and misunderstanding of culturally informed experiences and distress. Potential causes of over-rating due to misinterpretation of culturally shared beliefs and practices were also discussed.

The discussion at Wuchopperen Health Service led to the development of four guiding principles to assist clinicians when completing Outcomes ratings with adult Indigenous consumers. Principles One and Four were modified as a result of the findings of the research. The final proposed principles are briefly described below:

- **Principle One**

Involve additional informants in the assessment process, including a family member/carer and a local practitioner, preferably an Indigenous Health/Mental Health Worker who knows the consumer. This is of fundamental importance as a basis for employing the next three principles.

- **Principle Two**

Objectively reflect the underlying social disadvantage experienced by the consumer in their scoring, and thus avoid under-rating issues even when the level of disadvantage is widely experienced in the consumer's community.

- **Principle Three**

Objectively reflect non-sanctioned behaviours in their scoring, and thus avoid under-rating socially and culturally unacceptable behaviours even when they are common in the community.

- **Principle Four**

Exclude from HoNOS items 2 and 6, behaviours, experiences and beliefs associated with bereavement, burial rites and traditional activities when their form, intensity and duration fall within social and cultural norms that are recognised and accepted within the community. This must be determined through consultation with family/carer and local practitioner informants. However, mental health problems, such as depressed mood, anxiety and threatening behaviour that result from such experiences should not be excluded from other items.

Although HoNOS and LSP are clinician-rated tools, these guiding principles require the clinician to engage and collaborate with the consumer, family member/carer and local practitioner informants to inform their ratings. As one Indigenous workshop participant observed and argued by Gulash et al. (1999), the most important additional aspect of any mental health assessment with Indigenous consumers is using Principle One, **engaging additional informants**, which is essential to understanding the distress surrounding culturally 'normalised' behaviours.

These principles were incorporated into the content of an extended training module by the Team Leader of the Zonal Outcomes Team and added to the standard Outcomes training program delivered to all mental health clinicians in the Cairns Network. Refresher sessions featuring the principles were also conducted with clinicians by the locally-based Zonal Outcomes Coordinator.

Additional questions on the Outcomes Information System (OIS)

In addition to the inclusion of the four guiding principles in clinician training for Mental Health Outcomes, questions were added to the OIS that allowed clinicians to inform the research about:

- The frequency of involvement of family and practitioner informants in their assessment
- The degree of engagement they felt they achieved with the consumer, and with informants when included;
- The degree to which the clinician felt the Outcomes assessment accurately reflected the mental health problems of the consumer;
- The additional difficulty (if any) experienced by clinicians in rating Indigenous consumers, compared to rating non-Indigenous consumers.

Quantitative Analysis of Mental Health Outcomes and Corollary Data

Responses to these additional questions were analysed along with collection occasion details and HoNOS and LSP data collected during 496 occasions between July 1, 2004 and June 30, 2005 with Indigenous adult consumers in the Cairns Network. While LSP collections were completed only in the community setting, HoNOS collections were undertaken in both community and inpatient settings. This analysis was also informed by additional data on inpatient admissions to the Mental Health Unit and lengths of stay from the Advanced Health Worker (Mental Health) Register and Hospital Based Corporate Information System of Cairns Base Hospital (Haswell et al., 2006).

Qualitative Inquiry: Consultation and Engagement Processes and Interviews with Consumers and Carers of Cape York Peninsula

Consultations through regular Steering Group meetings, two Health Worker Forums, four workshops and presentations at state and national forums throughout the project provided continual input into the research design and interpretation of findings. These events enabled

discussion of the Initiative, exploration of principles and issues and documentation of views on how to enhance the value of Indigenous Mental Health Outcomes data collection and use.

Interviews conducted with consumers and carers in remote Indigenous communities in Cape York Peninsula provided information on the content validity of the HoNOS and LSP instruments.

A range of the key findings and recommendations that emerged from this project and are listed below. Further detail regarding these findings, as well as a rationale for the recommendations, are detailed in the full report.

Key Findings and Recommendations

This report presents information from the research findings that have substantial implications in the delivery, analysis and interpretation of Mental Health Outcomes data with Indigenous consumers. As in most applied research, these findings require follow up research to more firmly substantiate cause and effect relationships, to confirm the observations in situations where the potential for sampling bias is less (the data analysed here represent only 30 to 40% of the occasions where Outcomes assessment should have been completed), and to assess transferability of lessons learned to a broader range of Indigenous groups and environments. At this point, however, the following findings have emerged from the research.

1. Content Validity of the HoNOS and LSP

In all consultation phases of this project it was clear that Indigenous stakeholders welcomed the use of Mental Health Outcomes measures and emphasised the need for clinicians and services to be able to demonstrate accountability to the consumer. The value of collecting quantitative data that reflected not only services provided (the domain of existing mental health databases), but also the Outcomes achieved with Indigenous consumers, was recognised. The use of the same data collection system for Indigenous and non-Indigenous consumers was supported. Support was also expressed for the four guiding principles as an appropriate means of enhancing the reliability and validity of HoNOS and LSP data for Indigenous consumers with the hope of achieving sufficient accuracy to compare results of the scales across location, time and with non-Indigenous groups.

There is substantial overlap in the way that Indigenous adult consumers and carers describe aspects of the consumers' wellness and illness (feeling, thinking, relating to others, saying and doing and self-care) and the categories of items that HoNOS and LSP seek to measure, supporting the content validity of the scales. However, three concerns persist in the use of

these tools as the dominant measures of Mental Health Outcomes for Indigenous people: the absence of some domains that are of great importance to Indigenous mental health (for example spirituality and connection with land and culture), the lack of positive direction (i.e. higher scores reflect greater severity of problems rather than greater wellness) in the currently used versions of the scales and the absence of indicators of a broader orientation towards recovery in these tools. Although the Mental Health Inventory (MHI) currently used as part of Queensland's Mental Health Outcomes Initiative has a number of positive features, its completion rate and appropriateness for Indigenous consumers has not been documented and was not part of this project.

As HoNOS and LSP were not designed to measure broader aspects of mental health and recovery, these points are not raised as criticism of the tools. However, it should be remembered that even if these scales have confirmed cross-cultural reliability in measurement, the extent to which the resulting scores reflect a person's broader mental health will vary across cultures. The predominance of HoNOS as an extensively used international instrument makes it tempting to overlook its limitations in scope.

In 75% of Outcomes occasions completed over 12 months, clinicians reported that they felt the Outcomes scales provided a good to reasonable reflection of the underlying mental health problems of the consumer, while the scores were considered an inadequate to poor reflection in 17% of occasions. In nearly 50% of occasions with Indigenous consumers, clinicians reported at least some additional difficulty in making ratings as compared with ratings completed with non-Indigenous consumers.

<p><i>These findings and considerations have led to Recommendations 1 through 3.</i></p>

Strengths and Limitations of the First Principle

Consultations and existing documents in Indigenous mental health assessment support approaches that engage family/carers and Indigenous Mental Health workers, to bridge the gap between consumer and non-Indigenous clinician and between clinical consultations and everyday life in the community. Principle One aimed to direct clinicians to capture the strength of a partnered approach to assessment and Outcomes ratings as proposed by Gulash et al. (1999).

Data collected in this project have demonstrated the value of engagement of consumers, families/carers and local health practitioners in the assessment process. Cross-tabulations

demonstrated positive links between involvement and levels of engagement with consumer, carer and local practitioner, and clinicians' views of the validity and ease of the assessment.

Ratings for most HoNOS and LSP items completed without a family member/carer and/or a local practitioner were, on average, significantly lower than ratings that did include information from these informants. Differences associated with the absence or presence of these informants were greater for consumers under 30 years of age compared to older consumers and for collection occasions in the community, compared to those taking place in the in-patient hospital setting.

An essential challenge for this project was to distinguish cause and effect in the relationship between the presence of informants and higher scores on HoNOS and LSP items. This is a crucial point when interpreting the validity of scores collected in occasions with versus without informants. There are several possible explanations for the higher scores (representing greater severity) associated with the presence of informants, such as:

1. greater communication of the experience and meaning of the consumers' problems by informants led to greater recognition of severity and inclusion in the ratings, with the inference that those made without informants are underestimated (inclusion would enhance validity);
2. a tendency for consumers to under-report their own mental health issues, with the inference that those made without informants are underestimated (inclusion would enhance validity);
3. an increased likelihood that carers would accompany consumers with more severe illness or a lack of interest or ability to engage with the clinician, with the inference that scores are accurately capturing lower severity of problems among those occasions that did not include informants (inclusion would reflect rather than influence validity);
4. that families routinely exaggerate severity of problems in order to seek hospitalisation for consumers or otherwise influence care (inclusion would reduce validity);
5. the inclusion of family hardship (which is not meant to be included) in ratings made where the clinician has received family input, with the inference that scores made with informants are over-estimating the severity of problems experienced by the consumer (inclusion would reduce validity).

The first two explanations, which indicate that the use of these outcome measures with Indigenous consumers in the absence of informants systematically and substantially underestimate the severity of mental health problems, are entirely consistent with the understandings that led to the collaborative identification of Principle One. This principle highlights the importance of including family members and a local practitioner as the most important condition for making ratings with Indigenous consumers. These explanations are also consistent with the experience and understandings gained by psychiatrists whose careers have focussed on the mental health of Indigenous people. Considerable support for the explanation that underrating occurs without informants, including a loss of age-related trends clearly visible in concurrent psychiatric hospitalisation data, was found across a range of data analyses and is presented in this report.

In contrast the analysis did not reveal evidence supporting a systematic influence of the latter three explanations. The third explanation suggests that the higher ratings associated with informants are simply reflective of their likelihood of being more available in more severe circumstances (hence the higher ratings). However, the greatest differences in scores between the two situations (with and without informants) were found in occasions where the clinician reported that the consumer was partly to fully interested and engaged in the assessment process. In contrast, smaller, rather than larger, differences were associated with informants where the consumer was not interested or engaged, in hospital, or not well enough to be involved in the assessment. Differences were also consistent within the diagnostic groups that had sufficient numbers to test (psychotic disorders and unrecorded diagnosis); hence the trends were not simply reflecting more frequent involvement in more severe types of illness.

The fourth and fifth explanations infer that clinicians are inaccurately influenced by informants to over-rate the severity of problems through family motives or the inclusion of family distress. Family burden should be captured in other outcomes measures, but not in the HoNOS and LSP. This explanation is suggested from other research with non-Indigenous consumers which compared ratings made by clinicians versus family members. Those studies found that family members tended to rate higher than clinicians and investigations suggested that their own distress was influencing the way that problem severity was perceived. However, in this study – which did not involve families or consumers making separate ratings but only to provide clinicians with information - no evidence emerged to indicate that family burden systematically led clinicians to make higher HoNOS or LSP scores. The elevation in clinician-rated scores was no higher when family members/carers provided the information as compared to those where local practitioners provided the input.

Furthermore, the scores most likely to involve the rating clinicians' direct observation of the consumers' greatest severity of problems (i.e. at hospital admission) varied the least between occasions with and without informants.

In summary, the findings support the importance of Principle One in ensuring that carers/ family members and local practitioners provide clinicians with knowledge of the extent and nature of problems experienced by the consumer which they are otherwise unable to collect. This incomplete understanding appears to be associated with substantial underrating of severity on both HoNOS and LSP.

These findings and considerations have led to Recommendations 4 through 6.

2. Limitations of the Originally Proposed Fourth Principle

The aim of the Principle Four, which is not contested, was to avoid the classification of culturally appropriate and understandable behaviours, experiences and beliefs as symptoms of illness. The Steering Group surmised that the best approach would be to instruct clinicians not to include reported or observed findings in any of the assessment items if these were identified as socially and culturally acceptable and appropriate through discussion with the family or local practitioner. However, several concerns arose during the project. These included the recognition that family/carer and/or local practitioners were involved in only half of all collection occasions, which suggests that clinicians were applying the Principle without full understanding of the form, intensity and duration of culturally understood experiences to compare those with consumers' experiences. Hence, it is imperative that clinicians receive clearer guidance on the meaning of 'culturally acceptable' experiences such that anything that "sounds cultural" is not simply accepted at face value and excluded.

It is also now recognised that the original Principle Four did not make it clear whether to rate the frequency and severity of mental health problems that **result from** such situations in other items. Clarifying these instructions through modification of Principle Four is deemed necessary to protect against selective inaccuracy in assessing the severity of mental health problems that Indigenous people experience as a result of either incorrect determination of consistency with cultural norms or to the dismissal of mental health problems which result from culturally consistent experiences and beliefs.

These findings and considerations have led to Recommendation 7.

3. Strengths and Limitations of the Implementation Process of the Outcomes Information System in Far North Queensland

Mental Health Outcomes assessments were completed at least once with 30 to 40% of Indigenous consumers who received mental health care in the community and with over 80% of those admitted to hospital. While the collection rate of Outcomes measures during inpatient admissions was high, few assessments were completed on discharge from hospital.

In practice, Outcomes assessments with Indigenous consumers in the Cairns Network from July 2004 to June 2005 did not include information from a family member/carer or a local practitioner in over half of occasions and rarely involved both (8% of collection occasions). The proportion of occasions that involved informants was greater for younger adult consumers (under age 30) than for older consumers and greater in the inpatient as opposed to the community setting. Thus clinicians were frequently completing assessments without the benefit of either a family member or carer who had observed first hand the consumers' experience or an Indigenous Health Worker who could play a key cultural and clinical communication role.

Tools (e.g. modified pamphlets and reporting capacities built into the OIS) and processes (e.g. Indigenous Mental Health Worker Forums) to enhance local practitioner, Indigenous consumers and carer involvement supported awareness of the Mental Health Outcomes Initiative to some extent. However, more effort is needed to achieve an increase the frequency of their involvement in assessment.

Needless to say, confidentiality issues are important in mental health and must be respected. However, it is notable that amongst 496 occasions, there were only 4 notations (<1%) provided by clinicians regarding preference expressed by the consumer not to involve anyone else in their assessment.

Consultations with Indigenous stakeholders indicated that while there will be times when a consumer genuinely does not want to have anyone else involved, the structure of the service and general attitudes toward Indigenous health/mental health workers and family involvement is an important factor influencing whether their involvement meaningfully occurs. Thus it is argued that a service that is culturally safe and appropriate places Indigenous health/mental health workers at the forefront of the consultation to provide an Indigenous perspective and in turn play a key role in enabling families to confidently contribute to the clinical process.

Clinicians more frequently expressed additional moderate to substantial difficulty and less agreement in ratings where additional informants were involved, compared to occasions where they were not involved. That is, clinicians reported additional difficulty in 10% of occasions without informants, compared to 18 -26% of occasions with informants. Clinicians reported inadequate to poor agreement in 15% of occasions without informants compared to 16 to 30% of occasions with informants.

These findings and considerations have led to recommendations 8 through 11.

5. Validity of the Data Collected with Indigenous Consumers

Despite the probability of routine underestimation based on the findings discussed above, HoNOS and LSP scores (with informants) showed consistent patterns with age, location, treatment setting, diagnostic category and temporal patterns, as expected from previous studies (Stedman et al., 1997; Trauer, 2004; Trauer, Eager, Gaines & Bower, 2004 and Eager, Trauer & Mellsop, 2005). The following key points emerged from analysis of data from 496 Outcomes collection occasions with adult consumers specified as Indigenous from July 2004 to June 2005.

As expected, HoNOS scores were significantly higher for occasions collected in inpatient as compared with those collected in community settings.

In community collection occasions which involved family/carer and/or local practitioner informants, scores of consumers under age 30 reflected more severe problems on HoNOS items associated with behaviour and symptoms, and on LSP items associated with withdrawal, compliance and anti-social behaviour, compared to older consumers. These items may be linked to the higher inpatient admission rates, longer stays and higher readmission rates experienced by younger, compared to older, consumers in 2004/2005 (Haswell et al., 2006).

Few age-related differences in HoNOS scores were observed in the inpatient setting, except for the Impairment Subscale (older consumers higher than younger consumers) and for Item 6 (problems with hallucinations and delusions more severe among younger compared to older consumers). The latter difference may be a contributor to the much longer length of stay in hospital experienced by younger consumers (those under 30 years of age).

HoNOS Item 8 (other mental and behavioural problems) revealed that severe sleep problems were experienced by more than one third of consumers assessed at hospital admission.

Anxiety and panic problems, as well as sleep problems, were much more prevalent in collection occasions in hospital compared to the community setting.

Comparison of HoNOS and LSP scores collected in community occasions by district suggested that consumers who participated in Outcomes assessments in Cairns District were experiencing the greatest severity of mental health problems. This observation is consistent with steep rises in the number of hospitalisations and length of stays of consumers resident in Cairns District. The main Indigenous population centres in the District are Cairns City and suburbs, rural towns e.g. Mossman, Cooktown and Kuranda, and the discrete Aboriginal communities of Yarrabah, Hope Vale and Wujal Wujal.

As expected, patterns in Outcomes scores on scales and subscales also varied according to the type of mental illness experienced by the consumer. Collection occasions with consumers with psychotic disorders had the highest total and subscale scores for both HoNOS and LSP while those with drug and alcohol disorders scored higher on LSP and slightly lower on HoNOS than those with affective disorders.

6. Usefulness of these Outcomes Data

As explained in this report, this project was undertaken at a time when Cairns Base Hospital was experiencing significantly increased occupancy rates in its Mental Health Unit. Indigenous consumers under the age of 30 (not those age 30 and over) experienced the largest share of the increased length of stay over the study period (2004/2005) as well as in the previous year (2003/2004) (Haswell, 2006).

The HoNOS and LSP data were explored to determine whether these could provide an indication of the cause of this rapid increase. This analysis was fruitful and the key findings below have contributed to discussions about specific causes of the increase and appropriate actions to be taken to effectively support this consumer group.

Across the four 3-month intervals between July 2004 and June 2005, significant increases were observed in the frequency and severity of cognitive problems, problems associated with living conditions, activities of daily living and occupation/activities of younger, but not older, Indigenous consumers. The increase was particularly apparent for cognitive problems that were infrequent and mild if present among Indigenous consumers under age 30 in the first 3 months (July to September 2004) but rose consistently throughout the year. These trends were observed in occasions with young consumers in hospital and community (with separate clinicians completing ratings) and were not apparent among consumers over age 30.

The researchers consider that the above findings demonstrate the utility of HoNOS and LSP (administered with informants) as a reliable data source to help inform action. The data assist in reflecting and characterising differences between groups of consumers likely to be experiencing different degrees of illness severity and risk in their environment. The analysis also suggests that the data are sufficiently sensitive to assist in planning approaches to identify and better support consumer groups who are most in need.

These findings and considerations have led to Recommendation 12.

7. Transferability of the Findings

A very important aspect of working in Indigenous health is the recognition that there is great heterogeneity in the historical, social, cultural, spiritual, economic and environmental aspects of Indigenous peoples' lives and situations. This project focussed specifically on Indigenous people in the Cairns Network and thus caution is needed when considering the application of the findings to other Indigenous peoples living in other places.

These findings and considerations have led to Recommendation 13.

8. Comparing Indigenous and non-Indigenous Mental Health Outcomes Data

At this stage, there has been no attempt to compare or differentiate Indigenous-specific issues, scores and considerations with or from those encountered in the mainstream within the Cairns Network. This was not within the scope of the project, and that to attempt such an undertaking would raise issues of validity and reliability (that could involve underestimation of severity linked to low adherence to Principle One). Such a comparison would also be hampered by the absence of parallel data on the frequency and impact of involvement of informants, degree of engagement and perceptions of reliability of clinicians assessing non-Indigenous consumers. Further, the considerations mentioned in Item 7 about heterogeneity within Indigenous population groups, plus differences observed between Districts in the Cairns Network, argues for care in comparing geographical areas.

This project also revealed that careful consideration is needed when comparing data with and without informants (which remains unknown in occasions with non-Indigenous consumers). Additionally, there appears to be stronger age-related trends in mental health indicators for Indigenous consumers than for non-Indigenous consumers. Finally, the 2004/2005 dataset did not contain sufficient 'end of episode' data to meaningfully compare change through time of Indigenous and non-Indigenous consumers.

These findings and considerations have led to Recommendation 14.

Additional General Suggestions for Continuation of the Process

For the Cairns Network, the researchers encourage:

- Wider acknowledgement and effort to ensure that accurate Outcomes assessment reaches its potential as a useful engagement, communication and measurement tool involving Indigenous Health and Mental Health Workers;
- Raising clinicians' awareness that severity of Indigenous consumers' mental health problems may be underestimated if additional informants are not accessed;
- Continued monitoring and analysis of Mental Health Outcomes data and the use of the additional questions on the OIS;
- Continued sharing of these findings at a local level, in conjunction with other data sets (such as hospitalisation and CESA data), which may assist in planning and evaluating both standard and innovative mental health care interventions;
- Advocating appropriate approaches to enhance the involvement of Indigenous Health Workers (in both Mental Health and Primary Health), consumers, families, peers and communities in all aspects of mental health care including Outcomes assessment;
- Considering the potential value of wider implementation of the additional questions on the OIS trialled within this project. The routine inclusion of additional informants is likely to offer advantages, (as argued by other researchers and demonstrated by this project amongst Indigenous consumers), to the wider population;
- Considering the variation between assessments of Indigenous consumers with and without additional informants as a potential confound when comparing an individual consumer's assessment scores over time. This may be similarly true for non-Indigenous consumers and requires further research.

For Queensland and the Northern Territory

It is suggested that wider Queensland and Northern Territory mental health networks gain a clear understanding of the methods and findings of this project to enhance their activities. This may be achieved through:

- Disseminating project findings amongst Indigenous mental health stakeholders in Queensland and Northern Territory and encouraging adoption of similar consultation, training and implementation activities to enhance wider Mental Health Outcomes use;

- Considering broader application of the additional questions on the OIS to enable similar monitoring in other mental health networks;
- Continuing to implement tools (e.g. modified pamphlets and reporting capacities built into the OIS) and processes (e.g. Indigenous Mental Health Worker Forums) to enhance local practitioner, consumer and carer involvement in Queensland and the Northern Territory;
- Emphasising the importance of developing and/or modifying consumer and carer-rated tools that capture developing strengths and progress towards recovery. Such tools can enhance discussion between consumers, carers and clinician about what outcomes are important to the consumer and how they can be achieved

Nationally

Finally, the researchers encourage the national leadership of the Mental Health Outcomes initiative in Australia to be increasingly responsive to the needs of culturally diverse groups and disadvantaged groups. This will require accurate measurement and effective planning to address mental health inequalities.

In conclusion, this study has demonstrated usefulness and validity, as well as the need for improvement, in the application of HoNOS and LSP with Indigenous consumers in the Cairns Network. It has recommended greater adherence to and further improvement of guiding principles used in routine Outcomes assessment with Indigenous consumers. It strongly supports continued engagement of Indigenous Health and Mental Health Workers, consumers and their families throughout the assessment process and in the interpretation and use of Outcomes data.

Road Map for the Report

Due to the variety of methods and the consultative development process used in this project, a document 'road map' is provided to help guide the reader through the material presented. It should be noted that this project was undertaken using an 'action research' approach, which involved a number of steps that were not undertaken in a precise, chronological way as they would within a traditional research methodology framework. Rather, many of the steps (such as the consultation processes) spurred and/or informed subsequent parts of the research. Further, opportunities to intervene and improve Outcomes collection were capitalised upon during the research period. The action research model used here fit well with the dual intentions of the project - to both analyse and inform the Outcomes collection process with Indigenous consumers. Although this approach differs from the dominant research paradigm, it was considered more culturally appropriate in the context of this project. Its benefits to services research is well recognised, for example:

"There is a dual commitment in action research to study a system and concurrently to collaborate with members of the system in changing it in what is together regarded as a desirable direction. Accomplishing this twin goal requires the active collaboration of researcher and client, and thus it stresses the importance of co-learning as a primary aspect of the research process." (Gilmore, Krantz & Ramirez, 1986, p.161).

Action research has formed the basis of all activities of the Indigenous Stream of the Australian Integrated Mental health Initiative (AIMhi) who conducted this project. Appendix 1 provides a list of this team's recent outputs in Far North Queensland and Northern Territory.

This report attempts to discuss a range of views and concerns raised by Indigenous mental health stakeholders regarding the use of the assessment tools. Given the detailed statistics, the fuller report is not aimed at wider readerships who are unfamiliar with the background and details of systematic and standardised mental health outcomes data collection and use. Readers are encouraged to seek such information from the listed references, and particularly the recent report by the Queensland Transcultural Mental Health Centre (2005) for specifically relevant information about transcultural application of tools within the Queensland's Mental Health Outcomes Initiative. This report has focused on the specific issues addressed within this research project that was embedded within the implementation of the Initiative in one Mental Health Network (Cairns). It is hoped that readers will find that the non-traditional, qualitative format of this report - with chapters organised according to issues rather than by the steps of the traditional scientific method – enhances the ability to

explore methodology, findings and interpretation in greater depth, which was made possible through the employment of an action research framework.

The **Executive Summary** provides a very brief background, approaches, key findings and specific recommendations of the project.

The **Detailed Summary** provides more detail and discussion of the methodology and findings of the project, its limitations, the link between the project's findings and the recommendations and additional general suggestions for future action.

Chapter 1 presents a brief introduction to key relevant issues in Indigenous mental health and the use of mainstream tools for Mental Health Outcomes assessments amongst Indigenous consumers. The research questions defined after pre-consultation workshops and the importance of the project to key mental health policies are also discussed.

Chapter 2 defines the specific aims and objectives derived from the research questions. It also describes methodology used in each component of the project. This encompasses:

- The formative process (the first workshop, development of guiding principles, additional questions on the OIS) and the implementation process (inclusion of guiding principles in the training and support of mental health clinicians, activities promoting engagement of Indigenous communities and mental health workers and examination of background information on completed Outcomes occasions as they accumulated into the OIS) [results detailed in Chapter 3 to 5].
- The evaluation process which included analysis of the data collected in the system over the 12 month period (July 2004 to June 2005) [results presented in Chapters 6 to 9] and in depth interviews with consumers and carers [Chapter 10].
- The process that guided finalisation of the project's activities and the dissemination of information.

Chapter 3 provides detailed findings of formative project processes, including issues raised in consultations (Workshop 1), the resulting 'intervention tool' (the four guiding principles), and the five questions added to the OIS. A rationale regarding recommendations for the modification of Principle One and Principle Four (as discussed and endorsed in the final workshop) is provided.

Chapter 4 describes the activities of the Cairns Network Zonal Outcomes Coordinator and the Indigenous Mental Health Coordinator in engaging Indigenous consumers and families

(creation of a reader-friendly pamphlet) and Indigenous Mental Health Workers (Health Worker Forums).

Chapter 5 presents a background description of the collection of Mental Health Outcomes information with Indigenous consumers in the Cairns Network. It details the number of Outcome collection occasions by age, gender and Indigenous status over time, location, setting and reason for collection.

Chapter 6 explores the internal consistency of the scales and additional 5 questions, and the correlations within and between subscales of the HoNOS and LSP using the data collected from adult Indigenous consumers in the Cairns Network over the 12 month period.

Chapter 7 presents an analysis of responses to the 5 additional questions on the OIS, relating to demographic characteristics and inter-relationships found between the additional questions them. These analyses inform the frequency of the use of the guiding principles.

Chapter 8 presents an analysis of scores associated with application of Principle One - with comparisons of HoNOS and LSP in the presence and absence of family and local practitioner informants.

Chapter 9 presents the findings of the HoNOS and LSP scores collected over the 12 month period. This includes analysis by location (community/ambulatory versus hospital inpatient), trends in scores by age, gender, district and diagnostic group. In order to inform the validity of the age-related differences in scores, patterns observed in hospitalisation data for the Cairns Network over the same period are compared with patterns seen in Outcomes data.

Chapter 10 critically examines analyses presented in Chapter 7 to 9 in relation to validity of HoNOS and LSP data collected with and without adherence to Principle One. It also explores the content validity of HoNOS and LSP with data collected in interviews with consumers and carers describing the signs of wellness and illness that they recognise. Similarities and differences between these descriptors and the items on HoNOS and LSP are discussed.

Chapter 11 summarises the findings in relation to each outcome proposed for achievement at project commencement. Detailed discussion of validity and its association with the application of the guiding Principles is provided. This uses information from all of the results chapters and discusses the need for consumer-rated measures.

Chapter 12 provides conclusions supported by the findings and recommends how these should inform action to meet future challenges. General recommendations relevant to the Cairns Network, State and national level are also provided.

1

Introduction, Research Questions and Contribution to Policy

“Culturally valid understandings must shape the provision of services and must guide assessment, care and management of Aboriginal and Torres Strait Islander peoples’ health problems generally, and mental health problems in particular”. (Swan and Raphael, 1995, np).

Brief Introduction to Indigenous Mental Health in Australia

Indigenous Health Disparity

The disparity in virtually all areas of health and mental health between Indigenous and non-Indigenous Australians has been exhaustively documented. Indigenous Australians experience much higher levels of illness and premature death than non-Indigenous people and are more likely to be incarcerated, experience family violence, family separation including removal of children and institutionalisation, have lower education and fewer employment prospects, face many more major life stress events in childhood and suffer from excessive use of alcohol and other substances (AIHW, 2004; 2005). The recently completed Indigenous Burden of Disease Study has generated startling information on Indigenous ill health. For example, it was discovered that Indigenous people in the Northern Territory share equal numbers of disability-adjusted life years (DALY) by the age of 35-44 as that experienced by non-Indigenous people aged 65-74 years (Zhao et al., 2004).

Recognising Indigenous health disparity, the Senate Select Committee on Mental Health (First Report, 2006, p 478-479) highlighted major mental health and service issues, e.g.:

16.54 Data set out in evidence before the committee establishes the uncontrovertible truth that Indigenous Australians have neither the life expectancy, the emotional or psychological security, nor level of material comfort other Australians enjoy:

- the perinatal mortality rate for babies born to Indigenous women is twice as high as that for babies born to non-Indigenous women;
- Indigenous Australians have at birth a life expectancy of twenty years less than other Australians;
- Indigenous people have much higher rates of premature death due to external causes, 16 per cent of all deaths compared with 6 per cent for other Australians. Death due to deliberate self harm [among all injury-related deaths] was 33 per cent for men and 15 per cent for women;
- Indigenous people have a significantly higher risk of experiencing major life stressors than other Australians, which affects their mental health and general wellbeing. Indigenous children are at higher risk of clinically significant emotional or behavioural difficulties; at 24 per cent compared with an equivalent figure of 15 per cent in the general population;
- Indigenous people are twice as likely to die of alcohol attributable diseases, despite the fact that alcohol intake is equivalent to that of the general population;
- Indigenous youth self-harm and suicide rates are much higher compared with other Australian youth. Of Indigenous youth 12 to 24 years, 31.1 per cent per 100 000 intentionally self harmed, compared with 6.4 per cent in a 100 000 of other Australian youth. More than one in six, 16 per cent, of Indigenous young people aged 12–17 years had seriously considered ending their own life in the 12 months before the survey; of these, 39 per cent had attempted suicide.
- Indigenous Australians have higher rates of unemployment, poorer educational outcomes and lower rates of home ownership; and
- at June 2002, Indigenous people were 11 times more likely than non-Indigenous people to be in gaol.

16.55 The marginalisation of people with mental illness is therefore compounded in the lived experiences of Indigenous peoples, making them potentially, as the United Nations recently suggested, the most disadvantaged community in the world today.

Research and Service Ethics in Indigenous Mental Health

While some of the health differentials can be “explained” by the influence that social and economic disadvantage exerts on people’s health, there is much more to the story of health inequality among Aboriginal peoples. In common with Indigenous peoples of other developed countries, the legacy of their historical loss and profound disempowerment since colonisation continues to impact upon their present. Hunter (1989; 1997; 2001) has argued that denial of the depth of the loss and desire to forget or “move on” are common responses among outsiders, especially where there is an awareness of inherited, if not direct, responsibility for its perpetration. Under-recognition and a lack of commitment to effectively understand and address the impact of disempowering history is probably an important component of Australia’s inability to achieve improvement in the health of its Indigenous peoples on par with that achieved in Canada, the US and New Zealand (Ring & Firman 1998; Ring & Brown 2003). Hunter (2002) warns that well-intentioned actions based on simplistic understandings of Indigenous perspectives continue to compound, rather than alleviate, the ongoing suffering and injustices experienced by Australian Aboriginal people.

Health services generally, and mental health services in particular, for Indigenous Australians are, in many cases, notably deficient in their capacity to address these issues. The prevalent lack of cross-cultural understanding, communication gaps and denial of difference prevent the capacity for non-Indigenous services to work with Indigenous people in a way that promotes strength and resilience. The damaging impact of “difference-blindness” is explored in the National Health and Medical Research Council’s publication, “Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research” (NHMRC, 2003 p 3). Quoting from Taylor (1992), the document explains:

“To misrecognise or fail to recognise (cultural difference) can inflict harm, can be a form of oppression, imprisoning someone [or a group] in a false, distorted and reduced model of being” ... Research cannot be difference-blind”.

When considering issues of Survival and Protection, the NHMRC Guidelines further state:

“Aboriginal and Torres Strait Islander peoples vigorously oppose the assimilation, integration or subjugation of their values and will defend them against perceived or actual encroachment...”

... the distinctive cultures and community life of Aboriginal and Torres Strait Islander Peoples rests at the heart of these [ethical] guidelines. It is, therefore, essential that researchers engage with Aboriginal and Torres Strait Islander communities collectively, not just with individuals.”

... the importance of the personal and collective bond within Aboriginal and Torres Strait Islander communities and its critical function in their social lives ... this collective bond reflects and draws strength from the values base of Aboriginal and Torres Strait Islander Peoples and cultures”.

Clearly these issues are as relevant to all aspects of service delivery across the spectrum of mental and physical health activities, most particularly in making mental health assessments for diagnostic purposes and measurement of mental health outcomes as they are for research. Therapeutic and research relationships alike need to be built on trust, understanding of the collective nature of Indigenous cultural and identity and adherence to Indigenous understandings of identity, health and well-being, if any progress is to be made.

Addressing Indigenous Mental Health

Given the background of historical physical and emotional trauma and ongoing profound social and economic disadvantage that Aboriginal people experience, it is no surprise that mental illnesses, either singularly but more often in association with drug and/or alcohol abuse, are common (Hunter et al 1991, Swan and Raphael 1995). The risk factors and

resulting dimensions of mental disorders among Indigenous, compared to non-Indigenous people can be characterised by the following:

- present earlier in life, including the antenatal period
- multiple and mutually reinforcing
- recurrent and persistent
- widely experienced in community and cohort
- less likely to be offset by protective factors
- less likely to be experienced as dissonant or abnormal
- less likely to be recognised as a need
- likely to be seen as unmodifiable.

It is worth mentioning here that this list of factors is also relevant for Indigenous physical health, for example, diabetes and the metabolic syndrome that drives much of the excess chronic disease mortality borne by Indigenous people. Based on current understandings of the link between stress, distress and social and emotional well being on chronic disease, it is easily argued that mental health disparity plays an important aetiological role in all dimensions of Indigenous health and social inequality (Haswell et al, 2005). The traditional social determinants of health, e.g. education, housing, employment, social exclusion, racism, etc., further cause and compound the consequences of this disparity.

There has also been a paucity of research addressing the impact of these issues on the assessment of mental health among Indigenous consumers at the individual, community and population level. Past research and psychiatric frameworks of Aboriginal health have left a legacy of distrust between mental health clinicians and researchers and Aboriginal communities. However, much progress has been made in recent years addressing this mistrust and guiding clinicians and researchers in appropriate ways to engage and work with Indigenous communities to conduct clinical practice and research that benefits Indigenous health (e.g. via NHMRC's Research Agenda Working Group and Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research, the Cooperative Research Centre for Aboriginal Health). Santhanam et al (2006) have identified the need for clinical services to put these same principles into practice. The project has aimed to fully embrace all dimensions of these guidelines in its development, implementation and interpretation.

Measuring Mental Ill Health among Indigenous Peoples

Quantitative researchers in Indigenous mental health face particular challenges within this new framework. Past research usually employed a deficit-based framework, which largely

focussed around demonstration of the poor health and social statistics of Indigenous Australians relative to that of non-Indigenous people. The continuous reminder of the poor state of Indigenous health, in the relative absence of using that information towards positive change, has added to a broader sense of hopelessness. The absence of accompanying qualitative data to discern a deeper understanding of Indigenous experience and guide interventions that are likely to be appropriate, has amplified the difficulty. Thus combining poor statistics, a lack of understanding of the influence of historical and social experiences of Indigenous people on these statistics and a desire to “forget and move on” by mainstream contributes to a climate of distrust and tension. To address this effectively, quantitative researchers must not only present the most accurate numbers as possible, but also understand the meaning of those numbers in the context of a deeper understanding of the reality in which Indigenous health sits and an orientation of strength and positive change.

Lack of reliable statistical data prevents estimates of the prevalence and economic costs of mental illness among Indigenous people, but available evidence indicates two to three times higher rates of severe depression, anxiety and psychotic illnesses like schizophrenia among Aboriginal populations compared to the mainstream (AIHW 2004; 2005; Haswell et al., 2006). These illnesses cause immense degrees of pain and suffering for individuals and families. Uncontrolled psychotic disorders, combined with drug and alcohol use, increase the risk of additional tragic consequences like self-harm, suicide, injury, very poor physical health and imprisonment. The clear visibility of these events in the community enhances the perception that these are normal, rather than exceptional, consequences of mental illness.

Major costs are borne by medical and legal systems in dealing with the consequences of poorly managed mental illness in remote areas as consumers move between home, specialist hospitals and criminal justice systems. Clearly there is enormous justification for innovative preventative, early intervention and self-care approaches to support communities, consumers and families to better understand mental illness and play a much more active role in managing the illness (CDHAC 2000a, 2000b). However, such initiatives will rely on accurate data to be guided and evaluated to ensure maximum effectiveness. There is much work to be done towards this need as most systematic data collections that attempt to capture indicators of Indigenous ill health face major reliability problems.

Indigenous people are much more likely to access care provided through public and primary health services, as opposed to the private setting. There has historically been a separation of mental and physical health care services in primary care settings that contribute to the lack of defined pathways and, in remote areas, an adequate mental health workforce to address

consumer's needs confidently and effectively (Haswell et al., 2006). This has contributed to stigma and fear of mental illnesses, a lack of understanding of consumer and carer needs, resources and support and, since mental health is often poorly managed as a result, major emphasis on crisis management and not on proactive health promoting approaches (Parker 1991; O'Kane & Tsey, 2004, Hunter & Tsey 2003, Rosen 2004). The situation is more serious in rural and remote areas where services are isolated and under-resourced with staff and infrastructure, and most of all for Indigenous Australians for whom social and cultural factors, beliefs and understandings are different than for mainstream leaving a wide gap in mental health communication (Hunter 1997, 2002; Nagel and Thompson, 2005). Little evaluated work has been done to bridge the gap between mainstream and Indigenous understandings of mental health, thus there is a lack of appropriate mental health literacy and promotion materials and even fewer models of delivering this to consumers, carers and communities (Brown 2001).

This is the setting in which this project, the Indigenous Adult Mental Health Outcomes project, commenced in Far North Queensland. The need to examine the appropriateness of HoNOS and LSP as tools to assess mental health of Indigenous consumers was identified as a core component of the broader agenda of the Indigenous Stream of the Australian Integrated Mental Health Initiative in North Queensland and the Northern Territory (Appendix 1; Haswell et al., 2006). More information on this topic will be forthcoming from the activities in Queensland and Northern Territory.

Measuring Mental Health Outcomes of Indigenous Consumers

As Mental Health Outcomes data is playing an increasingly key role in many processes locally, statewide and nationally; there is a danger that systematically inaccurate or invalid outcomes assessment could misguide efforts to improve mental health. The accurate measurement of health outcomes, or of health status change influenced by services provided in a population over time, potentially provides major benefits to all levels of the health care system (Andrews, Peters & Teesson, 1994; Stedman et al., 1997, Morris-Yates & Andrews, 1997; Commonwealth Dept Health and Ageing, 2002; Eagar, Trauer & Mellsop, 2005).

Although there is a relatively large body of work published in the research literature about the processes and tools to measure mental health outcomes, there are only a small number of papers examining their validity and use with specific population groups defined by language and/or culture (reviewed by the Queensland Transcultural Mental Health Centre, 2005). A limited Medline / PubMed / PsychInfo literature search revealed four informative Australian

publications combining key words of 'Indigenous' or 'Aboriginal', 'mental health' and 'health outcomes' up to 2006 (Appendix 2). No publications were found in this search that described the use of standard mental health outcomes measurements with Indigenous Australians. Similar searches using Google identified a range of informative unpublished papers and powerpoint presentations; the most relevant from Australia and New Zealand are referenced in this document. Hence this is a highly under-researched field in Australia.

Despite the lack of published data, it is widely accepted that cultural differences between mental health clinicians and Indigenous consumers often results in inadequate clinician understanding for a range of reasons (Sheldon, 2001; Vicary & Westerman 2004; Nagel & Thompson, 2005). Most obviously, clinicians can misinterpret the culturally acceptability of practices, particularly around matters relating to consumers' spiritual practices and deceased persons. Misunderstanding may also simply arise from differences in vocal and body language and processes of effective engagement and communication and gaining trust. These problems are likely to affect the way items are assessed (Queensland Health, 1996; Gulash et al., 1999; Westerman, 2002; 2003a; 2004, McKendrick, 2000; Queensland Transcultural Mental Health Centre 2005, Levy & Kingi 2003; Levy et al., 2005a, 2005b; Nagel & Thompson, 2005), such that the validity and reliability of mainstream tools for the assessment of consumers of minority cultures deserves scrutiny. In addition, there are likely to be many culturally-determined factors surrounding the presentation of mental health symptoms and manifestations amongst consumers of minority groups that are overlooked by mainstream clinician-rated tools (Rosen, 1994; Bhui & Bhugra, 1997; Kingi & Durie, 2000; Kirmayer, Brass & Tait, 2000; Krishnan et al., 2001; Australian Health Ministers Advisory Council, 2004; Trauer et al., 2004).

A lack of validated tools and systems for assessing and reporting on mental health status has been a major barrier to demonstrating improvement in the management of mental illness among Aboriginal and Torres Strait Islander Australians (Gulash et al., 1999; Westerman, 2002; 2003a, 2004; McKendrick, 2000). Some have questioned the validity and usability of existing mainstream tools and argued that it is necessary to develop Indigenous-specific outcome tools. Others have suggested that attempts should be made to examine, modify and trial the existing tools with Indigenous consumers. In Australia, the national focus has generally been on commencing measurement for all consumers in the same timeframe to generate comparable Outcomes data for Indigenous and non-Indigenous consumers and thus inform policy and resource allocations (Australian Mental Health Outcomes and Classification Network, 2005).

Queensland Health, in accordance with the National Information Development Agreements (Commonwealth Department of Health and Ageing, 2002), has adopted and systematised a set of tools and protocols for measuring Mental Health Outcomes across the state (see Appendix 3 for details). For adults (aged 18 to 64), these include background information on the consumer, reason for collection, diagnosis and mental health legal status, focus of care, the Resource Utilization Groups – Activities of Daily Living (RUG-ADL), the Mental Health Inventory (MHI, consumer-rated measure), the Health of the Nation Outcomes Scales (HoNOS) and the Life Skills Profile (LSP). The completion of all items on these scales at designated times is compulsory, with the exception of the MHI, which must be offered to consumers to complete themselves. In practice, Mental Health Outcomes are used in conjunction with other clinical assessment tools, including clinical judgement of the clinician. While clinicians are encouraged to include information from others in assessments that lead to outcomes ratings, in addition to direct observation and consultation with the consumer, this appears to occur at a low frequency in practice and remains unrecorded in the outcomes data (Lambert, Caputi and Dean, 2001).

The research questions identified for this research project focus on the HoNOS (12 items) and LSP (16 items), with some exploration of appropriate approaches to consumer-rated measures (such as the MHI). While HoNOS and LSP have been carefully validated in a number of mainly mainstream settings, the usefulness of these scales for assessing mental health status of Indigenous consumers from non-English speaking cultures in the Australian setting had not been systematically explored. Two complementary research initiatives have been completed to enhance the use of these tools when applied across a range of non-English speaking cultures (Queensland Transcultural Mental Health Centre, 2005) and with Indigenous consumers (this project) to gain better understanding of the data collected.

Research Questions

The Indigenous Mental Health Outcomes project commenced in 2003. Through discussions with stakeholders and a review of the literature, the following research questions were identified:

- Is there general consensus across key stakeholders in Indigenous mental health in Far North Queensland that HoNOS and LSP are potentially useful instruments that should be formally assessed, or should the preference be to develop new clinician rated instruments specifically designed for Indigenous people?

- What are the easily foreseen problems that clinicians may experience when using the current HoNOS and LSP preambles, instructions and instruments with Indigenous consumers?
- Can these problems be solved with modifications in the preambles and glossaries of the tools and with changes to the clinician training process without affecting the well-documented validity and reliability of the tools?
 - What is the reliability of HoNOS and LSP measures when used with Indigenous consumers by non-Indigenous clinicians?
 - How valid are the assessments in relation to the standard definitions of mental health status of people with chronic and recurring mental illness?
 - Do these tools measure aspects of mental health that are important to Indigenous consumers and carers – are they socially and culturally valid as well as clinically valid measurements of mental health?
 - Can a set of consumer-rated mental health outcome measures be developed which captures the perspectives of the consumer and is able to be implemented alongside the clinician rated measures?
 - Can information tools and consultations explaining how and why Outcomes measures are useful enhance acceptability of their use among Indigenous consumers, carers and clinicians?
 - Can the results of HoNOS and LSP and consumer rated measures be effectively communicated by the clinician to consumers and carers to enhance each parties' understanding of the illness and its management?
 - What is the best process for implementing collection of, and retrieving data from outcome measurement tools widely across Indigenous communities in Far North Queensland?
 - What does the information retrieved from these Outcomes tools tell us about the effectiveness of mental health service delivery in Far North Queensland for consumers?
 - Are these tools valid, reliable and sensitive enough to be included in evaluations of mental health interventions?

Contribution to Policy

The activities described in this report support the initiatives of the Queensland Aboriginal and Torres Strait Islander Mental Health Policy Statement (1996). They specifically contribute to the strategies outline in Section 5– Information, Monitoring and Evaluation as shown below:

- 5.1 Assemble and analyse data on Aboriginal and Torres Strait Islander Mental Health from existing available resources to identify priority groups with a view to evaluating policy initiatives and new services;
- 5.2 Review quality management systems (MHMSS, QAR, MHA Audits) to ensure they include adequate procedures and standards for Aboriginal and Torres Strait Islander people, and ensure adequate staff training to meet requirements;
- 5.3 Work with Commonwealth Mental Health Branch on the development of a national Aboriginal and Torres Strait islander data collection, which is developed and delivered in a culturally appropriate manner; and
- 5.4 Develop data collection protocols to ensure that Aboriginal and Torres Strait people have ownership and control of information and data on mental health relating to their communities.

Similarly, the project has aimed to operate according to the approach outlined in the National Mental Health Strategy and to provide a contribution towards a number of its proposed national actions and outcomes, particularly with regard to the outcome: “Awareness within mainstream services of the impact of cultural issues on the mental health of Aboriginal peoples and Torres Strait Islander peoples” (Commonwealth Department of Health and Aged Care, 2000a, 2000b).

The preparation of this final report was also informed by the recently released “*Social and Emotional Well Being Framework: a National Strategic Framework for Aboriginal and Torres Strait Islander Peoples’ Mental Health and Social and Emotional Well Being 2004-2009*” (Social Health Reference Group, 2004). This framework is likely to have a major influence on future Indigenous mental health service delivery and evaluation in Australia.

The project has aimed to fully embrace all dimensions of the NHMRC-endorsed Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research in its development, implementation and interpretation.

In summary, this final report details important findings and research-based recommendations on the use of Mental Health Outcome indicators for Indigenous consumers living in small urban, rural and remote communities in Far North Queensland. Other activities of the Australian Integrated Mental Health Initiative (AIMhi) Indigenous Stream research team in North Queensland and the Northern Territory have provided data and tools complementary to this project that help to validate and promote better understanding of Indigenous mental health in Northern Australia (see Appendix 1).

2

Project Aims, Objectives and Methodology

Project Aims and Objectives

The aim of this project was to modify, then assess the validity, reliability and usefulness of the Health of the Nations Outcomes Scale and the Life Skills Profile with Indigenous adult (aged 18 to 64) mental health consumers in the Cairns Network of Far North Queensland. Feedback from the assessment was to be used to develop further modifications and fine-tuning of the tools and process if necessary. The project was expected to progress through the guidance and advice of a Steering Committee, with representation across the key stakeholder organisations at an initial consultative workshop.

The research was designed to achieve the following objectives:

- Evaluate the reliability and repeatability of HoNOS and LSP as Mental Health Outcomes measures among Indigenous consumers, with modifications to these measures if necessary.
- Assess the social and cultural validity of HoNOS and LSP as general measures of outcome across diagnostic categories and differing severities of mental illness.
- Increase understanding of the strengths, weaknesses and limitations of HoNOS and LSP in assessing Mental Health Outcomes for indigenous consumers and investigate how weaknesses may be minimised via modification of training, instructions or tools.
- Document the effectiveness of engagement and feedback protocols aimed at enhancing the understanding of Mental Health Outcomes measurements among consumers, carers and clinicians.
- Provide an analysis of an initial set of Mental Health Outcomes data that will begin to provide multiple benefits to mental health service delivery, ideally including:

- Enhancement of the communication process between clinician, consumer and carers about consumers progress over time;
 - A reflection of the impact of management and treatment protocols on the consumers' well being and functioning;
 - A basis for comparing Outcomes for indigenous and non-indigenous consumers;
 - Assessment of the impact of efforts to improve mental health services to remote areas.
- Provide recommendations and a proposal for the development and validation of consumer rated outcome measures.

Methodology

A list of major activities and the timeline of the project is shown in Appendix 4.

1. The consultation process

Wuchopperen Workshop 1

In order to establish guiding principles for the project, Queensland Health provided support for an Indigenous Mental Health Outcomes Workshop at Wuchopperen Community-controlled Health Service in Cairns in June 2003. The workshop brought together workers with expertise in mental health outcome measures and workers with expertise in Aboriginal and Torres Strait Islander mental health service delivery to discuss issues relating to Outcomes measurement and seek consensus on the way forward. Comprehensive minutes, including details of discussions and ideas, were documented and a report was distributed to all attendees and major stakeholders. A summary of this Workshop is found in Appendix 5.

Establishing the Steering Group

A smaller steering group was established to facilitate implementation of the recommendations of Wuchopperen Workshop 1. The purpose of the group was to advise on the modifications of clinician-rated outcome tools (HoNOS and LSP) and the development of consumer-rated measures, review proposals for supplemental funding, give expert advice on reliability and validity research, provide Indigenous and clinicians' perspectives, review progress, advise on engagement and feedback protocols and advise on data analysis and

interpretation. The steering group provided valuable expertise during the implementation and validation of clinician-rated Mental Health Outcome tools and in development of recommendations for consumer-rated measures for indigenous consumers.

The Steering Group had members from the Australian Integrated Mental Health Initiative - Indigenous Stream in North Queensland (University of Queensland) and Northern Territory (Menzies School of Health Research), Queensland Health Mental Health Information Systems and Management, the Mental Health Unit at Cairns Base Hospital, Queensland Health's Northern Area Health Service - Mental Health, Apunipima Cape York Health Council, Wuchopperen Health Service, Northern Territory Health, Royal Flying Doctors Service and two widely acknowledged experts in the field of Mental Health Outcomes, who were engaged as consultants.

The Four Principles to Guide Clinicians' Rating with Indigenous Consumers

Development of the Principles Document

Shortly after the first Wuchopperen meeting, a set of guiding principles and supporting materials for completing HoNOS and LSP with Indigenous consumers was drafted and distributed to the Steering Group. This document was based on meeting outcomes. Several teleconferences were held to refine the principles and materials prior to submission of the final document.

The Principles document (Appendix 6) includes key definitions, instructions on the importance of identifying the Indigenous status of all consumers by asking (not through assumption based on appearance), explanation of the four principles, an item by item glossary for applying the principles, common questions and answers, and a series of short scenarios identifying recommended actions in situations commonly experienced by clinicians working with Indigenous consumers.

Extended Training Module, Clinician Support and Refresher Sessions

In 2003 Queensland Health developed a Statewide approach to train all mental health service clinicians in the use of outcome measures. The information from the principles document was incorporated into an extended module added to the standard Mental Health Outcomes training program used in the Cairns Network (Appendix 6). The module included a discussion of the importance of the identification of Indigenous status, the principles, instructions for specific items on HoNOS and LSP and a scenario to be worked through in the training session to demonstrate the use of the principles. These were used to inform the

development of training resources and strategies to build clinician knowledge, skills and confidence to use the outcome measures with all consumers.

All clinical staff members in the Cairns Network were trained in a one day workshop over a period of two weeks. The clinicians completed the training, which included completion of detailed case vignette applying the modifications of HoNOS and LSP-16. Clinicians also completed pre and post evaluation regarding their perceived competence, confidence and attitude in utilising the outcome measures. The ratings for the case vignette were also collected and compared to recommended ratings.

At the completion of the Statewide training in December 2003, a Zonal Outcomes Team provided ongoing support and training to clinical and managerial staff in the use of outcome measures and development of strategies to build a culture of information in mental health services. The Zonal Outcomes Team provided a range of resources and interventions aimed at maintaining clinician competence in the use of the measures and to support the embedding of the guidelines in the pilot site (see Information Sheet in Appendix 7 for more detail on these activities). Specific strategic workplace interventions included skills enhancement seminars, discipline-specific professional development sessions, advocating the importance of Outcomes collection with District management, and development of clinical processes to support the collection and use of outcome measures.

Ongoing support within the Cairns Network specifically included refresher sessions on the Indigenous principles with groups of clinicians (Appendix 7), and increasing learning by working through both Indigenous and non-Indigenous cases that clinicians brought forward.

The Northern Zonal Outcomes Coordinator also engaged with the Cairns Network Indigenous Mental Health Program Coordinator to develop and implement strategies for enhanced engagement of consumers, families and particularly Indigenous Mental Health Workers in the Outcomes assessment process. This led to the development of an Indigenous-friendly information pamphlet and the facilitation of two forums for Indigenous workers in the region (see Appendix 7 for examples).

Additional Screens on the Outcomes Information System

The first additional screen developed and implemented on the OIS was an Indigenous identification question requiring clinicians to ascertain the Indigenous identity (recorded as Aboriginal, Torres Strait Islander, both or neither) of the consumer. Instructions in the principles document - heavily emphasised in the clinician training - were to 'ask, don't assume' the cultural identity of the consumer. These instructions are consistent with those

routinely used by Queensland Health for all instances where Indigenous identification is required.

To facilitate evaluation of the implementation process as well as the use of HoNOS and LSP and occasions achieving adherence to the guiding principles (particularly Principle One), a second screen with 6 questions was added to the OIS. These questions (shown in their actual format on the OIS on the next page and with the full range of potential answers in Appendix 6) asked the clinician to provide details of:

- Their view of the degree of engagement of the consumer, family member or carer and a local practitioner (preferably an Indigenous Health Worker);
- Their view of the degree of engagement of the consumer, family member or carer and a local practitioner (preferably an Indigenous Health Worker);
- Their view of the reliability of the rating in reflecting the consumer's mental health; and
- Additional difficulty, if any, in completing the rating with the consumer.

The clinician was also invited to use the large space provided to comment about any other noteworthy factors arising out of the collection occasion.

Collection Occasions - Dean Lewin - Red-Cab
 File Help

FRED NURK

Collection occasion date: 24/2/2004
 Service type: Acute mental health inpatient
 Treating unit: Cab Ward II
 Age group: Adult (18-64)
 Measures completed by: Cab, Red
 PSP:
 Date of completion: 24/02/2004

New episode: referred from other mental health service type within network

Dx/MHA/FoC HoNOS HoNOSCA LSP16 Indigenous RUGADL FIHS CGAS SDQ MHI

In order to assist in evaluation of the Indigenous Mental Health Outcomes Implementation process, we would be extremely grateful if you would provide the following feedback.

In completing the outcome measures for this consumer, did your assessment include information from a family member/carer AND a local health practitioner (preferably an Indigenous health practitioner)? Please specify by selecting one choice below:

1. Compared to your experience with the mainstream measures, has there been additional difficulty in completing the measures with this Indigenous consumer?
 Family /Carer
2. How well do you feel the scales reflect the underlying mental health problems of this Indigenous consumer?
 some
3. How interested and / or engaged do you feel the consumer was when you were conducting the assessment that informed the completion of the HoNOS and LSP-16?
 reasonable
4. How interested and / or engaged do you feel the carer/family member(s) were in being involved in the assessment process?
 mixed response
5. How interested / engaged do you feel the local practitioner was in being involved in the assessment process?
 mixed response
6. How would you feel if you were able to provide any additional comments in relation to your own experience filling out these instruments and observations you made about the response of the consumer, other key informants you spoke with and the health centre or community to the use of these instruments?
 mixed response

This is where you would enter any free text

Clinical Profile Clinical History Save & Close Cancel

Figure 1

Analysis of Indigenous Data from the Information System

At three times during the project (30 August 2004; 27 February 2005; 19 July 2005), data from all collection occasions within the Cairns Network Outcomes Information System that identified the consumer as Aboriginal, Torres Strait Islander or both, was harvested by the Information Systems and Management Team and provided to the researchers for analysis. This data included age, sex, reason for collection, type of service (inpatient/hospital and community/ambulatory), district where the occasion occurred, diagnosis, responses to the additional questions on the OIS described above and HoNOS and LSP scores. The data were then cleaned and systematically analysed using SPSS Version 13. The tests used included: descriptive statistics including frequencies and cross tabulation, (using Pearson's chi-square (χ^2) and chisquare for linear trend) correlations (Kendall's and Pearson's), mean comparisons, Kruskal Wallis, Cronbach's alpha and univariate analyses of variance. Cross checking between parametric and non-parametric test results was performed frequently to confirm statistically significant differences indicated by the parametric tests, due to the frequent departure from a normal distribution (assessed by Kolmogorov-Smirnov test) and lack of homogeneity of variances in the HoNOS and LSP scores. Unless otherwise indicated, all statements in this report about data comparing groups are statistically significant at the 5% level ($p < 0.05$).

Intermediate Reporting and Communication

The Steering Group met face to face on four occasions and through teleconference on eight occasions. While this process was beneficial in the initial phases of the project, the use of telephone for discussing sensitive issues had limitations and was in some cases counter-productive. One major problem was the inability of local Indigenous and non-Indigenous members to speak out over the telephone, and different and sometimes conflicting priorities and views became apparent through time. The research team attempted to address these difficulties by holding two additional face to face meetings and ensuring a focus on Indigenous views through the participation of Maori Monitoring and Review Group members, who were addressing similar issues on a national level in the MH-SMART initiative.

Two interim reports were completed and submitted to the Information Systems and Management Unit in October 2004 (analysis of data collected from June to August) and March 2005 (analysis of data collected in 2004). These were discussed in Steering Group teleconferences and preliminary findings were presented in detail in the April 2005 workshop. These interim reports had similar content to Chapters 5 to 9 of this report, but with less detail. These reports were submitted to the Steering Group for discussion in teleconferences and on

two occasions with the Principal Investigator presenting in person. Interim recommendations, or essentially 'alerts', concerning Indigenous identification, numbers of collection occasions being captured across the network, levels of family and local practitioner involvement and clinician views were provided through these reports.

In addition to these formal meetings, the researchers and the Zonal Outcomes Coordinator met frequently in Cairns throughout the study period to share findings, provide a joint refresher session to remote area clinicians, and to discuss ways to support each others' ongoing work. The Zonal Outcomes Coordinator for Far North Queensland had previous experience with Indigenous consumers as a clinician and was co-located with the Indigenous Mental Health Coordinator for most of the initial Outcomes implementation period, ensuring constant awareness and discussion of Indigenous mental health issues.

Consumer and Carer Interviews

This project, as part of the broader Indigenous Stream of the Australian Integrated Mental Health Initiative (AIMhi), was able to add questions to in depth interviews conducted with Indigenous consumers and carers in remote communities of Cape York. The aim of these questions was to explore the usefulness of items being assessed on the HoNOS and LSP, as viewed by consumers and carers, and to offer background data with which to analyse gaps in these measures. Given project limitations, a relatively simple set of questions was designed to elicit information from consumers and carers about factors surrounding wellness within themselves or the consumer they care for. These questions were:

- *What are you like when you are... well, getting ill, definitely crook [sick], getting better?* (consumer's question)
- *What is the person you care for like when he or she is ... well, getting ill, definitely crook, getting better?* (carer's question)

The questions were asked within semi-structured in-depth interviews conducted with 14 consumers and 15 carers living in several communities of Cape York. Two interviewers were present in interviews, a non-Indigenous male with experience as a carer and a female Indigenous research officer with experience in mental health work. Participants were selected via the visiting specialist psychiatrists and consent to be approached by the interviewer was requested by the specialist. Carers were accessed in a similar manner. The purpose and process of the study was fully explained and the principles of informed consent were adhered to throughout the interview process.

Each 'time point' ('well', 'ill', 'getting better') was covered before the next 'time point' was introduced. Answers offered by the interviewee were recorded, and following the open-ended descriptions, a series of prompting questions covering the items of HoNOS and LSP that were as yet undiscussed were asked. Items the interviewee felt correctly applied to them (or the person they care for) were entered using a different colour pen to allow distinction of prompted and unprompted responses.

Individual responses were tallied (prompted answers kept separately from the unprompted) and organised into 6 emerging categories, namely: 'How I'm feeling', 'What's going on in my mind', 'Being with other people', 'What I'm saying', 'What I'm doing' and 'Taking care of myself'. These categories were applied at three time points: 'When I'm well', 'When I'm getting ill or definitely crook [sick]' and 'When I'm getting better'. The two time points of the illness ('getting ill' and 'definitely crook') were combined for analysis because of their qualitative similarity. Next to each item, numbers were given in brackets to designate the number of times the item was mentioned by a consumer or carer. Numbers followed by a P indicated the number of times the response was made by the consumer or carer after a prompting question, rather than being offered spontaneously.

Wuchopperen Workshop 2, Local Forums and Other Dissemination of Findings

A second workshop, requested by the Steering Group, was held at Wuchopperen Health Service in April 2005. The focus of this workshop was on the analysis and interpretation of data collected through mainstream measures and the sharing of ideas and experiences between North Queensland researchers and service providers and a team of Maori leaders in mental health. The workshop outcomes are discussed in Chapter 10 and a summary of the attendees and issues discussed at the workshop is provided (Appendix 9).

A local forum sharing the findings of the project, examining key parts of the draft final report and discussing the modifications of Principle One and Four was held in January 2006 (Appendix 9). Thus local dissemination of information has thus far been through the three workshops held at Wuchopperen Health Service in Cairns at the beginning, middle and end of the project. A presentation was also made to the Cairns District Mental Health Executive in October 2005 and more are planned in 2006.

The Chief Investigator, Indigenous Research Officer and Queensland Health collaborators presented the project at the following conferences: The Mental Health Service (TheMHS) Conference, Gold Coast 2004; Health Outcomes Conference, Canberra 2005 and Australian Mental Health Outcomes & Classification Network National Forum, Brisbane 2005.

3 Addressing Concerns: The Development and Proposed Modification of the Guiding Principles

“The centrality of Aboriginal and Torres Strait Islander family and kinship must be recognised as well as the broader concepts of family and the bonds of reciprocal affection, responsibility and sharing”. (Swan & Raphael, 1995, np)

Consensus from the first Wuchopperen Workshop

Over two days the workshop group explored issues relating to Outcomes measurement. Themes explored included the pros and cons of using standardised Outcomes measurement with Indigenous people, problematic scale items, the validity of the questions to Indigenous people, and issues surrounding the reliability and accuracy of clinician ratings. Although there was considerable concern raised about the Outcomes process, three major conclusions were reached by consensus:

- There are potential major losses associated with disengaging from widely utilised measurement tools, which are likely to have a major long term impact on policy, resource allocation and practice;
- The optimal way forward for collecting Outcomes for Indigenous people is through cycles of modification, implementation, evaluation and remodification of the existing tools using a research-based approach, rather than starting afresh with newly developed tools;
- The limitations of clinician administered tools, which by definition need to be standardised and validated, can be at least partially offset by specifically designed consumer rated Outcomes tools which can be much more flexible. These should also be a major component of Outcomes measurement with Indigenous people.

The following items were identified as likely to be problematic, should they be rated (without clear guidelines) by non-Indigenous clinicians working with Indigenous consumers:

Potentially problematic HoNOS items: Items 1 through 3, Item 6, and Items 9 through 12:

- Concern exists that problems with relationships (item 9), activities of daily living (item 10), living conditions (item 11) and occupation (item 12), and activities that are associated with the overall degree of socio-economic disadvantage experienced by Indigenous communities may be under-rated by clinicians because these problems are common. On the other hand, cultural differences (e.g. heavy use of bush or garden foods where store foods are inadequate) or communication difficulties (lack of engagement and open discussion) within some of these items may lead to over-rating.
- Items 1 and 3 were identified for similar reasons: because some behaviours are more commonly experienced in Aboriginal communities, clinicians may under-rate unacceptable behaviours of a consumer, relative to the unacceptable behaviours of their peers in the community. This could result in an underestimation of the severity of illness, and the distress that these behaviours cause.
- Item 2, which refers to self harming behaviour and Item 6, which refers to hallucinations and delusions, were identified as potentially problematic items as they were likely to be over-rated in cases where culturally understandable behaviours or beliefs expressed by the consumer are perceived by the clinician as symptoms of a mental illness. However, clinicians who assume that a particular self-harming behaviour or an experience of seeing or hearing things is culturally appropriate and understandable, may under-rate an important aspect of an Indigenous consumer's mental illness.

LSP items: Items 3, 4 and 5

- Conversation, warmth and withdrawal – Concern about these items was expressed because a consumer's behaviour due to the alien assessment setting (and people present) may be misinterpreted by the clinician. It is possible that this misinterpretation would lead a clinician to overrate the consumer's withdrawal, or underrate their conversation or warmth, despite the consumer's behaviour being understandable in a cultural context.
- Friendships – The focus of relationships for Indigenous people is often with extended family and not with 'friends' in the same way as non-Indigenous people. Without guidance from a family member, carer, or Indigenous Mental Health worker, clinicians are likely to find understanding the social networks of the consumer difficult.
- Work – Many Indigenous people are involved in other meaningful activities besides paid employment, so a sole focus on paid work activities may not take into account other meaningful activities enjoyed by the consumer and lead to over-rating of problems.

Alternatively, clinicians might have a tendency to under-rate underlying social disadvantage (lack of work opportunities available) due to the high level of such disadvantage across the whole community, as described for HoNOS items 9 through 12.

In addition to these specific, potentially problematic issues, strong concern was expressed that the measures failed to reflect some constructs that were extremely important to Indigenous people's mental health. Some examples discussed were:

- Spirituality, including healthy spirituality and spiritual sickness or toxic shame.
- Strength and resilience
- Family, kinship and community support
- Physical strength
- Connection to land and place

As one Indigenous participant explained, "The spiritual dimension relates to how the information is interpreted, based on where you come from and we [health professionals] are unaware of those [spiritual considerations] at times. If HoNOS lacks the spiritual dimension, it is not very useful to Indigenous people". This statement was supported by other participants.

Another concern raised was the negative direction of both the HoNOS and the LSP, in that a higher score indicated higher severity on both of these scales. This reflects a more clinical orientation (striving towards reduction of problems and symptoms, measuring loss as opposed to gain) rather than a resilience and recovery orientation (working from strengths and striving towards higher levels of functionality and mental health).

The Expert Consultant to the project, Professor Alan Rosen, who played a key role in developing the LSP, explained the changes that the tool underwent since its first creation (Rosen et al., 1989; 2001). LSP was originally formatted as a longer tool that scored in a positive direction, giving a strengths perspective to scores. A 20-item LSP was subsequently produced that could be presented in either a negative (impairment perspective) or positive (strengths perspective) direction. However, an even shorter scale, the LSP-16 rating only from a negative direction (0 representing having no problems to 3 representing having severe problems) was adopted within the Mental Health – Classifications and Service Costs project and the National Mental Health Strategy (Commonwealth of Australia 2002) for administration with the HoNOS. This was done without consultation with the original authors of the tool who did not agree with the change to a deficits-oriented direction. Rosen et al.

(2001) argued that there is a possibility that the scale's negative orientation may subtly influence the way that issues are discussed and perceived by both clinician and consumer. In the Wuchopperen Workshop, Rosen further pointed out the importance of measuring in the strengths direction in order to be compatible with contemporary approaches to rehabilitation and recovery.

Concern was also expressed in the workshop about the general communication barriers and understandings of the clinician making the rating and the fact that consumer rated measures can tell the story "from the inside" (discussed in Rosen, 1995).

The Principles and Modifications Document

After much discussion and deliberation over the development of a detailed set of instructions for each question, it was recognised that there were four underlying key principles underlying the rating instructions. These four Principles were identified as:

Principle One

Although the clinician provides the final ratings for HoNOS and LSP, it is extremely important to involve additional informants when applying them to Indigenous consumers. Whenever possible, information for assessments must be gathered from a range of sources, including:

- at least one carer or family member involved in the consumers care, and;
- one local practitioner (preferably an Indigenous Health Worker) who knows the consumer and the community well.

Acknowledging that this may already be part of the clinician's standard practice, three major purposes for including additional informants were identified, namely:

- To gather a comprehensive picture of the consumer's experience over time;
- To help ensure that Indigenous people accepted the ratings as being socially and culturally informed; and
- To clarify the complex interactions between cultural practices, social circumstances and community standards. Principles Two through Four aim to provide guidance on how these should be taken into account in clinician ratings.

Principle Two

The rating assigned to all issues should objectively reflect underlying social disadvantage experienced by the consumer, and should not be influenced in circumstances where similar disadvantage is widely experienced in the consumer's community. The Outcomes measurements should capture these prevailing levels of social disadvantage as well as any additional disadvantage experienced by the consumer as a result of their illness or disability.

The following are examples of issues that should be included in ratings:

- lack of adequate food supply to the community
- overcrowding in households
- lack of support services to be accessed
- lack of opportunity for employment or other meaningful activity
- weekly/fortnightly cycle of income and expenditure

Principle Two is relevant to the following items:

HoNOS – Item 8 (Other Mental & Behavioural Problems) & Items 9 through 12 (Social Problems)

LSP – Items 4, 5, 9, 13, 16

Principle Three

Ratings of behaviours that are socially and culturally unacceptable should not be influenced by how common such behaviours are in the community. That is, the ratings should objectively reflect behaviours not sanctioned or accepted, even if they are common.

Examples of behaviours that are not socially or culturally acceptable to any community include:

- excessive alcohol consumption
- domestic or community violence
- disruptive behaviour and self-harm behaviour which is clearly unconnected to cultural
- practices or beliefs shared by others in the community

Principle Three is relevant to the following items:

HoNOS – Items 1 through 3 (Behavioural), Item 8 (Other Mental and Behavioural Problems)

LSP – Items 4, 5, 7, 13 through 16

Principle Four

Socially and culturally acceptable behaviours, experiences and beliefs associated with funerals, religious or traditional activities should not be included in any assessment items. Through discussions with a family member/carer, the local practitioner and/or Indigenous Mental Health Worker, the clinician must identify whether the reported / observed findings are consistent with social or cultural practices that are recognised and accepted within the community.

Examples of socially and culturally acceptable behaviours, experiences and beliefs may include:

- Non-accidental self-injury occurring as part of mourning rituals and paranormal phenomena (such as visions and beliefs) in the context of funeral, healing, religious or other traditional rites (where these are recognised and accepted in the community);
- Instances where reported / observed findings are deemed to be acceptable in light of prevailing expectations and standards in the community (such as standards of grooming and dress, eg. going barefoot);
- Where an assessment of warmth and interpersonal interactions is made in an interview situation, the social and cultural context of the consumer's behaviour should be considered (eg. community standards, awareness of shame and considerations of privacy and confidentiality).

Principle Four is relevant to the following items:

HoNOS – Item 2 (Behavioural), Item 6 (Symptomatic Problems) Item 8 (Other Mental and Behavioural Problems, Item 10 (Social Problems)

LSP – Items 1 through 5

Discussion and Consensus for Modifications from the Third Wuchopperen Workshop - Principle One

These original principles were revisited during the final workshop attended by local stakeholders. The possible modification of Principles One and Four were discussed at

length. For Principle One, issues of confidentiality were considered, in light of the following comments entered in the Outcomes system by clinicians:

- “The client stated that he wanted to use the service when there was a need to do so, however had mixed feelings about the process of providing additional information about his private life”.
- “Patient refused for us to contact GP”
- “This client elects to have no involvement from an Indigenous practitioner in his care”.
- “My clients usually prefer to have their mental health status kept private. Involving family members or others in the community is not often acceptable.”

It is notable that comments referring to confidentiality were not frequent (4 out of 496 occasions) and did not appear to be a dominant concern amongst clinicians (4 out of the 29 offered comments addressed confidentiality). Nonetheless, the fourth comment in particular, because it is offered as a general comment, as opposed to relating to an individual occasion, reflects an attitude that is not conducive to culturally appropriate, family oriented practice. The group discussed the many subtle ways that involvement of family and Indigenous Health Workers / Mental Health workers is discouraged, which include the structure of the services (most based on individualised, non-indigenous care models), the frequent lack of clarity or recognition of the expertise and roles of Indigenous workers in the care pathway, and possibly clinicians’ lack of confidence or skills in working with families. The outcome of this discussion was to recommend an addition to Principle One that, while recognising the right of the consumer to refuse involvement of additional informants in their assessment, urges clinicians to continuously reflect on how their practice can eliminate barriers to greater meaningful involvement of families, carers and Health Workers.

Recommended Adjustments to Principle One

(Additions to the original Principle One are bolded and italicised.)

Although the clinician provides the final ratings for HoNOS and LSP, it is extremely important to involve **ADDITIONAL INFORMANTS** when applying them to Indigenous consumers. Whenever possible, information must be gathered for the assessments from a range of sources, including:

- at least one carer or family member involved in the consumers care **AND**
- one local practitioner (preferably an Indigenous Health Worker) who knows the consumer and the community well.

Acknowledging that this may already be part of the clinician's standard practice, three major purposes for including additional informants were identified, namely:

- To gather a comprehensive picture of the consumer's experience over time;
- To help ensure that Indigenous people will accept the ratings as being socially and culturally informed: and,
- To clarify the complex interactions between cultural practices, social circumstances and community standards. Principles Two through Four aim to provide guidance on how these should be taken into account in your ratings.

There may be times when an Indigenous consumer genuinely does not want others to know or be involved in their care and such desire for confidentiality must be respected as with all consumers. However, clinicians are advised to continuously reflect on the service pathway and their own attitude and practice in relation to encouraging family and health worker involvement. Culturally appropriate services that promote social and emotional wellbeing and healing place Indigenous Health Workers, consumers and family in the forefront of care. Services arranged differently may inadvertently discourage families and local people from the consumer's care.

Discussion and Local Consensus for Modifications from the Local Forum - Principle Four

The aim of the Principle Four, which is not contested, was to avoid the classification of culturally appropriate and understandable behaviours, experiences and beliefs as symptoms of illness. The Steering Group surmised that the best approach to this issue would be to instruct clinicians not to include reported or observed findings in any of the assessment items if these were identified as socially and culturally acceptable and appropriate through discussion with the family or local practitioner.

Several concerns have arisen about this Principle through the project's findings. First was the recognition that family/carers and/or local practitioners were involved in only half of all collection occasions, indicating that clinicians frequently make decisions regarding cultural validity of consumers' behaviours, experiences and beliefs without such input. Of particular

concern is the subtlety of these issues, hence the need for clinicians to gather a full understanding of the form, intensity and duration of culturally understood experiences as well as those that are being experienced by the consumer. Hence, it is imperative that clinicians receive clearer guidance on the meaning of ‘culturally acceptable’ experiences such that anything that “sounds cultural” is not simply accepted at face value.

It is also now recognised that the original Principle Four did not make it clear whether to rate the frequency and severity of mental health problems that **result from** such situations in other items. For example, the fear of sorcery, as commonly understood in some communities, causes considerable and long-lasting distress that can lead to anxiety, depression and social isolation. As a highly experienced psychiatrist on the project’s Steering Committee stated, “*For many of us a given stressor may be ‘associated with socially validated beliefs’ – the associated distress is the key issue we need to score.*” The original Principle Four advised clinicians to exclude all reported/observed findings associated with accepted practices and was inconsistent with the other principles with its focus on the reason for the problem as opposed to objectively rating the severity of the problem.

Clarifying these instructions through modification of Principle Four aims to protect against selective inaccuracy in assessing the severity of mental health problems that Indigenous people experience as a result of either incorrect determination of cultural appropriateness or dismissal of distressing or threatening behaviours because they result from culturally-associated experiences and beliefs. As shown later in this report, occasions where informants were included had markedly higher scores on HoNOS items 6 (hallucinations and delusions) and 8 (other problems) in community and hospital settings, while similar or lower scores were found for item 2 (self-harm) where informants were involved.

One member of the steering group (Nursing Director, Mental Health Unit, Cairns Base Hospital) commented that Principle Four had been identified as the most difficult to use in informal discussions conducted by the Zonal Mental Health Outcomes Coordinator among mental health clinicians in the Cairns Network.

The greater integration of mental health into a primary health care framework and the need for a social and emotional approach to Indigenous mental health care is now part of national policy (Social Health Reference Group, National Aboriginal and Torres Strait Islander Health Council and National Mental Health Working Group, 2004). Indigenous consumers should thus expect to receive effective assistance from services for mental health problems they are experiencing that are related to social and cultural issues. Clinicians and health workers will

therefore be expected to assist Indigenous consumers to make links with informal services (e.g. traditional healers, spiritual leaders, men's and women's groups) who have the skills to assist with mental health problems resulting from cultural experiences and distress as well as to appropriate staff within the health service.

Communications with a group of Maori leaders in the MH-SMART Initiative in New Zealand led to recognition of a difference in the way that they guide clinicians in such situations. In New Zealand, clinicians are instructed to :

“Identify through discussions with whanau [Maori-defined family and clan unit], Maori mental health practitioners or [through] cultural assessments, whether the reported/observed findings are consistent with cultural practices that are recognised and accepted within Maori belief systems (which themselves may be heterogenous). Only when this determination is made should the following [rule] be applied: culturally determined behaviours, experiences and beliefs associated with cultural norms and activities should **not** be included in any rating items [however] when considering the rating scales, cultural elements must be balanced by the degree of distress the problem causes and the effect it has on behaviour” (Levy et al., 2005a, 10-11).

These guidelines aim to ensure that “cultural elements are not used to minimise the impact of behaviours” on the consumer, family group and community (Levy et al., 2005a, p11).

Thus, similar to the principles developed in this study, the Maori Review and Monitoring Groups instructs clinicians **not** to rate socially and culturally valid experiences of Maori consumers as a symptom of mental illness and clearly identifies the importance of consultation with cultural informants (such as local practitioners and Indigenous Health Workers) to identify whether there is an accepted cultural element involved. However, the Maori Review and Monitoring Group directs clinicians to **include** distress and behaviour that causes risk to consumers and others, even when the behaviour is the result of recognised and accepted culturally valid experience.

Based on learning that occurred through the project's many consultation activities, particularly with the Maori Review and Monitoring Group and the finding that family members, carers and/or Indigenous Mental Health Workers are often not accessed in practice, the researchers recommend that Principle Four be adjusted. The adjusted Principle Four further defines the concept of culturally accepted beliefs, experiences and behaviours to include consistency in form, intensity and duration. It also guides clinicians to include mental

health problems resulting from such experiences even if the experience itself is determined to be socially and culturally acceptable and not a symptom of mental illness.

Recommended Modified Principle Four

Culturally informed behaviours, experiences and beliefs associated with funerals, religious or traditional activities should not be included in HoNOS assessment items 2 (self-harm) or 6 (hallucinations, delusions) when these are consistent in form, intensity and duration with accepted local norms. However, when these behaviours, experiences and beliefs are not consistent with local norms or when they cause significant mental health problems and/or danger to the consumer, their family or other people, these aspects of their experience should be included in the ratings of other items.

Relevant items include: HoNOS items 1 (aggressive behaviour), 7 (depressed mood), 8 (other problems), 10 (overall functioning), potentially all HoNOS/LSP items.

Example of an issue that should not be included in your rating if present:

- non-accidental self-injury occurring as part of mourning rituals and paranormal phenomena (e.g. visions and beliefs) in the context of funeral, healing, religious or other traditional activities, where these are recognised and accepted in form, intensity and duration in the community;

Examples of issues that should be included in your rating even if they result from culturally acceptable and shared beliefs:

- non-accidental self-injury or distressing events of greater intensity or duration than expected through shared cultural understandings even if the underlying belief is deemed appropriate
- significant anxiety, depression, sleep problems, alcohol or drug-taking or risk of harmful action against self or others associated with paranormal experiences regardless of their consistency with cultural understandings.

A corollary to this principle is that social mores that might appear to reflect mental unwellness amongst non-Indigenous consumers but are consistent with community norms should not be rated in any items.

For example, the following should not be included in your ratings:

- reported/observed findings deemed to be acceptable in light of prevailing expectations and standards in the community (e.g. grooming, dress, going barefoot);
- perceived lack of warmth and interpersonal interaction taking into account community standards,
- awareness of shame and considerations of privacy and confidentiality in the interview situation.

Relevant items include LSP Items 1, 2, 3, 4, 5

Principles Two and Three

No evidence of the need for modification of Principles Two and Three was found and no suggestions to alter them were raised in discussions, presentations and forums.

4

Developing engagement tools and process: Health Worker Forums

Engaging with Indigenous Workers and Community

Discussions during the Wuchopperen consultation workshop in 2003 emphasised that engagement of the community and demonstration of usefulness of the data collected were key requirements for successful implementation and sustainability of Outcomes initiatives. It was widely agreed that without engagement with the consumer, their family, Indigenous Health Workers and the community in the gathering and interpretation of Outcomes data, its accuracy and impact would be affected. Thus efforts to enhance involvement in the Outcomes assessment process by others besides the rating clinician was considered an important priority for both the implementation process being supported by the Zonal Outcomes Coordinator, and for this research project.

In the early implementation stages, the Indigenous Mental Health Coordinator for the Far North District and the Zonal Outcomes Coordinator collaborated to develop an additional project that aimed to assist in the broader engagement of Indigenous people in the Outcomes process. Entitled *Enhancing and Engaging Participation of Aboriginal and Torres Strait Islander Consumers, Carers and Health workers in the Outcomes Initiative through Culturally Relevant Resources and Activities*, this initiative involved Indigenous stakeholders in the Cairns Network including Cairns, Cape York, Innisfail, Tablelands and the Torres Strait and Northern Peninsula Area Health Service Districts. For further information on this additional project, see Stapley, Baird and Hatzipetrou (2005).

Development of a Poster and Pamphlets

The project consisted of two related activities. The first involved the development of Indigenous targeted resources (posters, pamphlets) about the Mental Health Outcomes initiative, designed with cultural relevance for Aboriginal and Torres Strait Islander people in mind. With the assistance of an Aboriginal artist from the local region, a culturally relevant

background was designed to attract the attention of Indigenous consumers, carers, families and community members to the resources.

Initially, translation of wording on the resources to local languages (for example Creole, the form of English commonly spoken throughout Torres Strait and Cape communities) was planned to assist in explaining the reasons for Outcomes measurement and introducing the HoNOS and LSP scales. However, a scoping exercise completed with Indigenous Health Workers for guidance revealed that writing in Creole was not necessarily appropriate. An Indigenous Health Worker explained *“even though Creole is the spoken language, it is not necessarily written in that way, therefore it is easier to read English”*. The pamphlet (shown in Appendix 7) was therefore printed in English.

It is important to note that this comment referred only to the use of written Creole in the Torres Strait region and decisions about the benefits of using Indigenous languages in other settings should be taken with appropriate local consultation.

Health Worker Forums

The second activity of this project aimed to promote the understanding and capacity of Indigenous Health Workers to become key participants in Outcomes assessment with Indigenous consumers. The forums were held as both a consultation activity and in order to provide information and training to workers. The forums enabled discussion about the process with Indigenous Health Workers, and the following points were raised:

- How is Outcomes data being collected?
- The importance of accurate and reliable Outcomes data collection;
- How should the Indigenous resources (described above) be provided to inform people clearly about the Initiative?
- What uses do Outcomes measures have, and what value do they have for consumers and carers?

Forums were held at Thursday Island in September 2004 and in Cairns in April 2005. In all, 15 attendants participated, the majority of whom were Mental Health Workers. Participants came from a number of regions across the Northern Area including Tully, Cairns, Atherton Tablelands, Yam and Thursday Island, and the rural and remote Aboriginal communities at Yarrabah, Weipa, Pormpuraaw and Kowanyama.

The forums were facilitated by the Indigenous Mental Health Coordinator and the Zonal Outcomes Coordinator. A Project Officer attended to document the issues and views discussed among the workers and to gather information on the usefulness of the Forum to enhance workers' understanding and participation in the Outcomes assessment process. Notes were taken from the discussions and the Health Workers were asked to complete an 11 question survey, of which three questions provided space to write in responses (see Appendix 7). All 15 participants filled out the form, though there were some missing values.

The first two questions asked participants to identify training or information they had received about measuring health Outcomes in health services generally and specifically, as part of the Mental Health Outcomes initiative, before attending the workshop. Of the 15 participants, five responded that he/she had never heard about Outcomes at all, while two had heard a little about Outcomes measurement but had not received any training about it. The remaining seven Health Workers had received both information and some training in Outcomes measurement.

The next questions canvassed whether Health Workers should play a role in explaining the Mental Health Outcomes initiative to community members and encouraging participation by families and consumers of the service. All 15 participants responded that Health Workers should have a major and important role in this process. Respondents explained:

“Health workers are seen as first point of contact. Health workers are able to interpret between services and the community...”

“Health workers need to be skilled in those areas because of remoteness; clinicians sometimes are away; if the client is ‘island hopping’ we need to access his/her chart to know medication...”

“It should be a shared responsibility and balanced out more...”

The Health workers were also asked if they had been requested by a Mental Health service clinician to help explain to consumers and/or carers what Mental Health Outcomes are and why they are completed. In responding to this, seven Health Workers commented that they are asked often while eight said that they had never been asked to help.

Asked how confident they felt about explaining to community members, families and consumers of mental health services about the Mental Health Outcomes initiative, nine

respondents said they felt some confidence but were still hesitant, and the remaining six Health Workers said they felt very confident.

When asked if they saw any value in using Outcomes tools to describe how the consumer is doing at different points in time, four participants responded that there is some value but it is not of high priority and 11 said that it is very valuable and a high priority. When asked how important they think it is for Mental Health service clinicians to gain information from a Health Worker and a family member / carer when doing Mental Health Outcomes assessments, all 15 participants responded that it is very important and necessary. A number of respondents commented on why additional informants are of value:

“Because of language barriers in the communities, culture and customs...”

“Because it will give a clear picture of the person’s lifestyle and background...”

“They are sometimes the main person in that area that has knowledge about the situation...”

When asked if they have played any role in helping a Mental Health service clinician to understand consumers’ behaviour or symptoms, three participants said they had not, four said they had a small role, while eight health workers felt that they had played a major role.

In response to the question regarding their confidence in helping a mental health service clinician to measure Mental Health Outcomes by providing information about a consumer in their community:

- Five participants said they had some confidence but were still hesitant
- The remaining 10 said they felt very confident.

The final two questions asked participants whether the workshop increased their awareness and understanding of Mental Health Outcomes measurements and whether participants could see any problems in putting in to practice the things that they learnt in the session. In response, six health workers indicated their understanding had increased a little, while nine health workers said their understanding had increased a lot. Two health workers said they would have no problems at all putting the understanding into practice, four said there would be a few problems that are easily solved, and eight health workers said that there would be some problems that would be challenging to solve. Additional comments in response to this question included:

“Indigenous Health Workers need more skills and education in mental health...”

“Health Workers and clinicians need to work more closely together and to share the workload...”

“Problems[?] – only in terms of changing clinicians’ attitudes towards being more open to using Indigenous Mental Health Workers...”

“Ongoing training would be important...”

“There needs to be more forums between Mental Health, Social Health Workers, DONs CNCs, RNs etc. Make them regular – not just one off. This forum could have a powerful influence on our communities. Today’s forum already has!”

Key Findings of Chapter 4

These workshops enabled Indigenous Mental Health Workers to learn more and express their views about Mental Health Outcomes processes. Overwhelmingly, there was high willingness to engage in the Outcomes process, and Health Workers were able to see the Outcomes initiative as an opportunity to contribute to the assessment process. However, many workers foresaw practical difficulties in putting this into practice. Further emphasis on providing formal (rather than the present range of ad hoc) opportunities for engagement of Indigenous Mental Health Workers and Indigenous Primary Health Workers in the Outcomes initiative, and more generally in the Mental Health care pathway, would have many benefits. The results presented in Chapters 7 to 9 provide further support for this.

5

Process Analysis: Implementation of the Outcomes initiative with Indigenous Consumers in the Cairns Network

a. Introduction

This chapter describes the analysis of downloaded data collected with Indigenous consumers from the Outcomes Information System (OIS) for the Cairns Network. This included all data from the Districts of Innisfail, Tablelands, Cairns, Cape York, Torres Strait and Northern Peninsula Area for which the Indigenous status of the consumer was one of the following: Aboriginal, Torres Strait Islander or both Aboriginal and Torres Strait Islander.

This report highlights some important aspects of data collection from March 2004 to June 2005 in order to demonstrate the early implementation process of the Outcomes Information System (OIS) in the Cairns Network. It provides an analysis of HoNOS and LSP data collected during the 12 months from July 2004 to June 2005, with the initial months (March to June 2004) excluded. The interval was chosen because of the low numbers of entries and high proportion of unspecified entries in the first months and to make it possible to consider these data in light of other data reported annually. Findings associated with the collection process are discussed, and an examination of responses to the additional questions on the OIS for assessments with Indigenous consumers is undertaken. An analysis of the missing values and internal consistency in the tools and their subscales is provided. It should be noted that sample sizes for analyses vary, and the (sometimes small) sample sizes have implications for both the analyses, and interpretation of results.

Over the 12 month period, a total of 518 relevant collection occasions were entered into the Outcomes Information System. In 22 occasions there was no valid data entered for either HoNOS or LSP. Therefore, for most analyses in this paper, these 22 non-data cases were excluded, giving an overall sample of 496.

b. Unspecified Indigenous Status

The initial downloaded data included entries for which Indigenous status was unspecified. Therefore the first interim data analysis report (Appendix 8) of collections between March and June 2004 and submitted in October 2004 explored the characteristics of the 'unspecified group' and compared these with those who were specified as Aboriginal, Torres Strait Islander or both. It is likely that the unspecified group includes an over-representation of Indigenous people, so a key recommendation stemming from the first download of data was to encourage clinicians to ask all consumers their Indigenous status and specify this in the Outcomes Information System at subsequent assessments. Information provided by the Information Systems and Management Team enabled tracking of monthly numbers of unspecified entries in the Cairns Network in 2004 (Table 1).

Table 1. Tracking of Entries by Indigenous Status for the Cairns Network

a. Preliminary Data Collection Period in Cairns Network

Month in 2004	Number of Collection Occasions				Total Entries
	Indigenous (%)	Unspecified Status (%)	Non-Indigenous (%)		
January	5 (2.3)	0	104 (48.6)	105 (49.1)	214
February	7 (3.9)	0	96 (53.3)	77 (42.9)	180
March	12 (5.5)	2	98 (45.0)	108 (49.5)	218
April	13 (7.1)	10	43 (23.4)	128 (69.6)	184
May	15 (8.5)	8	27 (15.3)	135 (76.3)	177
June	35 (14.9)	25	75 (31.9)	125 (53.2)	235
TOTAL	77 (6.5%)	43	443 (37.7%)	678 (57.8%)	1,174

b. 12 Month Data Collection Period in Cairns Network

Month in 2004	Number of Collection Occasions				Total Cairns Network
	Specified Indigenous (%)	Unspecified Status (%)	Specified Non-Indigenous (%)		
Jul	43 (13.3)	24	40 (16.0)	167 (66.8)	250
Aug	64 (18.2)	38	25 (7.1)	262 (74.6)	351
Sep	38 (13.3)	24	7 (2.5)	241 (84.3)	286
Oct	49 (15.2)	35	6 (1.9)	268 (83.0)	323
Nov	53 (14.5)	40	6 (1.6)	307 (83.9)	366
Dec	45 (13.4)	31	9 (2.7)	282 (83.9)	336
2005					
Jan	46 (15.2)	34	7 (2.3)	249 (82.5)	302
Feb	104 (25.9)	84	4 (1.0)	293 (73.1)	401
Mar	64 (16.5)	41	5 (1.3)	319 (82.2)	388
Apr	84 (17.1)	59	8 (1.6)	399 (81.3)	491
May	70 (15.6)	41	9 (2.0)	371 (82.4)	450
Jun	67 (17.6)	45	4 (1.1)	310 (81.4)	381
TOTAL	727 (16.8)	496*	130 (3.0)	3468 (80.2)	4,325

Accurate for data downloaded on July 16, 2005 for data collected by June 30, 2005

* 496 collection occasions with valid HoNOS or LSP data present at download date

NB: The difference between the total number of occasions examined in this report (496) and the total entered into the OIS according to Queensland Health (727) occurred because when a consumer is identified in subsequent collection occasions as Indigenous, their status is retrospectively assigned as Indigenous to prior collections. Because the downloads must occur at a specific date, they will not include occasions with Indigenous consumers whose status was identified at a later time. This suggests that there has been and may continue to be continual retrospective increase in the proportion of Indigenous occasions in the system. This technical issue needs to be considered when examining the findings here, since time when Indigenous status is identified may vary for non-random reasons and is a source of potential systematic bias in the sample being analysed. That is, the data being analysed at any given time may fail to include a number of Indigenous consumers who have not yet had their Indigenous status identified.

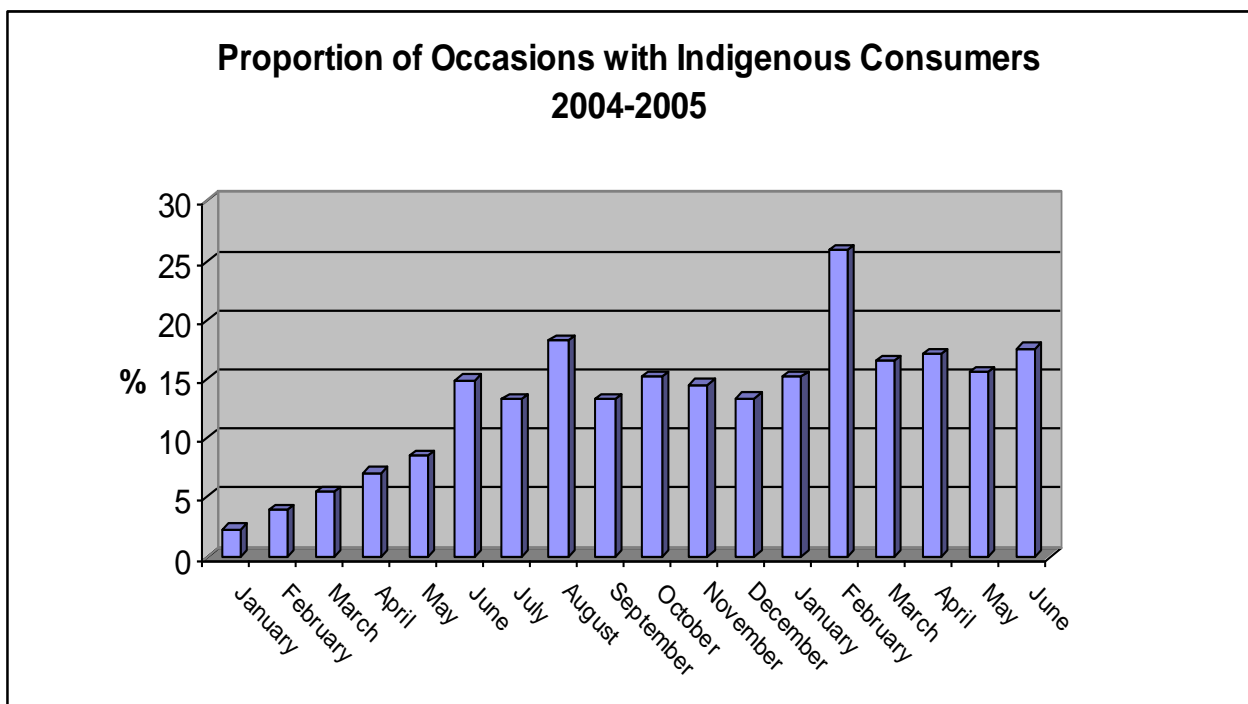


Figure 2

It can be seen from Figure 2 and Figure 3 that from June 2004 onwards, the proportion of all occasions in the Cairns Network involving Indigenous consumers varied little, between 13 and 18% (up to 26% in February). There was a steep decline in the numbers and proportion of entries that had unspecified Indigenous status from over 50% in February to less than 3% from September to December 2004, which suggested that clinician collection of this data markedly improved over the course of this project. Factors contributing to this effect are likely to have included clinician training in Outcomes measures, and increased clinician familiarity with Outcomes and the OIS.

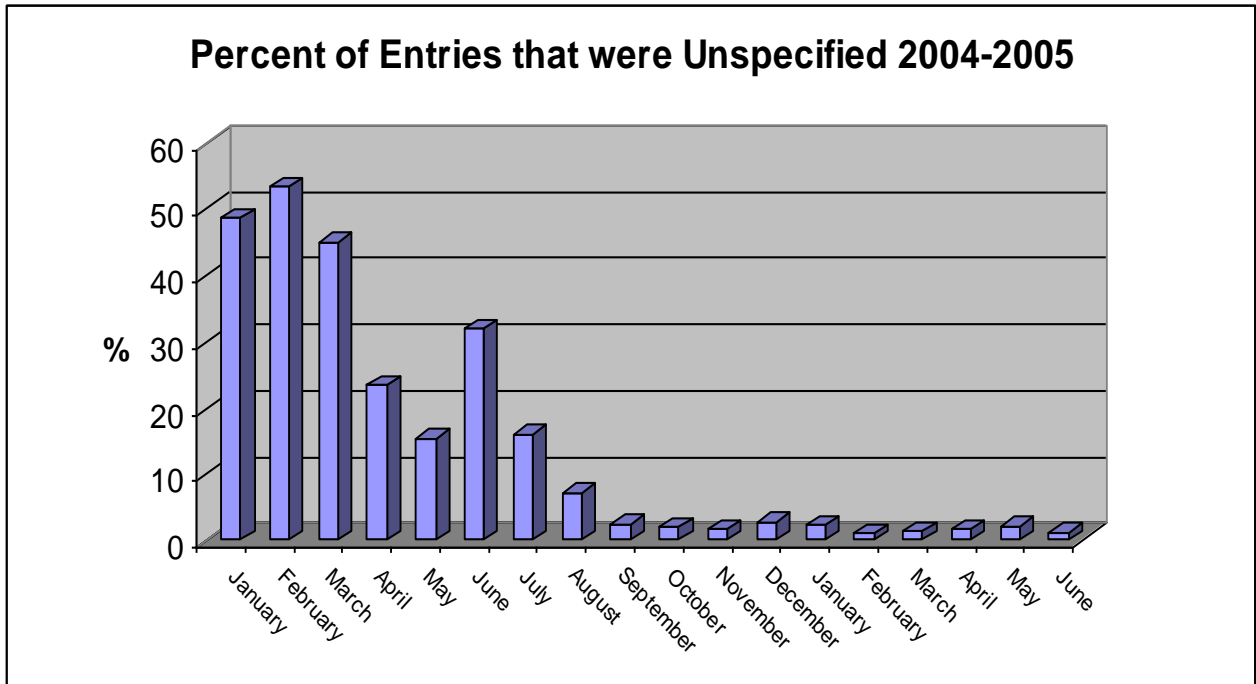


Figure 3

c. Estimation of Coverage Rates for Indigenous Consumers in the Cairns Network

Outcomes data was collected with a total of 271 consumers who identified themselves as Indigenous in the Cairns Network over the 12 month period. One weakness of this dataset is that the number of Indigenous consumers wrongly specified as non-Indigenous (and therefore excluded from data downloads) is indeterminable. It is also not possible to determine how many consumers who should be recorded in the system, have not had their Outcomes assessments completed. It is possible to estimate what proportion of Indigenous consumers are not being included in the Outcomes system by looking at data from Indigenous consumers in the Client Event Services Application (CESA) information system. Table 2 provides data from the CESA database for all Indigenous consumers attending community facilities in 2004/2005 and compares this with the number of Indigenous consumers identified on the OIS.

Table 2. Crude estimation of coverage of distinct consumers in Outcomes assessments in the community setting using CESA data as a guide

District	Distinct Indigenous Consumer Counts - CESA	Distinct Indigenous Consumers: Outcomes	Proportion Outcomes/CESA
Cairns (Community only)	323	100	31.0%
Innisfail	81	30	37.0%
Torres Strait and NPA	96	43	44.8%
Cape York	109	53	48.6%
Tablelands	139	7	5.0%
TOTAL	748	233	31.1%

This rough comparison suggests a trend towards more comprehensive identification and inclusion of Indigenous consumers in the Outcomes system in remote areas (Torres Strait & NPA and Cape York); somewhat lower coverage in the Cairns and Innisfail Districts and poor coverage in the Tablelands District.

A more precise estimation of coverage, both of consumers and of occasions, can be made on the Outcomes assessments conducted in the inpatient setting. The Outcomes database included a total of 140 occasions with 93 different Indigenous consumers. Of these, 105 were conducted upon admission, 11 upon review and 25 upon discharge to another service or with no further care. Monitoring of the Indigenous admissions that occurred over the same time period (July 04 to June 05) by the Indigenous Advanced Mental Health Worker (Talita Wheeler) estimated there was a total of 155 admissions of 106 consumers. While it isn't possible to confirm matching at the individual level, this analysis suggests coverage at Cairns Base Hospital of 67.7% upon admission but much lower completion upon discharge. Furthermore, the data show that at least one assessment was made of 88% (93 out of 106) of all Indigenous consumers admitted during the year.

While this coverage is considerably higher than that achieved in community settings, coverage at discharge from the hospital (end of episode) was low throughout the year (16.1%). There are a range of possible explanations for this result; among them a lack of time and resources associated with high occupancy rates experienced in the Mental Health Unit during this time period. Given failure to collect Outcome measures at discharge, it is not possible to assess levels of change that occurred for consumers whilst in hospital and hence, the true Outcomes associated with hospital care. Nevertheless, the high coverage upon admission provides previously unavailable, useful information on acuity of illness upon entry

to the Mental Health Unit. It should be noted that an analysis of coverage for non-Indigenous consumers was outside the scope of this project.

d. Application of the HoNOS and LSP within Reported Occasions

A high percentage of all valid entries into the Outcomes Information System (95.4%) contained HoNOS assessments, and a majority of these (89.7%) were fully completed with no missing values. In contrast, LSP assessments were completed on 205 occasions, which is 39.6% of the total, or 54.4% of the community occasions. Full completion of LSP scales without missing values also occurred less frequently (72.7%) than for HoNOS.

The lower frequency of LSP assessments is expected because of the more limited times where its application is appropriate, namely in the community setting (not in the inpatient setting) and sometimes upon review and discharge (not for new referrals). Examining only potentially appropriate times for application revealed that LSP was completed in 95% of standard and ad hoc reviews that were entered in the system, in 58% of end of episodes with no further care required and in 92% of cases (only 11 were reported) with referral to another service, which is almost identical to the proportions of HoNOS completions (63%, 92%, respectively). These figures are similar to those reported nationally (Table 3, Australian Mental Health Outcomes and Classification Network (AMHOCN), 2005).

*Table 3. Application of HoNOS & LSP in Community/Ambulatory Occasions Only****

Reason	This Study HoNOS Done (Indigenous consumers)	AMHOCN, 2005* HoNOS Done	This Study LSP Done (Indigenous consumers)	AMHOCN, 2005* LSP Done
New referral	99%	88%	Not applicable	Not applicable
Review (Standard/ad hoc)	96%	90%	95%	85%
Discharge no further care	63%	67%	58%	61%
Moved to new setting	92%	63%	92%	45%

*Australian Mental Health Outcomes and Classification Network, 2005, Table 2.1.1

It is important to note that these percentages are based on HoNOS and LSP performed only during those community collection occasions that were entered into the system, and do not represent overall coverage of Outcomes assessment during the appropriate occasions. The 22 occasions in the system where no data were collected are included in this analysis – a majority of these occurred on discharge with no further care.

e. Implementation Timeline and Monthly Completion of Occasions

Outcomes training for all clinicians in the Cairns Network occurred in November and December 2003. This included both the standard training provided throughout Queensland plus an extended module that focussed on the use of Outcomes measures with Indigenous consumers. The extended module focussed on the introduction of, and familiarisation with, the four principles when making ratings with Indigenous consumers. There was a small lag time between the training and the on line availability of the Outcomes Information System for clinicians in the Cairns Network. However, the Indigenous additions used within the Cairns Network (Indigenous specification item and the required additional questions on the OIS to be completed) were on line and available to clinicians by April 2004.

Figure 4 (below) demonstrates the number of completed occasions each month with consumers specified as Indigenous from January 2004 (just before the system was implemented) to June 2005. There was some fluctuation between months, and a particularly large number of assessments were completed in February 2005. For the most part, however, numbers of Outcomes entries for Indigenous consumers became fairly stable from June 2004. Many collection occasions occurred in February 2005 because the Mental Health Information Systems Support Officer travelled to districts in the Network to encourage and assist in completing Outcomes collection. Although there was a drop following this visit, all four subsequent months showed entries above 40 per month that had not occurred prior to the visit, with nearly 60 occasions in April.

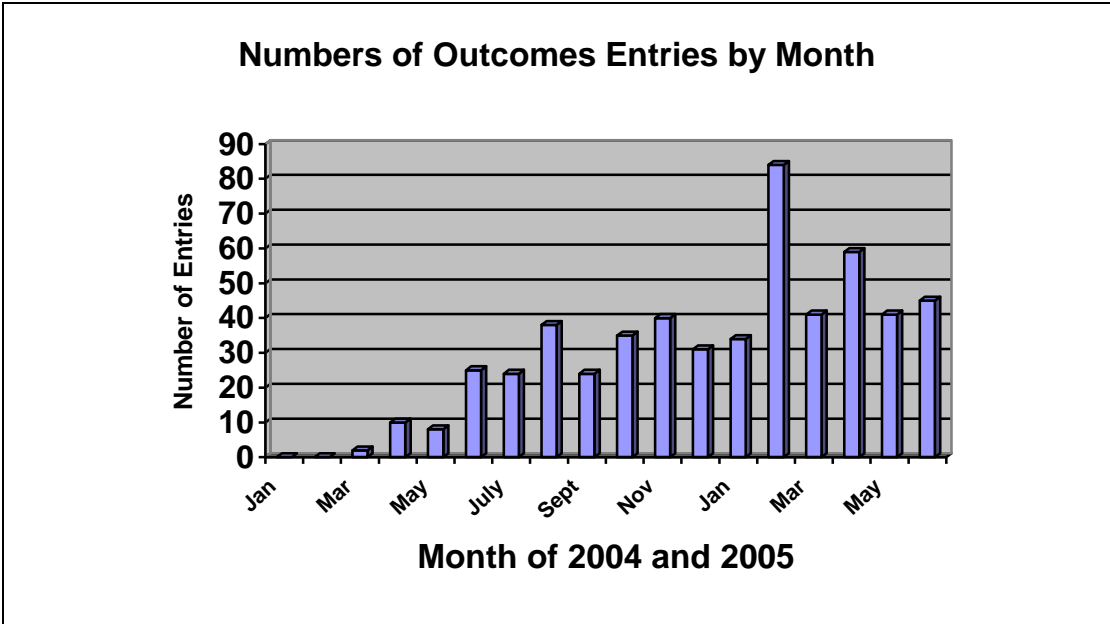


Figure 4

Two interim reports were completed, submitted and discussed by the AIMhi Indigenous Mental Health Outcomes Steering Group which analysed the first 3 months of data, and then all of the data collected in 2004 (Appendix 8). The current report presents 12 months of data collected from July 2004 to June 2005, after a preliminary collection period before July 2004.

f. Characteristics of the Consumers and the Collection Occasions in 04/05

Between July 2004 and June 2005, 518 Outcomes assessments with Indigenous specified consumers were entered into the Outcomes Information System from the Cairns Network of Queensland Health and 22 entries were excluded because no HoNOS or LSP data was entered. These excluded entries occurred most frequently in occasions conducted at the end of episode where no further care was required (30%). Only one of the 22 occasions occurred in hospital.

Of the 496 valid collections, 181 (36.5%) were with female consumers and 315 (63.5%) were with male consumers. Some variables had missing data, such that sample sizes vary slightly between different analyses. The collection occasions involved a total of 271 distinct consumers, of whom 113 (41.7%) were female and 158 (58.3%) were male.

The average number of collection occasions per consumer was 1.8, however there was a skewed distribution. There was only one collection occasion entered in the database for 55% of consumers, while 23.6% were assessed twice, 11.1% were assessed three times and 10.3% were assessed four or more times. The maximum number of collection occasions for a single consumer was 8. Comparing the frequency of collection occasions across genders, it was observed that men were likely to have more occasions than women ($p < 0.01$), as shown in Figure 5 (below).

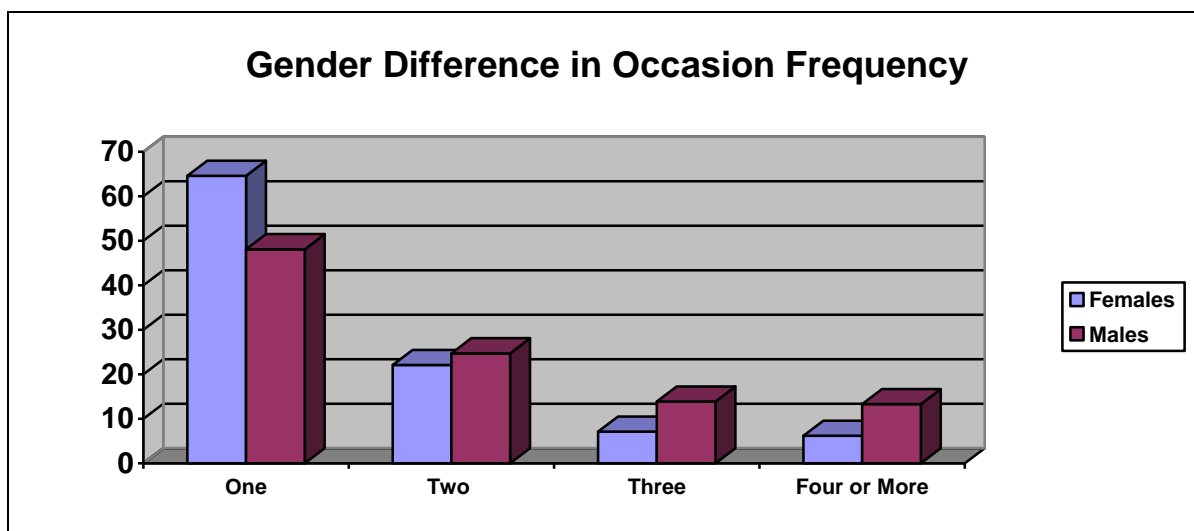


Figure 5

The age of Indigenous consumers assessed during the 12 month period ranged from 15 (only one consumer was under 17 years of age) to 63 years, with a mean age of 33.2 years. The median age was 31 years. 70% of collection occasions occurred with consumers aged 20 to 39 years.

Table 4. Age distribution of the consumers and their collection occasions.

Age:	15-19 No. (%)	20-29 No. (%)	30-39 No. (%)	40-49 No. (%)	50 plus No. (%)	Total
Consumers	19 (7.0)	96 (35.4)	83 (30.6)	50 (18.5)	23 (8.5)	271
Occasions	33 (6.7)	204 (41.1)	145 (29.2)	77 (15.5)	37 (7.5)	496

Due to small numbers in some of the age groups, the sample was divided into two larger groups; younger consumers, aged from 15 to 29 years (n = 237, 47.8%); and consumers aged 30 years and over (n = 259, 52.2%) were used for further analysis. In addition to providing fairly equal sized groups, this stratification also reflects two groups with markedly different hospitalisation usage rates, with Indigenous consumers under 30 having higher lengths of stay and hospitalisation rates adjusted for population than consumers 30 years and over.

Comparing the age profiles of males and females involved in the collections, it was noticed that although the overall mean age did not differ significantly for males and females, a slightly different age distribution was evident. While the majority (74%) of occasions were conducted with men either in their 20's or 30's, and only 19% of occasions were with men over 40 years, nearly 30% of collection occasions with women occurred with consumers aged over 40 years. This different pattern with age across the genders is statistically significant (p=0.01)

and consistent with patterns seen in Indigenous inpatient admissions in the Cairns Network over the same time.

Among the 271 consumers who were included in the dataset, those who identified as Aboriginal made up the largest number (187; 69%), while 57 (21%) identified as Torres Strait Islander and 27 (10%) identified as both Aboriginal and Torres Strait Islander. The collection occasions undertaken with these consumers showed a very similar profile, with 65.9% of occasions with Aboriginal consumers, 23.2% with Torres Strait Islanders and 10.9% with consumers who identified as both. This indicates that there was a fairly even average number of collection occasions per person across the Indigenous identity groups.

g. Entries by Mental Health Service Type: Hospital Inpatient vs Community/Ambulatory Setting

Of the 496 collection occasions, 140 (28.2%) were conducted at the Mental Health Unit, Cairns Base Hospital, while 356 (71.8%) were completed in a Community / Ambulatory setting. Cairns was the only site to report Outcomes for inpatients as its Mental Health Unit is the sole inpatient Mental Health facility in the Network.

No significant gender differences in inpatient collection occasions were observed.. However, inpatient collection occasions occurred significantly more frequently with consumers aged under 30 years (33.3%) than with consumers aged 30 years and over (23.6%, $p = 0.02$). This finding may reflect the age profile of consumers admitted to the Mental Health Unit.

The Cairns District provided the highest number of entries to the Outcomes Information System (148 Community/Ambulatory and 140 Inpatient; combined 58.1% of all entries) followed by the two remote districts (Cape York and the Torres Strait and Northern Peninsula Area), and the two rural districts of Innisfail and the Tablelands. Due to the small numbers of occasions reported from the Tablelands (Table 5), these data were excluded in any further analysis stratified by District

Table 5. Collections by District and Mental Health Service Type

District Service	Health	Total Occasions By District	No.	Mental Health Inpatient No. (%)	Community/Ambulatory No. (%)
Cairns		288		140 (100)	148 (41.6)
Torres Strait & NPA		74		0	74 (20.8)
Cape York		76		0	76 (21.3)
Innisfail		48		0	48 (13.5)
Tablelands		10		0	10 (2.8)
Total		496		140	356

At District level, there was considerable fluctuation by month. For example, in the Torres Strait and Northern Peninsula Area, over 50% of collection occasions occurred in October 2004 and February 2005. Cairns District entries were relatively stable with 20 to 30 entries most months. Inpatient collection occasions ranged from four to 23 per month, while community/ ambulatory entries ranged from two to 26 per month. In the Cape District, over 50% of collection occasions were entered between February and April 2005.

Notably, the proportion of assessments in the community setting with consumers under the age of 30 years was surprisingly low in Cape York (27.6%) compared to the other four districts (between 40 and 50% of occasions).

h. Reason for Collection

Just under half (48.5%) of all collection occasions occurred during new episodes, including new referrals (35.6%) and new episodes referred from another mental health service type (12.9%). An additional 37% of collections occurred during standard or ad hoc review and a small number (14.5%) occurred at the end of an episode. As expected, reasons for collection in the community varied considerably from those in hospital, with a lower proportion due to new referral and a much higher proportion of collections conducted for review purposes (Table 6).

Table 6. Reason for Collection in the Hospital and Community Settings

Reason	Total Number No. (%)	Hospital No. (%)	Community No. (%)
1 – New Episode: New Referral	183 (36.9)	58 (41.4)	125 (35.1)
2 – New Episode: Referred from other MH Service type in Network	67 (13.5)	47 (33.6)	20 (5.6)
4 – Review: Standard	135 (27.2)	2 (1.4)	133 (37.4)
5 – Review: Ad hoc	52 (10.5)	9 (6.4)	43 (12.1)
6 - End of episode: no further care	32 (6.5)	8 (5.7)	24 (6.7)
7 - End of episode: movement of consumer to new service type	27 (5.4)	16 (11.4)	11 (3.1)
8 - Death	0	0	0
Total	496	140	356

Age differences in the reason for collection were minor, with consumers under 30 years involved in more collections related to new episodes with referral, than those aged 30 years and over. In contrast, collection reasons (in community assessments) differed significantly between genders (see Table 7, $p < 0.001$). Outcomes assessments were completed much

less frequently with females at standard review, compared to males. This adds detail to the finding that 60% of women were assessed only once during the 12 months (Table 7).

Table 7. Reason for Collection in the Community Setting by Gender

Reason	Community No. (%)	Females No. (%)	Males No. (%)
1 - New Episode: New Referral	125 (35.1)	56 (42.7)	69 (30.7)
2 - New Episode: Referred from other MH Service type in Network	20 (5.6)	8 (6.1)	12 (5.3)
4 -Review: Standard	133 (37.4)	28 (21.4)	105 (46.7)
5 -Review: Ad hoc	43 (12.1)	26 (19.8)	17 (7.6)
6 -End of episode: no further care	24 (6.7)	10 (7.6)	14 (6.2)
7-End of episode: movement of consumer to new service type	11 (3.1)	3 (2.3)	8 (3.6)
Total	356	131	225

For some analyses, the data were grouped into three broad categories in relation to the reason for the collection, namely new episode (reasons 1 & 2), review (4 & 5) and end of episode (6 & 7).

i. Diagnostic Group

Analysis by diagnosis is complicated by the complex variety of diagnostic codes and the need to combine 'like' groups with few entries into a collapsed coding system that is statistically and medically meaningful. For example, it is not possible to individually analyse 56 different diagnostic codes assigned within the dataset, particularly as most of the codes had few entries. Nevertheless, diagnosis is a very important determinant or predictor of Outcomes, particularly at the beginning of episodes. Another difficulty is that diagnosis is frequently not recorded on the OIS for a range of reasons. In this dataset, diagnosis was present in only 246 of the 496 collection occasions. Data on diagnosis was particularly lacking for occasions in the inpatient setting, where only 35 of the 140 occasions had a recorded diagnosis. This is possibly because nearly all of the collection occasions occurred upon admission, when diagnosis may not have yet been clear.

A coding scheme was adopted, similar to that used by Stedman et al. (1997). Three main coding groups were used to re-classify the available data; alcohol and drug-associated disorders (n=31); acute and chronic psychotic disorders (n=163); and affective disorders [including bipolar disorder] (n=41). A miscellaneous group including dementias and organic personality disorder were excluded from analysis due to small numbers (n = 11).

Psychotic disorders were the most common diagnosis for the occasions where diagnosis was specified (66.3%). However, there was some variation in frequency of diagnosis by gender and age group of the consumer. A higher proportion of occasions with male consumers involved a psychotic disorder (schizophrenia or acute or transient psychosis, 67.9%; 112 out of 165 occasions with a diagnosis) or an alcohol or drug-related disorder (15.2%, 25 out of 165) as compared with occasions with females, which less frequently involved substance disorders (7.4%, 6 out of 81) and more frequently involved affective disorders (24.7%, 20 out of 81). This difference is shown in Figure 6.

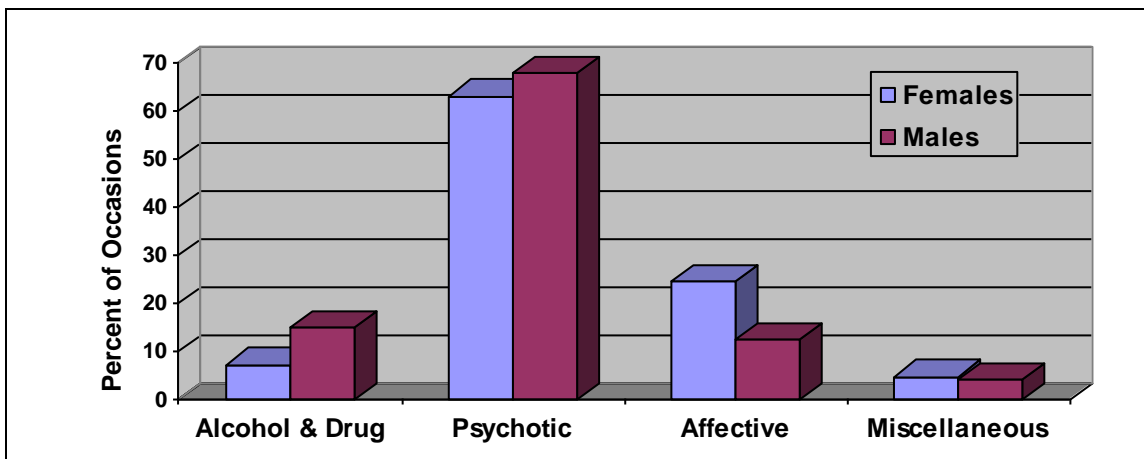


Figure 6

Occasions with younger consumers more frequently involved psychotic disorder (77.9%, 88 of 113) (Figure 7). 56.4% of occasions recorded for older consumers involved psychotic illness, and occasions involving alcohol or drug problems (18%, 24 of 133) and affective disorder (21.1%, 28 of 133) were more common for older than for younger consumers.

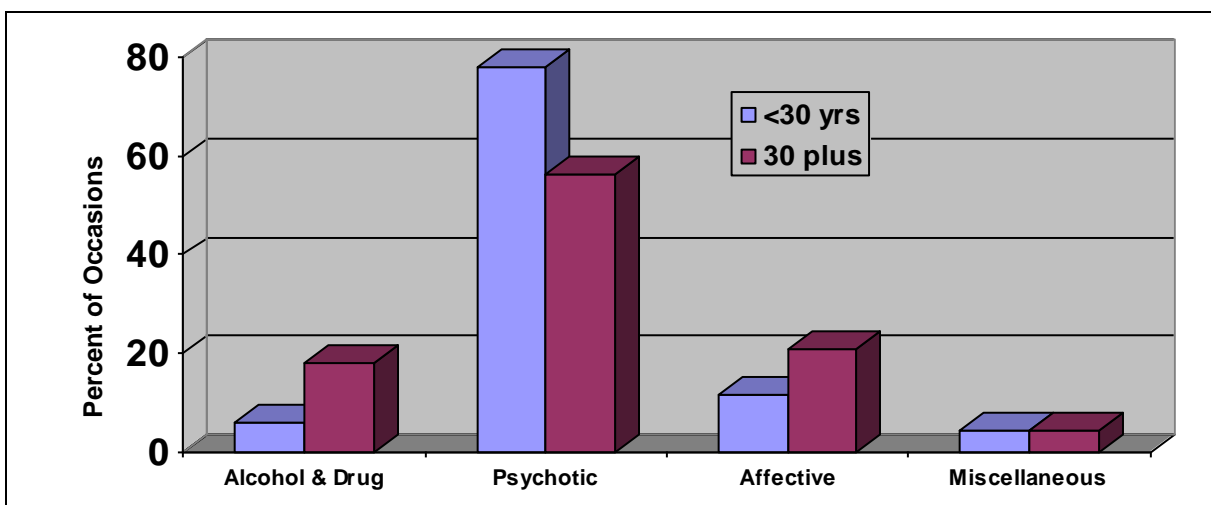


Figure 7

Key Findings of Chapter 5

I. Over the course of this project, it appeared that there was a marked reduction in the number of collection occasions where Indigenous status was unspecified by the clinician.

II. Comparisons with distinct Indigenous client counts from the CESA database suggest that about one third of Indigenous consumers accessing mental health services are included in the Outcomes Information System for HoNOS and LSP. Coverage was highest for admissions into hospital, followed by remote communities and rural and urban areas. The data suggest that females were assessed less often in standard review and more often in ad hoc review compared to males.

III. Of particular concern was the small number of end of episode assessments recorded, particularly in the inpatient setting. Paired assessments (conducted at the beginning and end of the episode) provide important information about changes in consumer Outcomes which are likely related to the care provided during the episode. Without this information, the impact of services on the mental health of individual consumers cannot be assessed.

IV. Differences were seen in the distribution of diagnostic categories across gender and age. For example, affective disorders more frequent among occasions with females compared to males and a higher proportion of occasions with younger consumers involved psychotic illnesses, while drug and alcohol and affective disorders were more frequent among occasions with older consumers.

6

Performance of the Scales: Missing Values and Internal Consistency

a. Missing Value Analysis : HoNOS and LSP

99.6% (494) of all entries (496) with HoNOS or LSP data in the Outcomes Information System contained HoNOS assessments, and a majority of these (443; 89.7%) were fully completed with no missing values. LSP assessments were completed on 205 occasions, (41.5% of the total) and full completion without missing values occurred in 72.7% of cases. Table 8 explores the items on HoNOS and LSP in relation to the frequency of missing values where the scales were applied in the full dataset. The 22 occasions where no HoNOS or LSP data was present were excluded.

Table 8. Missing value analyses for a) individual HoNOS and LSP Items and b) scales and subscales.

a. Individual Items

Proportion of cases with missing values	HoNOS Items	LSP Items
Less than 2%	1, 2, 4, 5, 8	1, 4, 5
>2 to 4%	3, 6, 7, 9, 10, 11, 12	2, 3, 6, 10, 12
4% to 8%	None	7, 9, 11, 15, 16
8% to 10%	None	None
>10%	None	8, 13, 14

b. Scale and Subscale Full Completion

Scale/ Subscale	Number (%) with Missing Values
HoNOS Full Scale	51 (10.3)
Behaviour	16 (3.2)
Impairment	7 (1.4)
Symptoms	20 (4.0)
Social Problems	31 (6.3)
LSP Full Scale	56 (27.3)
Withdrawal	25 (12.2)
Self-Care	20 (9.8)
Compliance	16 (7.8)
Anti-social	36 (17.6)

This analysis showed that there was a high rate of HoNOS completion without missing values, with no item having missing values more than 3.4% of the time. Therefore full HoNOS scores and subscales scores could be calculated for most collection occasions.

There were more missing values recorded for LSP and the proportion missing varied from 0% for Item 1 (Difficulty in Conversation) to over 10% for Items 8 (Maintain Friendships), 13 (Problems with Others) and 14 (Offensive Behaviour). One explanation for this observed pattern may be that clinicians experienced particularly difficulty rating items related to the consumer's interactions with others. However, other factors, such as the clinician's attitude to making ratings on these items, should also be considered. The LSP 'Anti-social' subscale had the smallest valid sample size among the subscales and full completion of LSP occurred at a lower frequency than for HoNOS.

b. Internal Consistency of and Correlations between LSP and HoNOS Subscales: Indigenous Consumers

Cronbach's alpha is a statistical coefficient routinely used to assess the internal consistency of individual (related) items that are added together to form a subscale. For example, the LSP is commonly grouped into four domains, represented as the 'Withdrawal', 'Self-care', 'Compliance' and 'Anti-social' subscales (Commonwealth Department of Health and Ageing 2002). The HoNOS is commonly grouped into four subscales measuring behaviour, impairment, symptoms and social skills, while Trauer (1999) suggested an alternate, five subscale structure.

Cronbach's alpha was used to determine the internal consistency of data collected from Indigenous consumers in the Cairns Network. Comparisons with the internal consistency of largely non-Indigenous datasets were undertaken. Table 9 (below) compares the alpha values in this study (observed alpha) with that found in 2 other studies, that of Stedman et al. (1997) in Australia and Trauer et al. (2004) in New Zealand. The current analysis is different than that of the previous published analyses since data exclusion was minimised using all occasions where relevant items for the comparisons were valid, giving each analysis a slightly different sample size. The previous internal validity analyses were conducted with all occasions excluded where any one item out of the 12 or 16 was missing (Stedman et al., 1997; Trauer et al., 2004).

Table 9. Internal Consistency Coefficients for LSP and HoNOS observed in this and other studies

	This Study (n)	Stedman et al*	Trauer et al**
LSP	LSP-16	LSP-39	LSP-16
Withdrawal	0.81 (180)	0.78 (social contact)	0.83
Self-Care	0.83 (185)	0.85 (self-care)	0.77
Compliance	0.85 (189)	0.75 (responsibility)	0.81
Anti-Social	0.87 (169)	0.88 (non-turbulence)	0.80
Total	0.94 (149)	0.94	0.89
HoNOS			
Behaviour	0.49 (478)	0.40	0.57
Impairment	0.36 (487)	0.30	0.44
Symptoms	0.57 (474)	0.06	0.30
Social Problems	0.69 (463)	0.69	0.76
Total	0.73 (443)	0.73	0.80
Alternate HoNOS		n.d.	
Behaviour	0.50		0.53
Social	0.69		0.76
Depression	0.61		0.62
Impairment	0.36		0.44
Hallucinations	(single item)		-

Stedman et al., 1997, p. 136

Trauer et al., 2004, p. 29

The internal consistency of the measures in this study was, for the most part, highly consistent with that observed in the other two studies. One marked difference was seen in the symptoms subscale of HoNOS, which showed much higher internal consistency in this study (0.57) compared to that seen in the other two studies (0.06 and 0.30). The higher alpha observed here may be due to the relatively strong correlations between HoNOS item 8 (Other Symptoms) and both HoNOS item 6 (Hallucinations) and HoNOS item 7 (Depression).

Associations between the various total and subscale scores for HoNOS and LSP were also measured using Kendall's rank correlation test (Table 10). The total HoNOS and LSP scores showed a strong correlation (Kendall's tau = 0.55) among the 145 cases where both scales were completed. Statistically significant positive correlations were also observed between the subscales within and across the two assessment tools. Generally, the social and behaviour subscales of HoNOS correlated most strongly with the LSP total score and subscales, while the impairment and particularly the symptom subscales were more weakly associated with the other subscales. These patterns are expected given the related aspects of these subscales and may reflect the fairly consistent rating patterns of clinicians using the two tools at the same time.

Table 10. Rank Correlations (Kendall's Tau) between subscales of HoNOS and LSP using the HoNOS and LSP data collected in this study with Indigenous consumers in the Cairns Network.

(a) Subscales of HoNOS

Scale/Subscale	HoNOS Total Tau (n) sig.	HoNOS Behaviour Tau (n) sig.	HoNOS Impairment Tau (n) sig.	HoNOS Symptom Tau (n) sig.
HoNOS Behaviour	0.57 (443) ***			
HoNOS Impairment	0.36 (443) ***	0.10 (472) **		
HoNOS Symptom	0.54 (443) ***	0.35 (463) ***	0.17 (471) ***	
HoNOS Social	0.65 (443) ***	0.33 (453) ***	0.21 (460) ***	0.25 (451) ***

Significance of correlation, ** p=0.01; *** = p<0.001

(b) Subscales of LSP

Scale/Subscale	LSP Total Tau (n) sig.	LSP Withdrawal Tau (n) sig.	LSP Self-Care Tau (n) sig.	LSP Compliance Tau (n) sig.
LSP Withdrawal	0.65 (149) ***			
LSP Self-Care	0.69 (149) ***	0.45 (173) ***		
LSP Compliance	0.71 (149) ***	0.44 (171) ***	0.45 (177) ***	
LSP Anti-social	0.72 (149) ***	0.45 (160) ***	0.51 (160) ***	0.59 (161) ***

Significance of correlation, *** = p<0.001

(c) Correlations between HoNOS subscales and LSP Subscales

Scale/Subscale	HoNOS Total	HoNOS Behaviour	HoNOS Impairment	HoNOS Symptom	HoNOS Social
LSP Total	0.55 (145) ***	0.58 (146) ***	0.34 (147) ***	0.31 (147) ***	0.47 (146) ***
LSP Withdrawal	0.42 (174) ***	0.34 (176) ***	0.27 (178) ***	0.22 (177) ***	0.37 (176) ***
LSP Self-Care	0.44 (178) ***	0.40 (181) ***	0.34 (183) ***	0.18 (181) ***	0.41 (181) ***
LSP Compliance	0.40 (180) ***	0.50 (184) ***	0.24 (187) ***	0.17 (183) **	0.36 (183) ***
LSP Anti-social	0.57 (164) ***	0.68 (166) ***	0.32 (167) ***	0.30 (166) ***	0.45 (165) ***

Significance of correlation, ** p=0.01; *** = p<0.001

c. Examining consistency of responses to the Additional Questions added to the OIS for this study

This was possibly the first time that a set of additional questions (as shown in Figure 1 and Appendix 4) have been developed and systematically implemented through an outcomes collection system to assist in monitoring and evaluation of the Outcomes process. Since the appropriateness of responding to some questions depended on information provided by a previous question, it was possible to examine the consistency in the flow of expected responses to indicate the clarity of or possible misunderstanding of the questions. Four examples are provided to demonstrate the findings of this analysis:

1 – Among 311 occasions where the clinician indicated in the introductory question that a family or carer did not provide additional information for the Outcomes assessment, 258 (83%) indicated in question number 4 that 'I could not access a carer or family member for the assessment'. On the remaining 53 (17%) occasions, the response to question number 4 unexpectedly indicated a level of engagement of carer/family member.

2 – Among 148 occasions where the clinician indicated that family/carer provided information for the assessment in the introductory question, 139 (93.9%) provided an expected response to question number 4. On 9 (6.1%) occasions, information on the level of engagement was not provided.

3 – Among the 363 occasions where the clinician indicated that the assessment did not include information from a local health practitioner, 291 (80.2%) responded to question number 5 that 'I could not access a local practitioner for the assessment'. Unexpected information on the level of engagement of a local practitioner was provided on 72 (19.8%) occasions.

4 – In 96 occasions the clinician indicated that a local health provided information for the outcomes assessment. Expected information on the level of engagement of the practitioner was provided in 85 (88.5%) occasions, but no information was provided on 11 (11.4%) occasions.

This analysis suggests that while there was fair consistency of expected responses across the questions, there may have been some confusion about time frame or the kind of involvement being specified. This led to disagreement in 17 to 20% of occasions where information on the degree of engagement of both family and local practitioner was unexpected when previous information suggested they were not involved. The rate of

completion of both questions when involvement was indicated was 88.5% to 93.9%. Thus the initial question may have underestimated the frequency of involvement of these additional informants or the engagement question may have overestimated this frequency. For future use of these questions, it may be helpful to trial and improve the wording of the questions to clarify interpretation in future.

Key Findings of Chapter 6

This examination of internal consistency and the relationships between various subscales of HoNOS and LSP with Indigenous consumers in the Cairns Network are consistent with findings using the scales with other populations. In fact, some of the relationships found here suggest greater consistency than previously observed. This helps to support the use of HoNOS, LSP and their subscales as technically reliable instruments for Indigenous consumers.

7

Patterns of Engagement of Consumers, Carers and Local Practitioners in the Outcomes Assessment

Data concerning responses to the additional questions (Appendix 6) was downloaded from the Outcomes Information System together with demographic data and HoNOS and LSP ratings. This provided an opportunity to examine frequencies and relationships between involvement and engagement of consumers, carers and local practitioners in the Outcomes assessment. This chapter presents the findings of this analysis.

a. Principle One in Practice: Who provided additional information for the ratings?

There were 37 collection occasions out of 496 (7.5%) where the response to the question, "...did your assessment include information from a family member/ carer AND a local health practitioner?" was missing or could not be answered. Occasions where values for the specific items being examined were missing were excluded from analysis (unless otherwise stated) and as such, sample sizes for each analysis differed. For this analysis, these missing data occasions were included in tables and calculations of proportion. It is possible that collection occasions which did not involve additional informants for the ratings were over-represented in 'missing data' occasions.

Of the Outcomes assessments that took place during the 12 month study period, approximately half (51%) were done without obtaining further information from a family member or local practitioner. Less than 10% of the occasions had involvement as recommended in Indigenous Principle One, i.e. "the clinician should consult whenever possible with BOTH a family member or carer AND a local health practitioner when completing the ratings".

Local practitioner involvement in the Outcomes process was slightly higher in the inpatient setting (15% of occasions) as compared to the Community/Ambulatory setting (10-11% of occasions). However, due to the larger proportion of cases where the information on

additional informants was missing, it was not possible to determine if there was a significant difference between settings.

Table 11. Frequency of Family and Local Practitioner Involvement by setting

	All (HoNOS or LSP) No. (%)	Hospital Inpatient HoNOS (%)	Community HoNOS No. (%)	Community LSP No. (%)
Neither family or practitioner	253 (51.0)	54 (38.6)	197 (55.6)	118 (57.6)
Family member/ Carer only	110 (22.2)	32 (22.8)	78 (22.0)	44 (21.5)
Local Health Practitioner only	58 (11.7)	21 (15.0)	37 (10.5)	24 (11.7)
Both Family Member and Local Health Practitioner	38 (7.7)	11 (7.9)	27 (7.6)	12 (5.9)
Not recorded	37 (7.5)	22 (15.7)	15 (4.2)	7 (3.4)
TOTAL	496	140	354	205

Family members provided further information in 43% of the collection occasions for consumers under age 30, (as compared to 18.2% of those over age 30. This difference is statistically significant ($p < 0.001$). The greater frequency of family involvement with young consumers was evident in collection occasions in both the Mental Health Unit and community/ambulatory services (Table 12).

Table 12. Frequency of Family and Local Practitioner Involvement by age group

	All No. (%)	Consumers <30 No. (%)	Consumers ≥30 No. (%)
Neither family or practitioner	253 (51.0)	89 (37.6)	164 (63.3)
Family member/ Carer only	110 (22.2)	73 (30.8)	37 (14.3)
Local Health Practitioner only	58 (11.7)	27 (11.4)	31 (12.0)
Both Family Member and Local Health Practitioner	38 (7.7)	28 (11.8)	10 (3.9)
Not recorded	37 (7.5)	20 (8.4)	17 (6.6)
TOTAL	496	237	259

Local health practitioner involvement varied less with consumer age than did family member involvement. Occasions where both family and practitioners were involved were almost three times more common for younger people – but this still represents a small minority of assessments (11.8%). Involvement of either type of additional informant was lowest (32.3%) for older consumers in the community setting.

Outcomes occasions in the community setting in the Cairns District had the highest frequency of involvement with additional informants (52.2%), followed by Innisfail District (41.7%), the Torres Strait and NPA District (34.2%) and the Cape District (26.7%). Family

involvement was lower in the latter two remote settings. It is important to note that the proportion of younger consumers was lowest in the Cape District so this finding may reflect the lower involvement of families in assessments of older consumers.

Local practitioner/Health Worker involvement occurred in approximately 10% of occasions in all settings, except for Cairns District where it was markedly higher (25.2%). The frequency of having additional informants varied little between genders and across reasons for collection.

An analysis of family and local practitioner involvement across the 4 three-monthly data sets (June – Sept 2004, Oct - Dec 2004, Jan - March 2005, April - June 2005) showed no statistically significant differences ($p = 0.26$) (Table 13). This suggested that there was no upward trend in involvement of family members, carers or local practitioners over the course of this study. These data provide a valuable baseline against which additional efforts toward enhancing adherence to Principle One can be monitored.

Table 13. Frequency of Family and Local Practitioner Involvement through Time

Additional information gained from:	Three Monthly Interval			
	First No. (%)	Second (%) No. (%)	Third (%) No. (%)	Fourth (%) No. (%)
Neither	34 (54.8)	67 (51.5)	80 (50.0)	72 (49.3)
Family member/carer only	11 (17.7)	29 (22.3)	37 (23.4)	33 (22.9)
Local Practitioner only	11 (17.7)	12 (9.2)	21 (13.3)	14 (9.7)
Both Family/carer + Practitioner	3 (4.8)	13 (10.0)	10 (6.3)	12 (8.3)
Not recorded	3 (4.8)	9	11	14
Total	62	130	159	145

b. Examination of Clinician Perceptions of Rating Difficulty

As part of the additional questions on the OIS, clinicians were asked, “compared to your experience with the mainstream measures, has there been additional difficulty in completing the measures with this Indigenous consumer?”. Of total 496 assessments 461 had indicated that they experienced no, some, moderate, or substantial additional difficulty, while in 35 (7.1%) occasions, information on this item was not provided.

Across the 496 assessments made with specified Indigenous consumers, 266 clinicians (53.6%) indicated that they experienced no additional difficulty, 125 (25.2%) responded ‘some’, 46 (9.3%) responded ‘moderate’ while 24 (4.8%) indicated that they experienced ‘substantial’ additional difficulty in completing the measures with the Indigenous consumer.

These responses did not differ significantly by age group (under 30 years, 30 years and over) or gender. Interestingly, they did not differ between occasions where both HoNOS and LSP were completed and occasions where only HoNOS was completed.

It is perhaps notable that 20 out of the 24 assessments that were rated substantially more difficult were collected in Cairns District. Within the assessments completed in Cairns, there was no significant difference between levels of additional difficulty reported by clinicians in the inpatient setting compared to the community setting.

Table 14 shows the responses for this question across 4 three-monthly data sets. The highest percent of responses of 'no additional difficulty' occurred in the first three month period (66%) while the period with the highest frequency of responses of 'substantial' difficulty was the last three months. Although the degree of variation between the time points approached statistical significance, there was no trend in the patterns of reported levels of difficulty – that is, clinicians did not report increasing levels of ease or difficulty as time progressed.

Table 14. Levels of Additional Difficulty in Rating perceived by the Clinician

Additional Difficulty:	None No. (%)	Some No. (%)	Moderate No. (%)	Substantial No. (%)	Missing No. (%)	Total
July, Aug, Sept	41 (66.1)	11 (17.7)	4 (6.5)	3 (4.8)	3 (4.8)	62
Oct, Nov, Dec	62 (47.7)	41 (31.5)	13 (10.0)	3 (2.3)	11 (8.5)	130
Jan, Feb, March	86 (54.1)	46 (28.9)	12 (7.5)	5 (3.1)	10 (6.3)	159
April, May, June	77 (53.1)	27 (18.6)	17 (11.7)	13 (9.0)	11 (7.6)	145
YEAR TOTAL	266 (53.6)	125 (25.2)	46 (9.3)	24 (4.8)	35 (7.1)	496

Pearson Chi-square, $p= 0.06$ (not significant)

c. Clinician's Assessment of Validity

Clinicians were asked "How well do you feel the scales reflect the underlying mental health problems of this consumer?" and were provided with the following fixed responses: 'good', 'reasonable', 'inadequate' and 'poor'. The question was answered on 445 occasions, and missing in 41 cases (8.3%). On 109 (24.5%) of occasions where the question was answered, the clinicians indicated that the reflection was 'good'; 262 (58.9%) were marked as 'reasonable'; 65 (14.6%) were reported as 'inadequate' and on 19 (4.3%) occasions, clinicians felt the scales poorly reflected the consumer's mental health problems.

These data suggest that clinicians believe that HoNOS and LSP applied with Indigenous consumers provide at least a reasonably valid measure in a majority (83.4%) of cases. It is

important to note that consumer, carer and local practitioner views of the scales' validity were not captured.

Clinician assessments of (this aspect of) validity of the scales did not vary significantly across consumer age groups, gender, specific Indigenous identity (Aboriginal, Torres Strait Islander or both), or mental health service type (Mental Health Unit versus community/ambulatory).

A trend towards more positive responses which approached statistical significance ($p=0.07$) was observed in the early phase of Outcomes implementation (between the first 2 three month intervals). This trend was also noted in the first 9 months of the 12 month data set: the proportion of occasions where clinicians reported 'good' or 'reasonable' agreement rose from 75.4% to 84.9%. However, in the final three months (March to June 2005), the percentage dropped to 78.6%.

d. Engagement of Consumer

For each collection occasion, clinicians were asked, "How interested and/or engaged do you feel the consumer was when you were conducting the assessment that informed the completion of the HoNOS and LSP-16?" In 40 cases (8.1%), clinicians reported that they "couldn't tell". Among the 456 cases where a response was provided, the clinician assessed the consumer as not interested, resistant and not engaged in 22.2% of cases, with a mixed response in 32.5%, both interested and engaged in 25.8% and not well enough to be involved in 11.5%. These results are shown in Table 15.

Comparing the four three-monthly intervals, little variation was observed in responses to this question across the three interest level categories or the frequency of the response "can't tell". However, the proportion of cases where the consumer was considered "not well enough to be involved" rose consistently from 5.1% in the first interval to 21% in the last interval. Thus, half of the 57 occasions in this category occurred between March and June 2005. There was also a rise in clinician-reported difficulty in rating (see above).

Consumer engagement and interest (as ascertained by clinicians) varied little between genders or reason for the occasion. However, consumers being assessed in a community/ambulatory setting showed more interest and engagement than those in the inpatient setting ($p<0.001$).

e. Engagement of Carer/Family Member(s) and Local Practitioners

As previously stated, the involvement and engagement of additional informants forms the basis of the first Indigenous rating principle. Two questions were added to the OIS to assess not only the frequency of involvement, but also the degree of engagement achieved in that involvement with both family member and local practitioner (Table 15).

Table 15. Clinician Responses regarding the Engagement and Interest of Consumers, Family Members and Local Practitioners with Outcomes Assessment

	Consumer No. (%)	Family/ Carer No. (%)	Local Practitioner No. (%)
Not interested or engaged	110 (24.1)	27 (13.7)	14 (8.6)
Mixed response	161 (35.3)	71 (36.0)	43 (26.5)
Interested & engaged	128 (28.1)	99 (50.3)	105 (64.8)
Not well enough	57 (12.5)	---	---
TOTAL with Valid Data	456	197	162
Not recorded, not present or couldn't tell	40	299	334

Perceived levels of interest in the assessment process by either family members or local practitioners did not differ across setting or age groups. However, the data suggest a slightly greater frequency of interest and engagement of family for assessments completed with male (56.2%) as compared with female (38.8%) consumers ($p=0.05$).

f. Exploring Links between Consumer, Carer & Practitioner Involvement and Engagement, Perceived Validity and Difficulty of Completing the Assessment

Although there was only a small (and potentially biased) number of collection occasions where cross-tabulation across these variables was possible, there was a high degree of consistency across levels of interest and engagement of the various informants and clinician-perceived validity of the resulting scores. Most strongly the data supported the contention that greater engagement of the consumer is associated with increased perceived validity of HoNOS and LSP. Table 16 shows an example of associations in the data that are consistent with this premise.

Table 16. Association between Consumer Engagement & Validity (Clinicians' view)

Clinicians' perspectives on engagement	Total number	Good to reasonable validity	Inadequate to poor validity	Couldn't tell, data missing
		No. (%)	No. (%)	No. (%)
Consumer not well enough to be involved	57	36 (63.2)	6 (10.5)	15 (26.3)
Consumer not engaged or interested	110	66 (60.0)	40 (36.4)	4 (3.6)
Consumer shows mixed response	161	135 (83.8)	23 (14.3)	3 (1.9)
Consumer is engaged and interested	128	120 (93.7)	8 (6.3)	0 (0.0)
Total	456	357	77	22
Not recorded, couldn't tell	40			40

Clinicians judged the scales to provide a 'good reflection' with the underlying mental health problems of the consumer in a much higher proportion of occasions (41.4%) where the consumer was fully interested and engaged as compared to the other circumstances (12 to 18%). Similarly, full engagement of the family was associated with a higher frequency (87 out of 99 cases, 87.9%) of 'good to reasonable reflection' compared to 62.9% (17 out of 27) and 70.4% (50 out of 71) of occasions where the family was not engaged or had a mixed response (χ^2 for linear trend, 8.95, df1, p=0.003). Similar trends between higher level of engagement and lower additional difficulty in completing the ratings were observed. For example, on the 97 occasions where family was fully engaged, 59 (60.8%) of clinicians reported 'no additional difficulty' in their assessment as compared to 43.8% (42 out of 96 cases) where families were involved but not fully engaged (χ^2 for linear trend, 5.5, df 1, p=0.02).

A relationship was also observed between the degree of engagement of the family members and local practitioner, and that of the consumer (Figure 8, Table 17). On the 53 occasions where the family informant was not engaged, 35.8% of consumers were also not engaged or interested and 30.2% were fully engaged. However, on the 40 occasions where family members were fully engaged, none of the consumers were considered 'not engaged at all' and 82.5% appeared fully engaged. Mixed responses showed intermediate levels across consumer and family. Associations across response levels of consumer and family members were statistically significant (χ^2 for linear trend, 32.7, df 1, p<0.001).

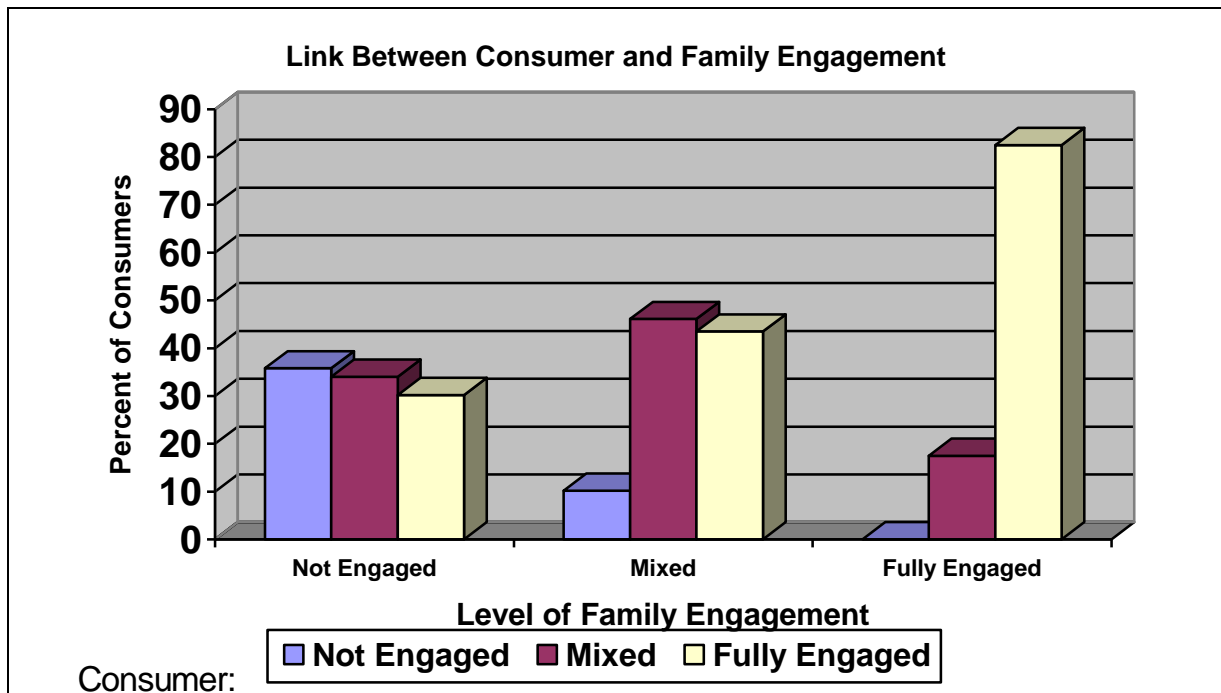


Figure 8

The data shown in Figure 8 is reported in Table 17.

Table 17. Association between levels of Consumer & Family engagement

(% given in brackets reflects proportion of consumer's engagement levels in relation to their family informants' perceived level of engagement)

Clinician view of consumer & family engagement	Total number	Family not engaged No. (%)	Family partly engaged/interested No. (%)	Family fully engaged/interested No. (%)
Consumer not engaged	27	19 (35.8)	8 (10.3)	0 (0.0)
Consumer shows mixed response	61	18 (34.0)	36 (46.1)	7 (17.5)
Consumer fully engaged	83	16 (30.2)	34 (43.6)	33 (82.5)
Total	171	53	78	40

A similar but weaker relationship was observed between local practitioner and consumer engagement (see Figure 9 and Table 18, χ^2 for linear trend, 12.3, df1, $p < 0.001$).

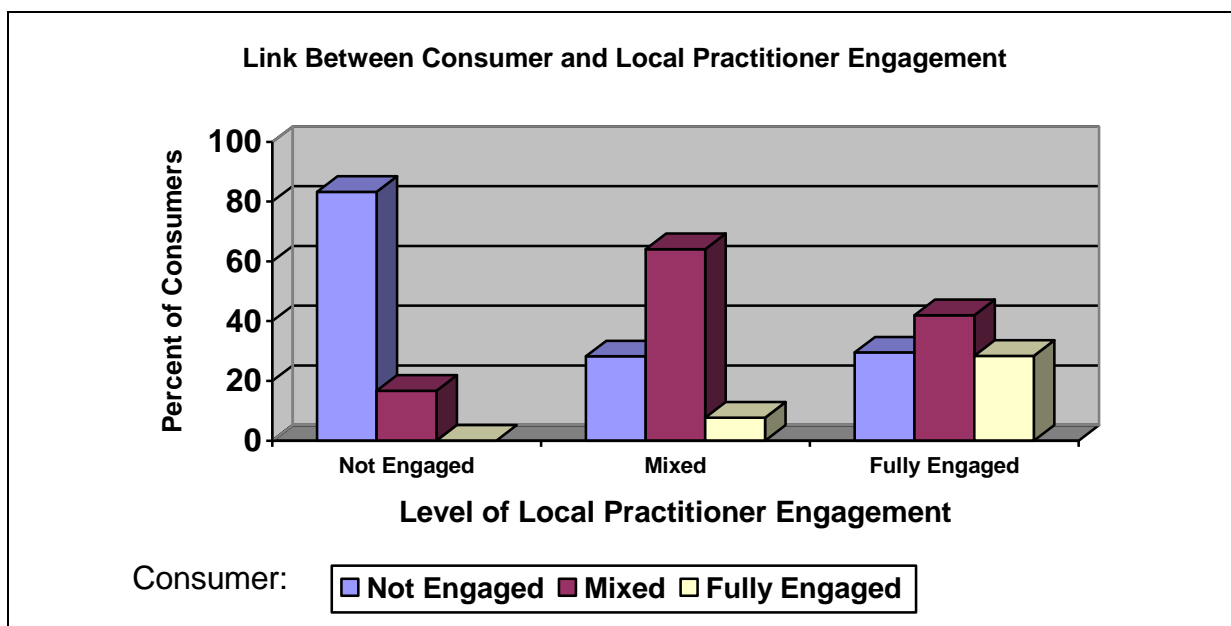


Figure 9

Table 18. Association between levels of Consumer & Practitioner engagement

(% figures in brackets reflects proportion of consumers' engagement levels in relation to their practitioner informant's level of engagement as perceived by the rating clinician)

Clinicians' perspectives of engagement	Total	Practitioner not engaged No. (%)	Practitioner partly engaged/interested No. (%)	Practitioner fully engaged/ interested No. (%)
Consumer not engaged	47	10 (83.3)	11 (28.2)	26 (29.5)
Consumer mixed response	64	2 (16.7)	25 (64.1)	37 (42.0)
Consumer fully engaged	28	0 (0.0)	3 (7.7)	25 (28.4)
Total	139	12	39	88

The association between levels of family/carer and local practitioner engagement as perceived by the rating clinician was very strong (Table 19, Figure 10, χ^2 for linear trend, 28.6, df1, $p < 0.001$).

Table 19. Association between levels of family and local practitioner engagement

(% figures in brackets reflects proportion of families' engagement levels in relation to their practitioner informant's level of engagement as perceived by the rating clinician)

Clinician view of engagement	Total	Practitioner not engaged No. (%)	Local Practitioner partly engaged No. (%)	Local practitioner fully engaged No. (%)
Family not engaged	15	7 (77.8)	3 (10.3)	5 (7.8)
Family mixed response	36	2 (22.2)	18 (62.1)	16 (25.0)
Family fully engaged	51	0 (0)	8 (27.6)	43 (67.2)
Total	102	9	29	64

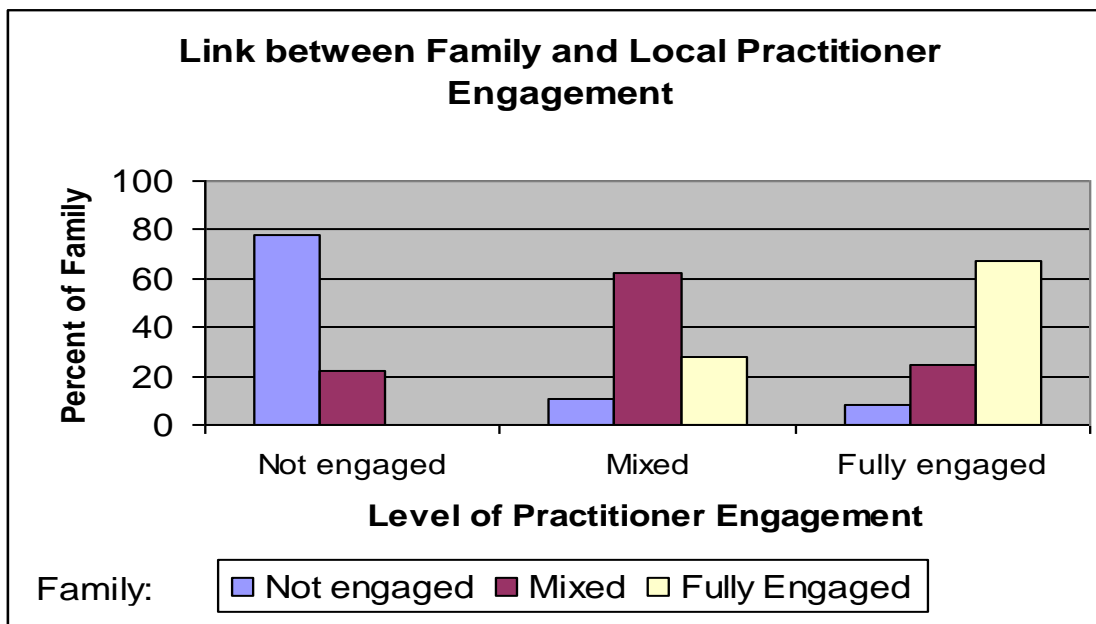


Figure 10

Interpretation of these findings should account for the lack of independence in rating. That is, the same clinician scored both the level of engagement achieved with the consumer, and the level of engagement achieved with the informant. Thus, the clinicians' perception and/or attitude may have acted as an extraneous variable that biased the results and enhanced the associations. Furthermore, clinicians who achieved full adherence to Principle One (which occurred rarely) may have had greater skill in engaging all three parties.

However, the finding that the level of family engagement was more strongly linked with the consumer's engagement than that of the local practitioner suggests that data reflects more than just a rating or skills bias. Furthermore, one of the fundamental roles of Indigenous Mental Health Workers is to enable greater engagement of Indigenous consumers and families in mental health care. It may be posited that the stronger link observed between consumer and family engagement is a consequence of the stronger intensity of the family member's relationship with the consumer. The strong link between family and local practitioner engagement and high frequency of full family engagement where a local practitioner was also engaged may reflect the power of culturally appropriate practice.

It was posited that gaining information from additional informants (family/ carer or Health Worker) might be associated with greater difficulty for the clinician making the ratings, who would need to incorporate this extra information when making their assessment. An analysis was undertaken, and data in Table 20 demonstrates the relationship between additional informants and difficulty of ratings.

Table 20. Relationship between additional informants and additional difficulty experienced by clinicians when rating

	Total	Neither No. (%)	Family No. (%)	Health Worker No. (%)	Both No. (%)
None to some additional difficulty	385	223 (90.3)	89 (80.9)	42 (73.7)	31 (81.6)
Moderate to substantial difficulty	67	24 (9.7)	21 (19.1)	15 (26.3)	7 (18.4)
Total	452	247	110	57	38

Table 20 indicates that where there were no additional informants, clinicians most often felt no to some additional difficulty in completing the ratings. Health worker involvement alone was most often associated with greater difficulty (Pearson’s chi square 13.0, df 3, p=0.005 across all informant categories and chi square 11.2, df 1, p=0.001 comparing the presence and absence of any or both additional informants).

Table 21. Clinicians view of the validity of the scales in reflecting the mental health problems of the consumer and the presence of additional informants

	Neither No. (%)	Family No. (%)	Health Worker No. (%)	Both No. (%)
Good to reasonable agreement	207 (85.2)	86 (78.9)	40 (70.2)	32 (84.2)
Inadequate to poor agreement	36 (14.8)	23 (21.1)	17 (29.8)	6 (15.8)
Total	243	109	57	38

Table 21 shows a similar trend: where there was no additional information, the clinician tended to indicate a high frequency of confidence in the scores (Pearson’s chi square 7.8, df 3, p=0.05 across all informant categories and chi square 3.9, df 1, p<0.05 comparing the presence and absence of any or both additional informants). Similar to the difficulty question, occasions where the clinician felt there was inadequate agreement occurred most often when information from a local practitioner (health worker) alone was provided. The highest frequencies of good agreement were seen where neither or both family member and health worker provided additional information.

Key Findings presented in Chapter 7

I. Clinicians stated that in approximately 75% of Outcomes assessments made during the twelve month period of this study, the assessment scales provided a “reasonable or good”

indication of the consumer's mental health problems. This suggested that the majority of clinicians perceived the scales to have adequate face validity.

II. In only a small proportion of occasions did clinicians comply with the first principle of Indigenous Outcomes measurement, i.e. inclusion of information from family members and a local practitioner, ideally an Indigenous Health/ Mental Health Worker.

III. The data illustrated linkages between presence and the degree of engagement of the consumer, family members and local Health Workers and the extent of difficulty experienced by the clinicians in doing the ratings. Similarly, a link was found between clinicians' opinions of the degree of agreement achieved between the ratings and the mental health problems of the consumer. These findings add strength to comments made by Wuchopperen workshop participants and suggest that families, carers and local practitioners may be important catalysts for engaging, and enhancing the interest of consumers in the activities of mental health clinicians. Further to this, the engagement of relevant parties may provide additional information to the clinician.

IV. It is noteworthy that the involvement of other informants in assessments showed no increase over the twelve month study period. Further efforts are required to overcome existing barriers which prevent the greater involvement of families, local practitioners and Indigenous Health Workers in the assessment process.

8

Application of Principle One and Outcomes Scores

Variation in HoNOS and LSP Scores Associated with Additional Informants

Introduction

This chapter examines responses to the first question added to the Outcomes information system regarding whether family/carer or a local practitioner provided additional information for the assessment. A comparison of HoNOS and LSP data from occasions where additional informants had been involved, and had been involved in assessments, was undertaken.

In some analyses, data were combined into two groups, namely 'no informants' (neither family/carer nor local practitioner) and 'with informants' (one party or both). In other analyses, scores were compared between four types of occasions which included information from neither family/carer or practitioner, family/carer only, local practitioner only and both family/carer and a local practitioner.

a. Comparing HoNOS Ratings With and Without Informants in the Community Setting

The analysis revealed a strong association between higher average scores of HoNOS and LSP, and the presence of additional informants for most individual items (see graphs below), every subscale, and for total scores in the community setting.

Differences seen between average HoNOS scores in occasions collected in the community where family and/or local practitioners were involved, compared with instances where neither were involved are shown in Table 22 (total, subscale scores) and Figure 11 (individual items).

Table 22. Mean HoNOS Scores in Community Occasions associated with the Presence or Absence of either Family/carer, Local Practitioner Informants or Both

Additional Informants	Total Score Mean (n)	Behaviour Mean (n)	Impairment Mean (n)	Symptom Mean (n)	Social Mean (n)
Neither	10.1 (187)	2.2 (193)	1.4 (195)	2.6 (194)	3.8(190)
Either or Both	14.9 (132)	3.1 (140)	2.6 (141)	3.9 (137)	5.8 (138)
Total	12.1 (319)	2.6 (333)	1.9 (336)	3.1 (331)	4.6 (328)

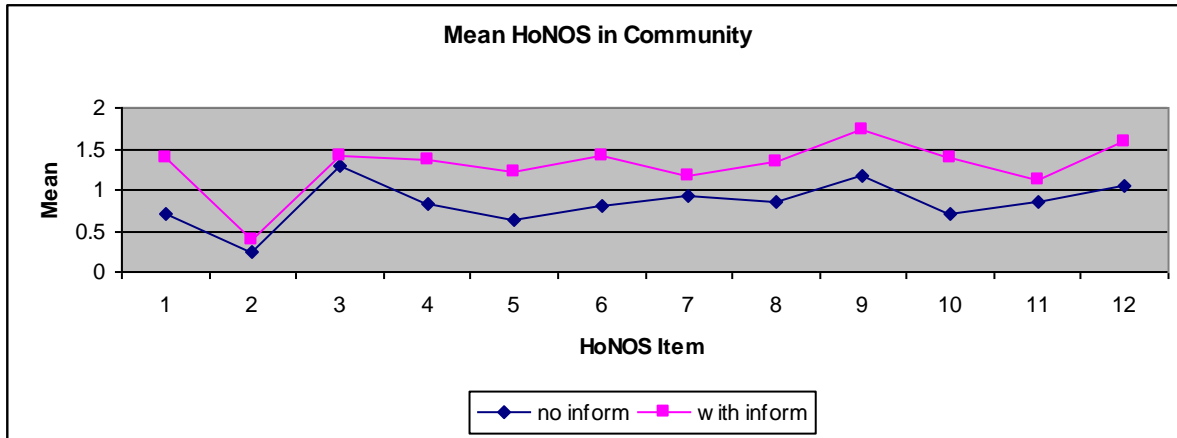


Figure 11

The average scores for HoNOS items 1, 4, 5, 6, 8, 9, 10 and 12 were significantly lower in occasions where these informants were not involved (Mann-Whitney U test, $p=0.003$ or less). The differences were not statistically significant for items 2 or 3, but they approached significance for items 7 ($p=0.08$) and 11 ($p=0.09$).

Total HoNOS scores did not vary between occasions with family/carer only and those with a local practitioner only; both were on average 4 points higher and significantly higher than scores made without either informant (Table 23, Mann-Whitney U test, $p<0.001$; $p=0.002$, respectively). However, there were differences in levels of increase across the subscales according to which types of informant was involved). While all four subscale scores were significantly higher where family/carer informants were involved ($p=0.01$ or less), significant differences were seen in the impairment and social subscales only where local practitioners were involved ($p=0.002$ or less).

Table 23. Mean HoNOS Scores in Community Occasions associated with Family/carer Informants, Local Practitioner Informants or Both

Additional Informants	Total Score Mean (n)	Behaviour Mean (n)	Impairment Mean (n)	Symptom Mean (n)	Social Mean (n)
Neither	10.1 (187)	2.2 (193)	1.4 (195)	2.6 (194)	3.8 (190)
Family/carer only	14.0 (75)	3.2 (77)	2.1 (78)	3.7 (77)	5.4 (76)
Local practitioner	14.0 (34)	2.2 (37)	2.9 (36)	3.2 (35)	6.1 (37)
Both	19.0 (23)	4.1 (26)	3.6 (27)	5.5 (25)	6.6 (25)
Total	12.1 (319)	2.6 (333)	1.9 (336)	3.1 (331)	4.6 (328)

In cases where a family member was involved in the assessment, scores related to the consumer's behaviour and symptoms were higher compared to occasions when only a local practitioner was involved. In contrast, impairment and social subscale scores were higher when (only) local practitioner information was utilised, compared to information from (only)

family informants. On occasions where both types of informants were involved, all mean scores were markedly higher than they were in occasions without informants or with a single informant.

The magnitude of difference between scores where informants were and were not involved varied by broad age group. Figure 12 displays data for younger consumers (under 30 years of age) and Figure 13 shows data for consumers aged 30 years and older. Minimum sample sizes were 61 and 131 for occasions without additional informants and 84 and 57 for occasions with informants for younger and older consumers, respectively.

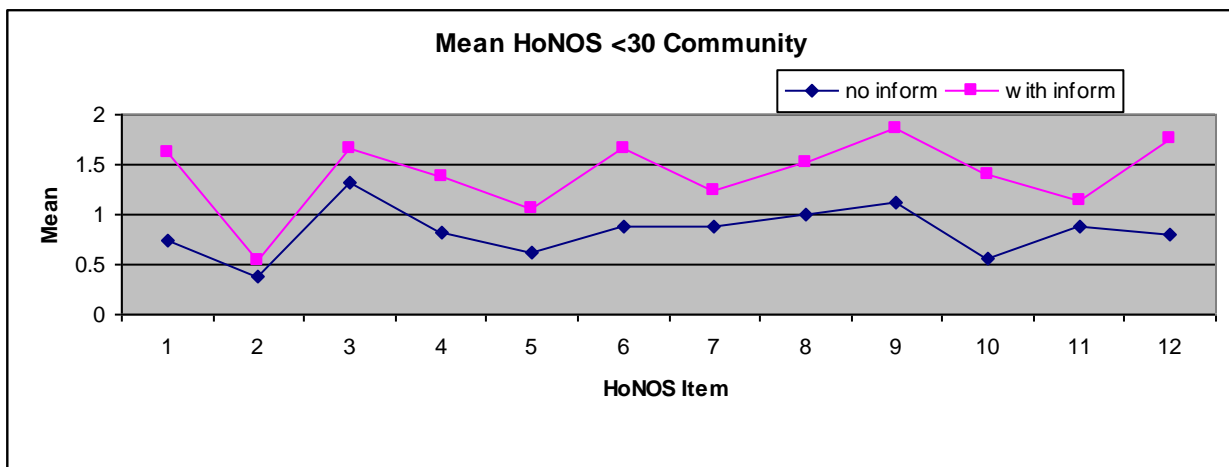


Figure 12

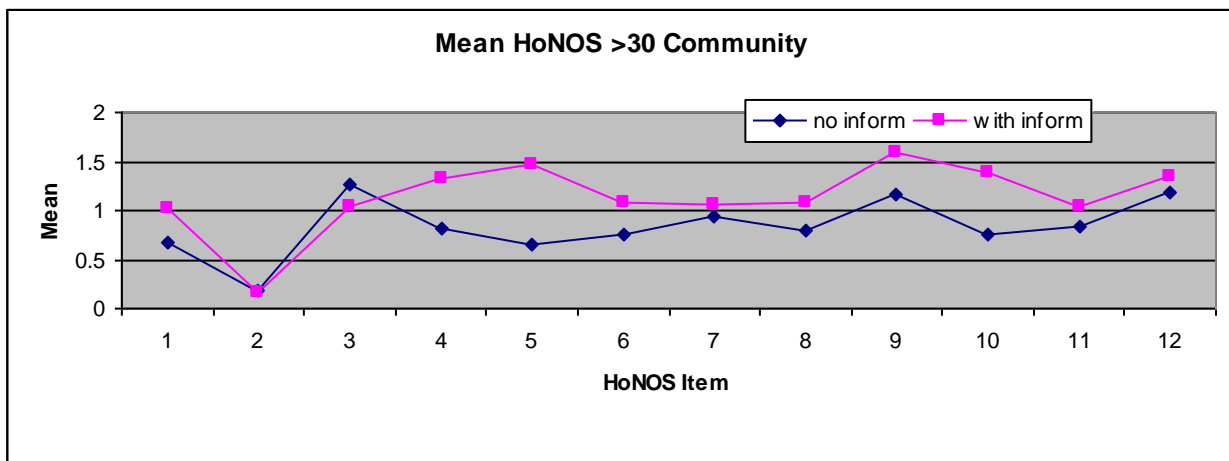


Figure 13

Higher average scores were recorded for many HoNOS items of both younger and older consumers when at least one informant provided information to the clinician for the ratings. Scores were significantly higher ($p < 0.05$) when informants were involved for Items 1, 4, 5, 6, 8, 9, 10 and 12 with younger consumers and 1, 4, 5, 9 and 10 with older consumers. The largest differences were seen for items 1 (behaviour), 6 (hallucinations), 9 (relationships), 10

(activities of daily living) and 12 (occupational activities) for younger consumers and items 5 (disability) and 10 (daily living) for older consumers.

Analyses were performed to determine whether the level of difference between occasions that did and did not involve these informants was associated with the level of engagement the clinician felt was achieved with the consumer. Table 24 demonstrates that there were large differences in the average total HoNOS scores with and without informants when the consumer was judged well enough to be involved in the assessment and occasions where the consumer was not well enough to be involved.

Table 24. Average total HoNOS scores where the consumer was considered well enough or not well enough to be involved in the assessment & by presence of additional informants (community occasions only)

	Not well enough Mean (n)	Well enough Mean (n)
No additional informants	17.7 (10)	9.4 (162)
Family, local practitioner, both	20.4 (13)	14.3 (111)

In both cases, whether the consumer was well enough or not well enough to be involved in his/her assessment, information from family or local practitioner was associated with significantly higher total HoNOS scores. Furthermore, the difference in average scores was greater for consumers considered well enough to be engaged than for those not well enough to participate.

HoNOS scores in groups further stratified by degree of engagement of the consumer and the presence of informants is given in Table 25.

Table 25. Mean HoNOS scores in relation to Additional Informants and Degrees of Consumer engagement

Consumer	Not well enough Mean (n)	Not engaged Mean (n)	Mixed response Mean (n)	Engaged & interested Mean (n)
Neither family or local practitioner	17.7 (10)	13.2 (26)	9.4 (62)	8.1 (74)
Family, local practitioner or both	20.4 (13)	16.0 (31)	15.0 (47)	11.6 (33)

This table shows that although there was a strong inverse trend between degree of engagement achieved with the consumer and HoNOS scores as expected (lower scores where engagement was higher), in every case the presence of additional informants was associated with higher scores. Thus even where the consumer was considered by the

clinician to be engaged and interested in the assessment process, HoNOS scores were on average 3 points higher where information from family or local practitioner was included. The degree of difference between scores with and without additional informants was greatest (6 points higher) among consumers considered to show mixed level of engagement.

b. Comparing LSP Ratings With and Without Informants in the Community Setting

Average LSP scores varied similarly between occasions where family and/or local practitioner informants were involved compared with those where they were not (Table 26). Sample sizes for these comparisons ranged from 100 to 118 occasions without informants and 68 to 80 occasions with informants.

Table 26. Mean LSP Scores by Presence or Absence of additional Informants

Additional Informants	Total Mean (n)	Withdrawal Mean (n)	Self-Care Mean (n)	Compliance Mean (n)	Anti-Social Mean (n)
Neither family or Local Practitioner	12.6 (88)	3.9 (105)	3.8 (108)	2.5 (112)	2.7 (95)
Either family or practitioner or both	16.2 (54)	4.9 (68)	5.0 (70)	3.5 (70)	4.2 (67)

Significantly higher scores were recorded in the total, withdrawal, compliance and anti-social subscales when additional informants were involved (Mann-Whitney U test, $p < 0.05$), while the difference in the self-care subscale approached statistical significance ($p = 0.07$).

Differences in mean scores for individual LSP items (Figure 14) were significant ($p < 0.05$) for items 1 (conversation), 3 (warmth), 7 (violent), 8 (friendships), 9 (diet), 10 (medications), 12 (cooperation with health services), 14 (offensive behaviour), 15 (irresponsible behaviour), 16 (ability to work) and approached significance ($p < 0.10$) for items 2 (withdrawal), 4 (grooming), 11 (psychiatric medications) and 13 (problems living in the household).

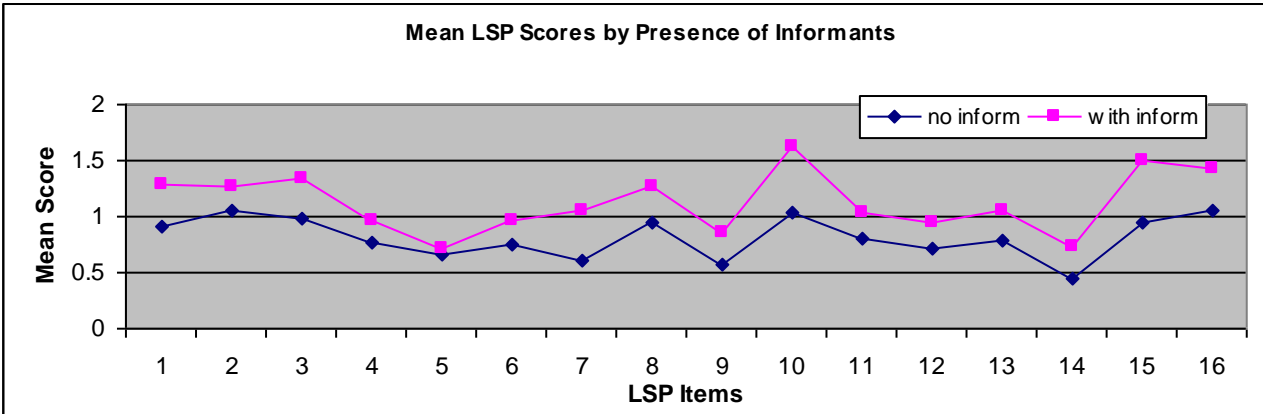


Figure 14

Although samples sizes (and therefore statistical power) for the LSP scores were considerably less than that of the HoNOS scores, a similar situation was observed in LSP subscale scores when comparing occasions with family/carer versus local practitioner informants as that found for HoNOS scores (Table 27). Total scores did not differ between the small number of fully completed LSP scores in occasions where a local practitioner (only) was involved and those where neither informants were involved. However, for each LSP subscale, the average scores for occasions where local practitioners (only) were involved were higher to a similar degree as that observed in occasions with family/carer involvement. The small number of occasions where both family and local practitioners were involved was markedly higher for all but the compliance subscale.

Table 27. Mean LSP Scores in Community Occasions associated with No informants, Family/ carer Informants, Local Practitioner Informants and Both

Additional Informants	Total Score Mean (n)	Withdrawal Mean (n)	Self-care Mean (n)	Compliance Mean (n)	Antisocial Mean (n)
Neither	12.6 (88)	3.9 (105)	3.8 (108)	2.5 (112)	2.7 (95)
Family/carer only	16.1 (33)	4.7 (39)	4.5 (41)	3.5 (43)	4.0 (39)
Local practitioner	12.2 (13)	4.4 (20)	4.7 (19)	3.2 (18)	3.9 (18)
Both	23.3 (8)	6.9 (9)	7.7 (10)	3.9 (9)	5.6 (10)

c. Comparing HoNOS Ratings With and Without Informants in the Inpatient Setting

In contrast to trends observed in association with informants in the community setting, no significant difference in subscale scores was observed across occasions with and without additional informants in the inpatient setting, although there were upward trends (Table 28).

Table 28. HoNOS Scores in Inpatient Occasions associated with Informants

Additional Informants	Total Score Mean (n)	Behaviour Mean (n)	Impairment Mean (n)	Symptom Mean (n)	Social Mean (n)
Neither	17.2 (43)	5.2 (53)	1.5 (53)	5.0 (49)	5.8 (46)
Family/carer only	18.9 (27)	4.7 (30)	2.3 (31)	5.2 (29)	6.9 (29)
Local practitioner	19.2 (18)	5.2 (19)	1.3 (21)	6.5 (20)	6.7 (20)
Both	21.1 (14)	6.9 (10)	0.8 (10)	6.8 (11)	7.2 (9)

Differences approaching statistical significance were observed in individual item scores for item 2 (non-accidental self-injury was rated lower on average with informants; $p=0.09$), and items 6 (hallucinations, $p=0.07$) and 8 (other problems, $p=0.10$), where mean scores were higher in occasions with informants (Figure 15).

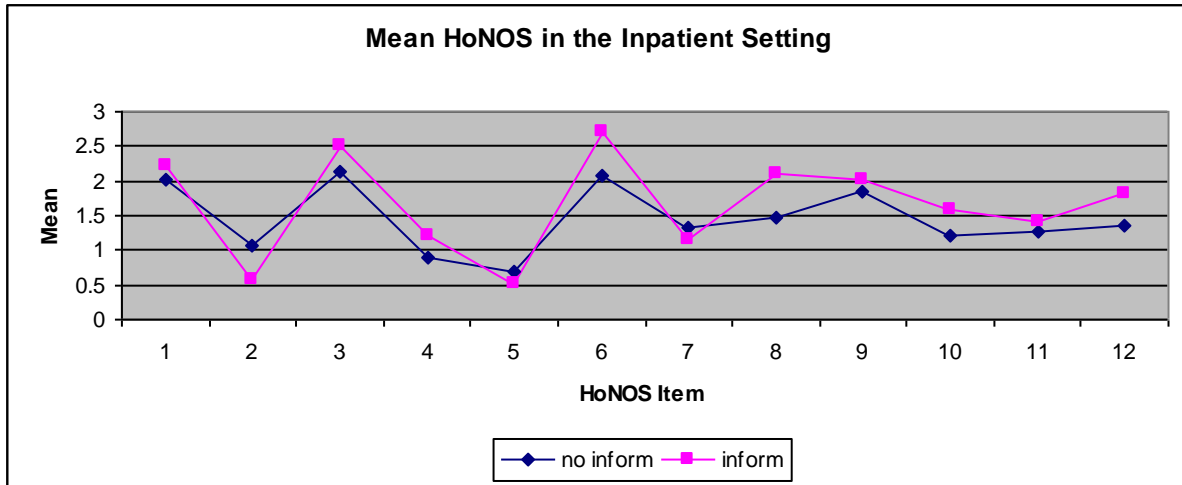


Figure 15

d. Comparing Ratings With and Without Informants within Diagnostic Groups

Analysis was also performed to examine whether the presence of informants was associated with higher HoNOS and LSP scores from collection occasions within diagnostic groups. The grouping of data into diagnostic categories is described in Chapter 5 (Section i). Adequate numbers for comparison with and without informants were only available for unrecorded diagnosis and psychotic disorders. Table 29 displays the average scores, rank orders and significance levels for comparisons with and without informants among these groups.

Table 29. Average HoNOS and LSP Scores stratified by Setting and Diagnostic Group in Circumstances With and Without a Family/Carer and/or Local Practitioner Providing Additional Information for the Outcomes Collection Occasion.

Scale & Conditions	n	Average Score	Mean Kruskal Wallis Rank (chisquare test, p value)
HoNOS Inpatient Setting – Diagnosis not recorded			
Without	33	17.4	30.1
With family/HW	32	19.3	36.0 (p=0.20)
HoNOS Inpatient – Schizophrenia, schizotypal, delusional disorders (F20-29)			
Without	7	17.7	9.4
With family/HW	17	21.3	13.8 (p=0.17)
HoNOS Community Setting – Diagnosis not recorded			
Without	74	10.4	52.0
With family/HW	52	15.8	79.9 (p<0.001)
Community Setting – Schizophrenia, schizotypal, delusional disorders			
LSP			
Without	57	13.9	44.5
With family/HW	42	17.9	57.4 (p=0.03)
HoNOS			
Without	67	11.0	54.2
With family/HW	56	14.3	71.3 (p=0.008)

In each case, average outcomes scores (and mean rank using Kruskal Wallis non-parametric test) were higher in occasions where a family member/carer or a local practitioner provided additional information for the assessment compared to occasions without these informants. The differences associated with the presence or absence of a family/carer and/or local practitioner were statistically significant for HoNOS and LSP in the community setting among consumers with a diagnosis of psychotic disorders and where no diagnosis was recorded.

Key Findings presented in Chapter 8

Chapter 8 has shown that average community HoNOS and LSP scale, subscale and item scores were markedly higher in collection occasions where a family member/carer and/or a local practitioner was involved in the assessment, compared to occasions where neither were involved. This difference in scores was not dependent on the degree of engagement achieved with the consumer (as perceived by the clinician) and was observed within diagnostic categories. Greater differences were observed in occasions where the consumer was under 30 years of age, compared to occasions with older consumers and in HoNOS occasions in the community compared to those in the hospital inpatient setting. Occasions where local practitioners alone and family members/carers alone showed little difference in total HoNOS and LSP score; both were markedly higher than in occasions where neither were involved and lower than occasions where both were involved. However, the two types of informant were associated with different patterns of higher subscale and item scores. For example, inclusion of family informants was associated with higher behavioural and symptom subscales on HoNOS while the inclusion of a local practitioner informant was linked to higher impairment and social subscales.

9

Analysis of HoNOS and LSP Scores Collected with Indigenous Consumers

a. Introduction

This section presents the results of analysis of the HoNOS and LSP data collected in the 12 month period from July 2004 to June 2005 for adult Indigenous consumers. The results presented in this section are guided by the following research questions (see Chapter 1):

- How valid are the assessments in relation to the standard definitions of mental health status of people with chronic and recurring mental illness?
- What does the information retrieved from these Outcomes tools tell us about the effectiveness of mental health service delivery in Far North Queensland in improving the mental health of consumers?
- Are these tools acceptably valid, reliable and sensitive to be included within an evaluation of mental health interventions?

The evaluation approach outlined in the proposal included a range of quantitative data analyses to be performed on the HoNOS and LSP data. This included analysing relationships between the ratings and relevant background data, such as age, gender, urban, rural and remote location, diagnoses, mental health service utilisation as well as other relevant incidents. The questions being examined through this analysis in relation to the validity of the HoNOS and LSP data were:

- Are there differences across these subgroups in rating patterns for various items?
- Do the differences appear to be valid reflection of the groups' mental health and well being or do they indicate something wrong in the assessment question or the process?

Collection and analysis of the data proceeded as anticipated in the study design, except that the Steering Group agreed to extend the data collection period to 12 months. This extended period was beneficial for four reasons. First, a developmental period in the system was observed (for example in the decline in numbers of unspecified Indigenous status entries) so

that waiting until July provided time for collection procedures to become routine. Second, the number of entries collected in various districts was not steady across months, so an extended period afforded larger sample sizes. Thirdly, it took longer to accumulate sufficient numbers of LSP occasions for analysis since LSP, in contrast to the HoNOS, is not applied in the inpatient setting or in initial clinical encounters (new referrals) with consumers. The fourth benefit was that adjusting the analysis period to July 2004 to June 2005 allowed for convenient cross referencing to be made between hospitalisation data for the network and Mental Health Outcomes data in the community and inpatient settings.

b. Inclusion of Corollary Data

Analysis of data on Indigenous hospitalisations in the Cairns Network enabled the researchers to explore consistency between age- and locality-related differences in HoNOS and LSP scores and patterns observed in mental health service usage at the tertiary level. A brief introduction to the patterns seen in hospitalisations, data limitations and the rationale for examining both outcomes and hospitalisation data is provided below.

The AIMhi team conducted a 6-year (July 1999-June 2005) review of admissions to the Mental Health Unit of Cairns Base Hospital through data extracted on November 28, 2005 from the Hospital Based Corporate Information System (HBCIS) (Haswell et al., 2006). The purpose of this review was to examine the rising occupancy rates and a perceived increased acuity of illness among consumers in the Unit. Identification of Indigenous patients was enhanced by a separate registry maintained by the Ward's Advanced Health Worker (Mental Health).

This analysis revealed a marked rise in average length of stay (LOS) of Indigenous consumers aged 20 to 29 years from 8.8 days in 2003/04 to 20.9 days in 2004/05 (see Figure 16). This contributed to an increase in occupied bed days of over 1,000 among Indigenous patients under age 30, compared to an increase of 300 bed days among Indigenous patients aged 30 and over.

Furthermore, the crude psychiatric separation rates (6 year average) for the Far North Queensland Indigenous population aged 15 to 29 years of age was 116.8 separations per 10,000 residents (Haswell et al., 2006). This rate is nearly twice that of the Indigenous population aged 30 years and over (61.1 per 10,000) and 2.4 times higher than that of the non-Indigenous population under age 30 (48.4 per 10,000).

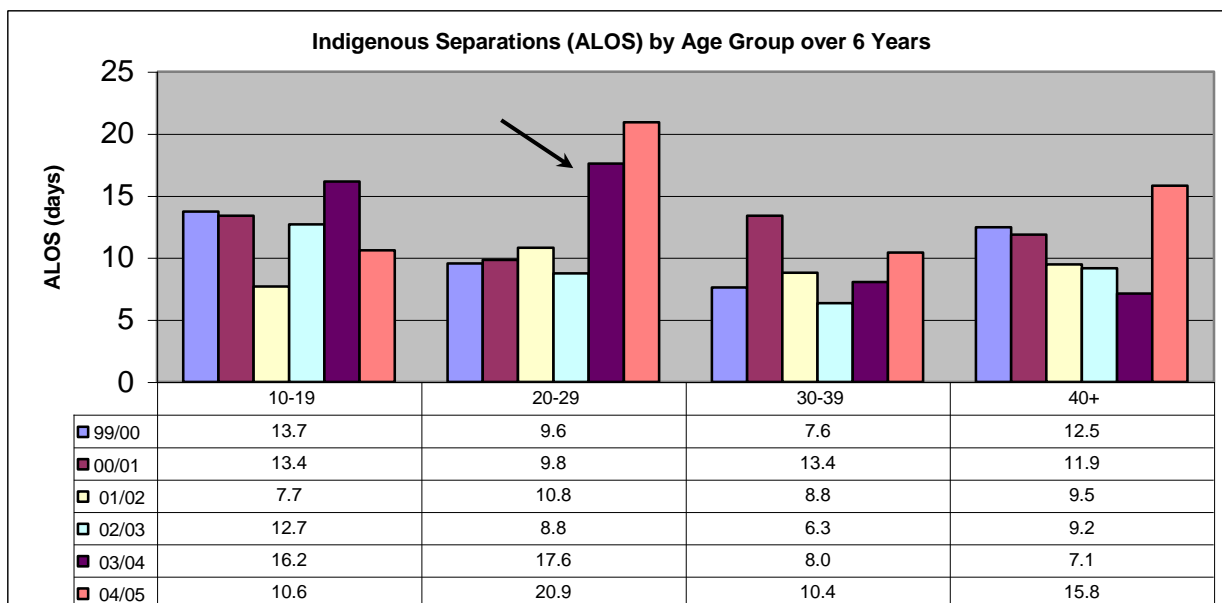


Figure 16

Detailed analysis revealed that the increase in the occupancy rate at the Mental Health Unit over the last two years was almost entirely due to increased length of stay among Indigenous consumers under age 30 with a diagnosis of ICD10 F20-29, which includes schizophrenia, schizotypal and delusional disorders. The increases were particularly large among residents of distinct Indigenous communities. Cairns District residents experienced the greatest increase in average lengths of stay and total occupied bed days (900 additional bed days) between 2002/03 and 2004/05.

There are of course many contributing factors to increased length of stay in hospital including increased complexity and acuity of illness, late presentation for medical care, not engaging and adhering to treatment, lack of acceptable accommodation options and social supports, concern for safety, Mental Health Act status, etc. These possible reasons are of course inter-related and are dimensions of Mental Health Outcomes that services aim to address and both LSP and HoNOS attempt to measure some of these accurately. Long stays suggest persistence of these concerns and delayed discharge despite a severe need for beds for new or other admitted patients.

While hospital information provide evidence of patterns of severe unwellness, systematic collection and analysis of HoNOS and LSP data from inpatient and community settings, if reliable and valid, may reveal problems the consumers are experiencing that underlie these patterns. Analyses were undertaken to explore to what extent patterns in Outcomes measures agree with those of hospitalisation usage.

Knowledge of these striking age-related patterns in the Indigenous hospitalisations data has allowed our analysis to examine whether the HoNOS and LSP data indicates differences in the severity of problems younger and older consumers are experiencing. Understanding the reasons can powerfully assist in guiding more strategic and effective responses not only at the individual and broader population level, but also at the local level where many service decisions are made.

c. Trends in HoNOS in Inpatient Setting & Association with Hospitalisation Data

As expected, the scores of many individual HoNOS items and all HoNOS subscales, with the exception of the impairment subscale, were higher for occasions collected with consumers in the Acute (Inpatient) Mental Health Unit of Cairns Base Hospital, compared to those collected in the community setting (Table 30).

Table 30. Overall Mean HoNOS Scores: Comparing Inpatient & Community Setting

Setting	Total Mean (n)	Behaviour Mean (n)	Impairment Mean (n)	Symptoms Mean (n)	Social Mean (n)
Community	12.2 (333)	2.6 (348)	1.9 (351)	3.2 (346)	4.7 (342)
Inpatient	18.7 (110)	5.3 (130)	1.8 (136)	5.5 (128)	6.4 (121)

HoNOS scores collected in the inpatient setting with consumers under 30 years of age (average LOS 20.6 days, n=79) and consumers 30 years and over (average LOS 12.1 days, n=61) are shown in Table 31. Differences in the average scores of females (n=50) and males (n=90) are also noted where potentially of interest.

Table 31. Mean HoNOS Scores in Hospital comparing Younger & Older Consumers

Subscale	<30 years Mean (n)	≥30 years Mean (n)	Trends with Gender
Total Score	18.7 (67)	18.8 (43)	Mean for females (20.3) > than males (17.8) in <30 but not significant
Behaviour	5.4 (74)	5.3 (56)	No significant difference
Impairment	1.4 (77)	2.3 (59)	Females >Males in ≥30 only
Symptoms	5.9 (75)	5.1 (53)	No significant difference
Social	6.5 (73)	6.3 (48)	No significant difference

Little difference was observed in HoNOS subscale and total scores between the age groups, except for a significantly higher level of impairment amongst older consumers, compared to younger consumers. The data did not reflect age-related patterns in lengths of stay.

Although subscale and total HoNOS scores did not suggest different levels of severity associated with age (and length of stay in hospital), individual item scores were explored since it was possible that the subscale structure could mask such differences. Some evidence for greater severity among younger consumers was observed for some items. Figure 17 shows mean scores for each HoNOS item stratified by age group.

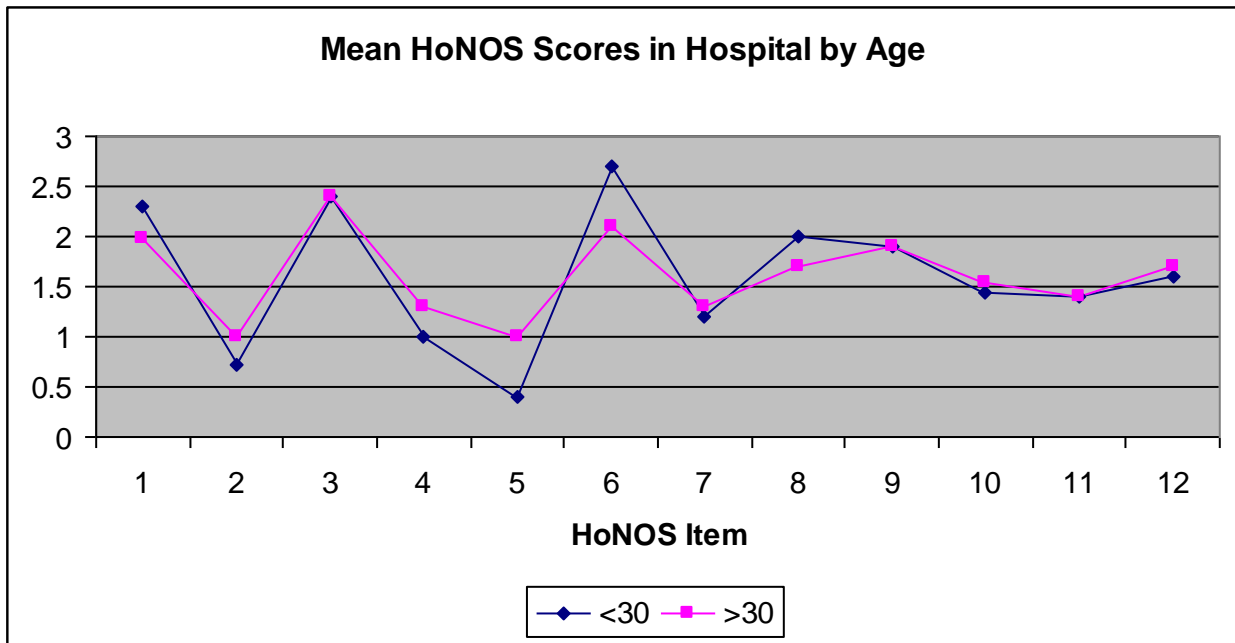


Figure 17

The mean differences were statistically significant for Item 5 (higher in older consumers) and 6 (higher in younger consumers). However, this representation of data is not as descriptively informative as compared to examining the frequencies of the problems by score. Cross-tabulation of individual HoNOS items by age group revealed the following:

- Item 1 - aggressive, agitated behaviour – while younger consumers in hospital were more likely to have at least some problem in this area (87.3%) as compared to older consumers (63.9%), there was no trend in the pattern of severity, since the numbers of older and younger consumers with moderate to severe problems were equivalent.
- Item 5 - problems with physical disability - showed much greater severity among older consumers compared to younger consumers. The subscale scoring structure tended to mask this sharp degree of difference by combining Item 5 with Item 4 (cognitive problems) which showed no difference with age. This age-related trend was inversely related to length of inpatient stay (higher problems with physical disability observed in older group, with shorter length of stay).

- Item 8 – other mental or behavioural problems – Similar to patterns described for Item 1, while having some additional problem was more frequent among younger consumers, there was no trend with increasing severity in the younger group.
- Item 6 – Hallucinations and delusions – Scores for this item showed a marked difference in both the frequency and severity between younger (n=77) and older (n=60) consumers assessed in hospital, as demonstrated in Figure 18.

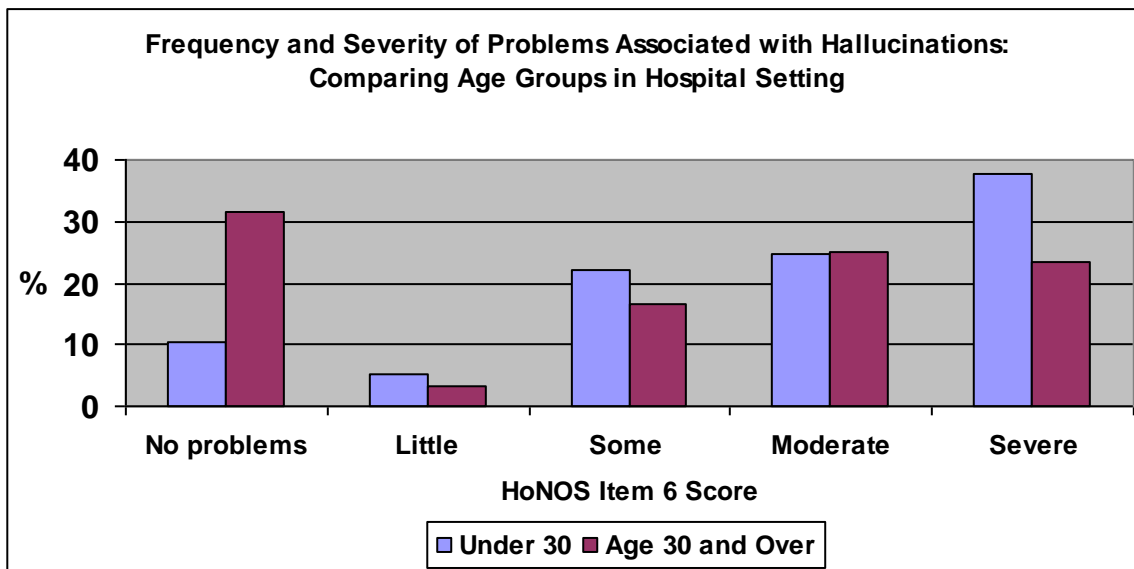


Figure 18

Only 10% (n=8) of consumers under 30 had no problems with hallucinations compared to over 30% (n=19) of older consumers. 37.7% (n=29) of younger consumers had severe problems associated with hallucinations, compared to 23.3% (n=14) of older consumers. These trends were statistically significant (χ^2 for linear trend, 7.4, df 1, p=0.006).

The unique ability of HoNOS Item 6 in demonstrating an observed difference in hospital use patterns across these age groups supports its importance on par with the other subscales as proposed in an alternate HoNOS scale structure by Trauer (1999).

d. Age- and Gender-associated Trends in HoNOS & LSP in Community Settings

The mean of each individual HoNOS item in groups stratified by age (under 30 years and 30 years and over) for collection occasions in the community setting are shown in Figure 19. Younger consumers had a higher average score on every item when compared with older consumers. The difference was statistically significant (p<0.05) for items 1, 2, 3, 6 and 8 and approached significance for item 9 (p=0.08).

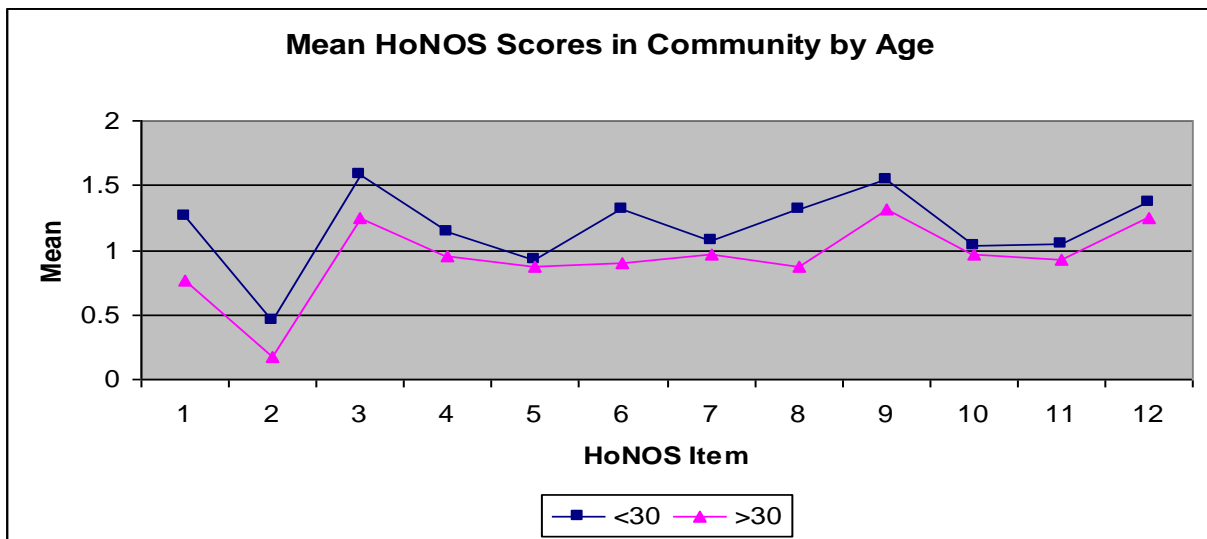


Figure 19

Table 32 presents average total and subscale scores for HoNOS data collected in the community setting (n=356) in relation to the broad age groups and explores patterns associated with gender (131 occasions with females, 225 with males).

Table 32. Patterns in Mean HoNOS scores from the Community Setting associated with Age and Gender

Subscale	<30 years Mean (n)	≥30 years Mean (n)	Trends with Gender
Total Score	13.5 (144)	11.2 (189)	Females>Males in both age groups
Behaviour	3.2 (152)	2.2 (196)	No significant difference
Impairment	2.0 (156)	1.8 (195)	Females>Males in ≥30 only
Symptoms	3.7 (150)	2.8 (196)	Remained high in females ≥30; dropped in older men
Social	4.9 (150)	4.5 (192)	Females >Males in younger group but equal in ≥30s

In the community setting, HoNOS scores of younger consumers were significantly higher than older consumers on the behaviour and symptoms subscales, and in total scores.

There were also some statistically significant gender-associated differences in HoNOS scores completed in the community setting. In all HoNOS subscales where there was a gender-associated difference, average scores for female consumers were higher than those for males. While few gender differences were observed in collections in the inpatient setting, in the community setting, the subscale scores for females were frequently higher than those for males. In some cases the sex-associated difference was more marked in the younger

group (eg. total scores, social subscale) while in others the difference was observed between females and males in the older group (eg. impairment, symptoms). Several of the LSP item scores also showed significant differences between the broad age groups. Figure 20 demonstrates differences in mean scores by age group.

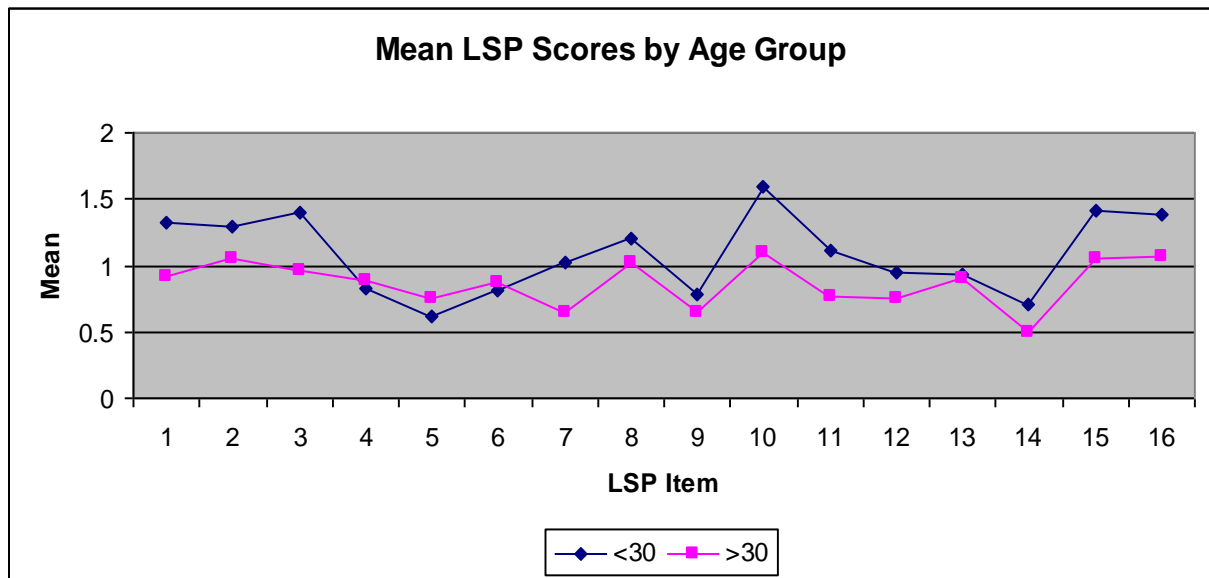


Figure 20

Mean LSP scores differed significantly between age groups for items 1, 2, 3, 7, 10, 11, 15 and 16, and approached significance for item 12. Table 33 presents average total and subscale scores for LSP data collected in the community setting in relation to these age groups and explores patterns associated with gender. Mean scores for younger consumers were significantly higher than those for older consumers on all subscales except self-care.

Table 33. Patterns with Age and Gender in LSP Data (Community Setting)

LSP Subscale	<30 Years	≥30 Years	Trends with Gender
Total Score	17.0 (64)	12.5 (85)	None
Withdrawal	5.0 (75)	4.0 (105)	None
Self-care	4.5 (77)	4.2 (108)	Females > Males in <30 Males > Females in ≥30
Compliance	3.6 (78)	2.5 (111)	None
Anti-social	4.0* (76)	3.0 (93)	None

LSP subscale scores and many individual item scores were frequently higher amongst younger (<30) compared to older consumers, but little difference was seen in subscale scores between male and female consumers. This pattern is similar to that observed with HoNOS data for community-based consumers.

e. Responses to HoNOS Item 8

Item 8 on HoNOS explores the presence and severity of problems associated with other mental and behavioural problems experienced by the consumer. If there is more than one problem present, the clinician is instructed to rate the most severe secondary problem. This response was fully completed in 481 collection occasions.

Overall, clinicians did not identify any additional problems in 45.3% (218) of all occasions, with a higher frequency of ‘no problems’ responses in community occasions (53.6%,188) as compared to inpatient occasions (23.1%,30). Among the 263 occasions where an additional problem was identified, three issues accounted for 73% (192) of those identified. Sleep problems were identified most frequently in both settings, followed by anxiety and reactions to trauma.

While the same three problems predominated in both the inpatient and community setting, the frequencies of item 8 responses differed markedly. Table 34 shows that sleep problems were identified in Item 8 in 35.4% of inpatient occasions, and among those, the rating was 3 or 4 (indicating moderate and severe) in 61% of cases. In community occasions, sleep problems were identified in 18% of cases and were rated as moderate or severe in 28% of those cases. Anxiety and panic problems were also more frequently identified as the main problem in inpatient settings (15.4%) than in community occasions (6.0%).

Table 34. Major Responses to Item 8 in Community and Inpatient Occasions

	Inpatient Setting	Community Setting
Sleep Problems	35.4%	18.2%
Anxiety and panic problems	15.4%	6.0%
Reactions to trauma, stress	9.2%	8.3%
Other problems	16.9%	14.0%
No problems	23.1%	53.6%

f. Differences in HoNOS and LSP Scores by District

There were considerable differences in average HoNOS subscale and total scores across districts. Collection occasions with consumers that occurred in the Cape District averaged lower on most of the subscales, followed by the Torres Strait and Northern Peninsula Area (NPA) District and Innisfail Districts. To facilitate comparison, mean scores for age groups in hospital are also given in Table 35.

Table 35. All Ages: Average HoNOS Total and Subscale Scores by District

District*	Total Mean (n)	Behaviour Mean (n)	Impairment Mean (n)	Symptoms Mean (n)	Social Mean (n)
Cape	9.3 (71)	2.2 (75)	0.9 (74)	1.7 (75)	4.4 (72)
TS&NPA	10.7 (72)	2.2 (72)	1.9 (74)	2.9 (74)	3.0 (73)
Innisfail	11.9 (43)	2.7 (45)	2.0 (46)	2.4 (43)	4.9 (44)
Cairns- Community	14.3 (137)	2.9 (146)	2.4 (147)	3.6 (144)	5.6 (143)
All Community	12.2 (333)	2.6 (348)	1.9 (351)	3.2 (346)	4.7 (342)
Cairns – Inpatient	18.7	5.3	1.8	5.5	6.4

*note that the 10 outcomes occasions in the Tablelands District were not included in the district-specific display but are included in the overall community scores.

Collection occasions in Cairns and Innisfail District produced the highest average scores, and the remote districts of Cape York and the Torres Strait having the lowest scores. Stratification by age group revealed similar patterns for both younger and older consumers, though older consumers in the Cairn Districts scored markedly higher than all other Districts; particularly for behaviour, impairment and social subscales (data not shown).

The recorded severity of illness across districts suggested by the HoNOS scores was consistent with patterns of admission and length of stay among consumers at the Cairns Base Hospital over the same time period. LSP scores for community occasions in Cairns District were also particularly high compared to data collected in the other districts. LSP subscale scores varied relatively little across the other districts (Table 36).

Table 36. Average LSP Total and Subscale Scores by District

District	Total Mean (n)	Withdrawal Mean (n)	Self-Care Mean (n)	Compliance Mean (n)	Anti-Social Mean (n)
Cape	11.6 (31)	3.2 (33)	3.8 (40)	2.6 (44)	3.0 (36)
TS&NPA	11.1 (34)	3.7 (38)	2.6 (38)	2.3 (38)	2.8 (34)
Innisfail	12.5 (28)	4.1 (33)	4.0 (34)	2.5 (37)	2.4 (34)
Cairns	19.1 (50)	5.6 (69)	5.6 (66)	3.8 (63)	4.7 (59)

g. Analysis of HoNOS and LSP according to Diagnosis

HoNOS in the Inpatient and Community Setting

The grouping of data into three diagnostic categories, namely alcohol and drug-associated disorders, psychotic disorders and affective disorders, is described in Chapter 5 (Section i).

As also explained in Chapter 5, only 35 of the 140 inpatient occasions had diagnosis information included. Although diagnosis-related scores across the three main classifications cannot be explored, the average scores for 26 inpatient collection occasions with consumers

with schizophrenia are shown in Table 37. The potential bias in these scores should be recognised, as these cases may selectively reflect illnesses with long established chronicity.

Table 37. Average HoNOS Total and Subscale Scores for Inpatient Occasions involving a diagnosis of Schizophrenia

Total HoNOS Mean (n)	Behaviour Mean (n)	Impairment Mean (n)	Symptoms Mean (n)	Social Mean (n)
20.3 (24)	4.8 (25)	2.0 (26)	5.2 (25)	8.1 (26)

Different patterns were seen across diagnostic groups in the HoNOS and LSP total and subscale scores in the community setting (Table 38).

Table 38. Average HoNOS Total and Subscale Scores collected in the Community by Diagnostic Group

Diagnosis Group	Total HoNOS Mean (n)	Behaviour Mean (n)	Impairment Mean (n)	Symptom Mean (n)	Social Mean (n)
Alcohol Drug	9.6 (26)	2.7 (26)	0.8 (26)	1.4 (26)	4.7 (26)
Psychotic	12.8 (129)	2.6 (132)	1.9 (135)	3.2 (131)	5.0 (132)
Affective	10.4 (36)	1.8 (37)	1.8 (37)	3.1 (37)	3.9 (36)

Comparison of average HoNOS scores in inpatient and community settings for occasions with a diagnosis of schizophrenia revealed greater severity across all subscales in inpatient collection occasions. Insufficient data were available from ‘end of episode’ inpatient collection occasions to enable comparison with data collected on admission or in the community.

Occasions in the community involving a consumer with a psychotic disorder scored, on average, well above the other categories on the total HoNOS, while the other two categories (‘Alcohol & Drug’, and ‘Affective’) had similar average total scores (Table 38). The subscale scores for psychotic disorders were also consistently high. While occasions with alcohol and drug disorders were similarly high on the behaviour and social subscales, this consumer groups’ scores were lower on the impairment and symptom subscales. In contrast, occasions with people with affective disorders scored comparatively low on behaviour and social problems, but higher on impairment and symptom subscales.

LSP scores showed a different pattern across diagnostic groups (Table 39). Occasions with consumers with psychotic disorders were highest in all categories. The consumer group with alcohol or drug disorders scored markedly higher than the affective disorder group on the LSP. The latter group scored consistently lower on LSP subscales than the other two.

Table 39. Average LSP Scores in the Community stratified by Diagnostic Group

Diagnosis Group	Total Mean (n)	Withdrawal Mean (n)	Self-Care Mean (n)	Compliance Mean (n)	Anti-Social Mean (n)
Alcohol & Drug	13.2 (16)	3.5 (18)	4.5 (22)	2.9 (24)	3.4 (19)
Psychotic	16.1 (103)	4.8 (120)	4.5 (124)	3.4 (130)	3.7 (111)
Affective	8.5 (26)	3.0 (31)	2.6 (29)	1.3 (31)	2.0 (30)

h. Age-related Differences Linked to the Presence of Informants

Section c and d of this chapter identified age-related trends in HoNOS and LSP scores that were consistent with patterns observed in hospitalisation data of Indigenous consumers (presented in Section b) over the same time period and geographic location. Because of the large difference observed in average scores reported with and without informants (presented in Chapter 8), this section examines whether the consistency in patterns is associated with the application of Principle One.

Table 40 summarises the findings of the hospitalisation data of higher admission and length of stay among consumers under age 30 compared to those aged 30 and over. It also presents average HoNOS and LSP ratings among occasions stratified by age where family/carer and/or a local practitioner were involved in the assessment.

Table 40. Age-stratified admission rates and average length of stay to the Mental Health Unit, Cairns Base Hospital, presented with average HoNOS and LSP Scores in the presence and absence of family/carer and/or local practitioner informants.

Age Group (years)	Hospitalisation Rate per 10 ⁵ *		ALOS* 04/05	Mean HoNOS no informants/ with informants Setting		Mean LSP Informants? Yes / No
	6 year average, 1999-2005	04/05 only		Community	Inpatient	
15-29	116.8	108	18.2	10.1/16.1 [^]	16.0 / 19.8	13.5 / 19.8 ^{^^}
≥30	61.1	77	12.0	10.1/13.2	18.5 / 18.3	12.1 / 12.5

[^], difference in HoNOS scores between age groups with informants, p=0.05

^{^^}, Difference in LSP scores between age groups with informants, p = 0.006

* (data from Haswell et al., 2006)

Table 40 shows that statistically significant age-related differences in community HoNOS (16.1 in <30 age group versus 13.2 in the 30 years and over age group) and LSP (19.8 versus 12.5, respectively) ratings were observed only where informants were included in the assessment process. In the absence of informants, no significant difference was observed in average community HoNOS (10.1 versus 10.1) and LSP (13.5 versus 12.1) scores of younger versus older Indigenous consumers, respectively. This is despite the fact that younger Indigenous people experienced a markedly higher hospitalisation rate (108 versus

77 per 10⁵ and average length of stay (18.2 days versus 12.0 days) than older Indigenous consumers.

These same patterns could be seen within the diagnostic group, ICD10 F20 to F29 (schizophrenia, schizotypal and delusional disorders) (Table 41). As explained in Section b, this is the diagnostic group of Indigenous consumers under age 30 who experienced major increases in length of hospital stay and occupied bed days between 2002/03 and 2004/05. Table 41 shows that the younger group experienced much greater hospitalisation rates, lengths of stay and occupied bed days than the older group. Age-related differences in average HoNOS (in community) and LSP scores were only observed in the presence of family/carer and/or local practitioner informants and were absent in occasions without these informants.

Table 41. Age-stratified admission rates, occupied bed days and average length of stay to the Mental Health Unit, Cairns Base Hospital of Consumers admitted with a diagnosis of ICD10 F20 to F29 (schizophrenia, schizotypal and delusional disorders), presented with average Community HoNOS and LSP Scores in the presence and absence of family/carer and/or local practitioner informants. All data are from 2004/2005.

Age Group	Hospitalisation Rate per 10 ⁵ *	Occupied Bed Days*	ALOS*	Community HoNOS Informants?		LSP Informants?	
				No	Yes	No	Yes
<30	79.1	1710	23.8	11.7	16.2 [^]	14.5	19.7 [^]
≥30	33.9	623	14.2	11.0	11.1	14.1	14.8

[^], difference in HoNOS scores between age groups with informants, p=0.05

^{^^}, Difference in LSP scores between age groups with informants, p = 0.006

* (data from Haswell et al., 2006)

i. Variation in some Items of HoNOS over Time

As discussed above, the average length of stay and total occupied bed days in the Mental Health Unit of Cairns Base Hospital increased dramatically among Indigenous consumers under age 30 between 2002/03 and 2004/2005 (see Figure 16; Haswell et al., 2006), suggesting worsening mental health within this group. HoNOS and LSP scores on individual items were therefore examined across three monthly intervals in the 04/05 time period to determine whether these data also indicated worsening of problems. The specificity of trends over time was tested by comparison with changes among occasions with older consumers, whose length of stay in hospital showed smaller rises over the same time period.

Comparing LSP total and subscale scores across three monthly intervals for all ages, no significant differences were seen for the total scores or for the self-care, compliance or antisocial subscales. There was variation in the withdrawal subscale associated with

changes in both the social contact and warmth items (2 and 3), however, the trends were not linear (i.e. high in the first and last 3 months and lower in the middle 2 periods). Furthermore, no differences between the age groups was seen.

In contrast a number of trends towards increasing severity were observed in the HoNOS data collected both in the inpatient and community setting. Average scores for individual items 1, 4, 10, 11 and 12 differed through time, with items 4, 10, 11 and 12 showing consistent upward trends. Trends in these four items are shown in Figure 21.

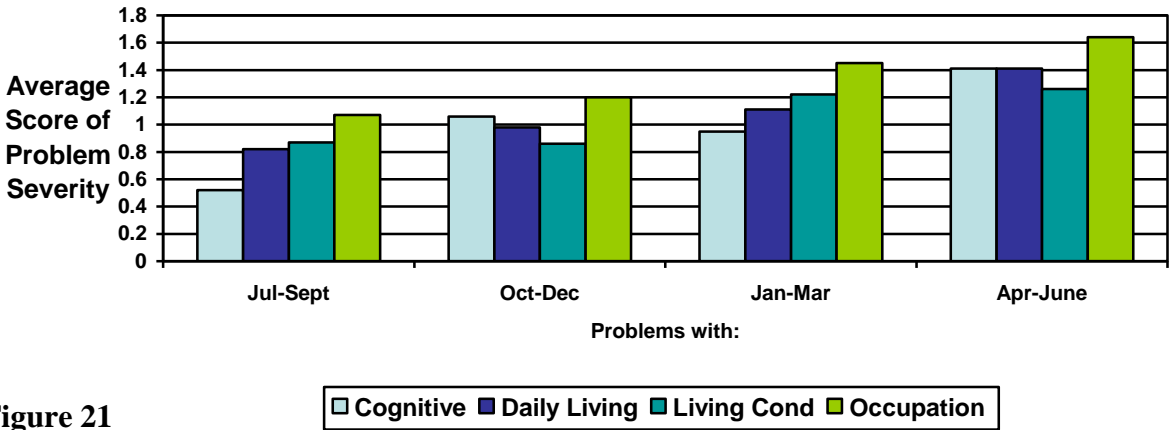


Figure 21

The following graphs (Figures 22 to 25) compare the trends in these four items across time within the two broad age groups. The upward trends in item 4 (cognitive problems), item 11 (living conditions) and item 12 (occupation and activities) were clearly observed among the younger consumers (χ^2 for linear trend, $p < 0.05$). Trends in item 10 (activities of daily living) were not statistically significant. In contrast, no consistent upward trends through time were observed in the older age group.

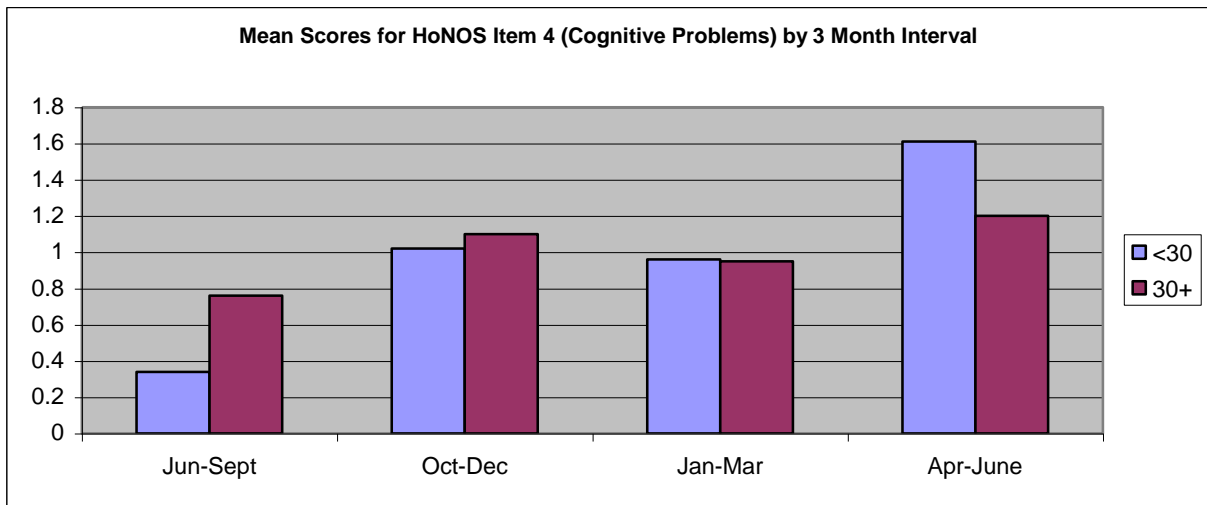


Figure 22

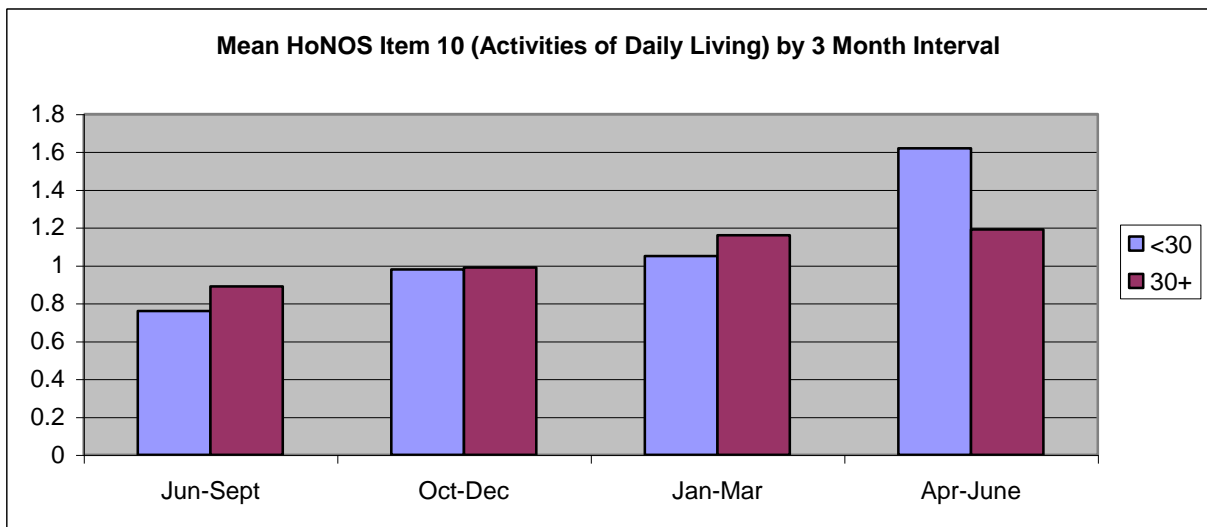


Figure 23

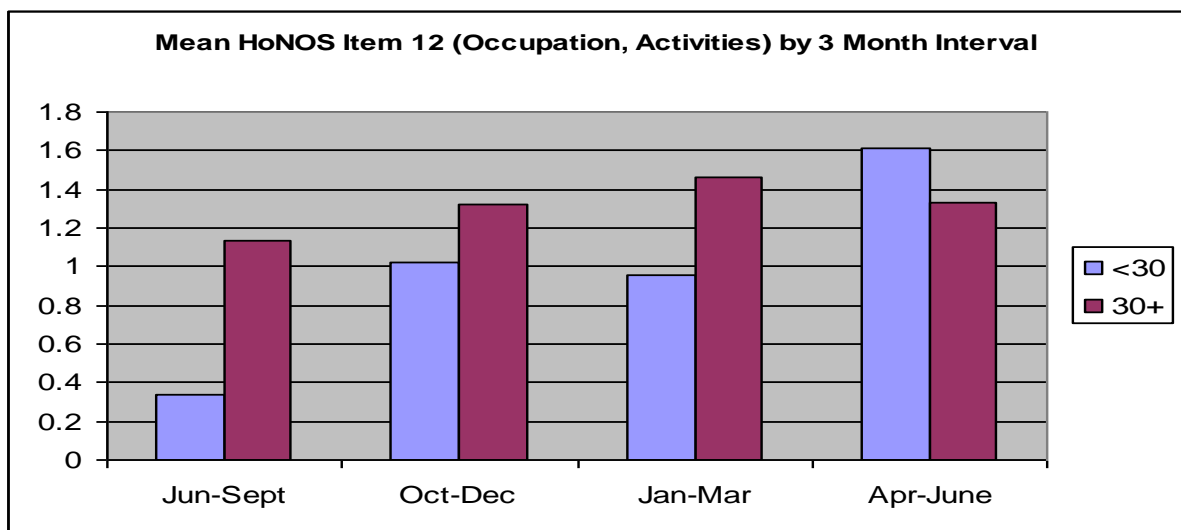


Figure 24

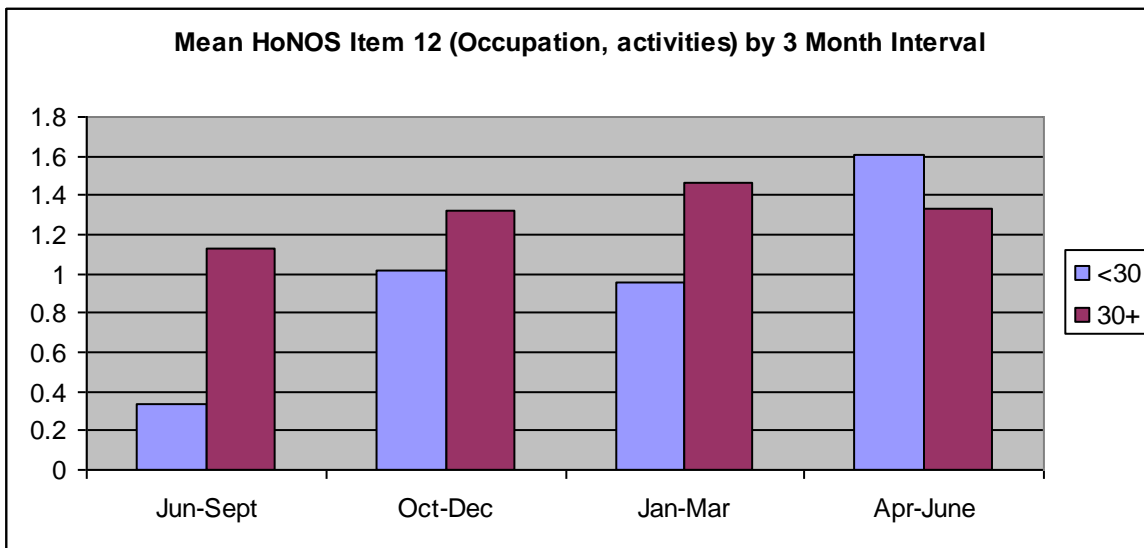


Figure 25

The upward pattern observed for cognitive problem severity (item 4) over time was particularly evident among younger consumers; and significance of the change can be best demonstrated through frequency graphs. Figures 26 and 27 (below) show the drop in frequency of consumers having 'no cognitive problems' recorded (from nearly 80% to 20%) and the increasing frequency of moderate to severe cognitive problems over the year. Confirming the reliability of this finding is the very similar pattern of change observed in both the hospital and community – these settings are virtually independent with regard to the clinicians who perform ratings; thus rating issues are unlikely to have acted as a confound.

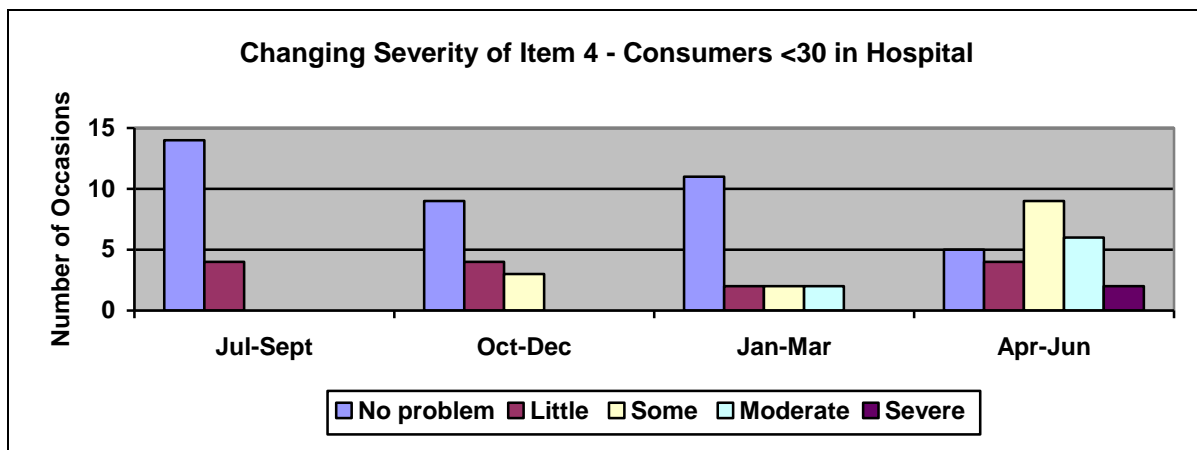


Figure 26

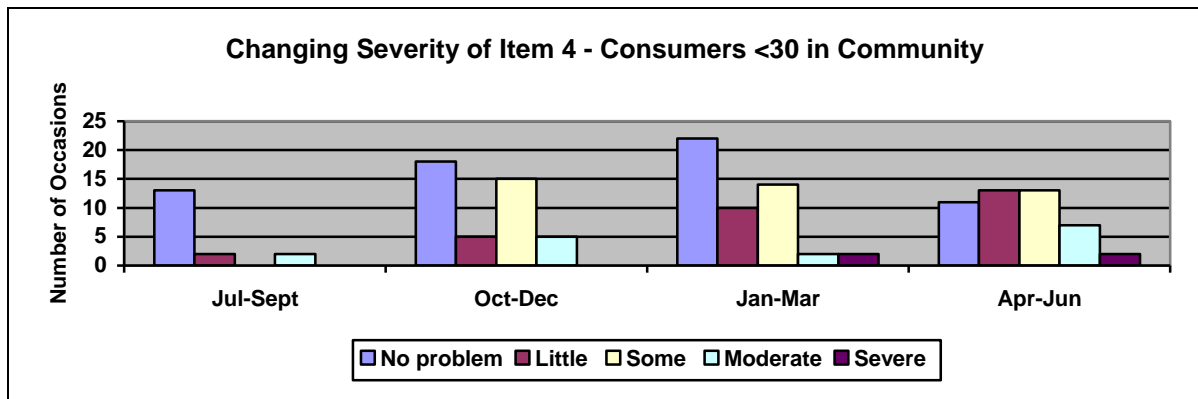


Figure 27

Although the sample sizes for these analyses were small, scores became significantly higher over time (χ^2 for linear trend, $p < 0.05$). The suggested deterioration in cognitive function detected among young Indigenous consumers in the two settings, combined with rising hospitalisation, warrants further investigation.

10

Exploration of Validity of the Mental Health Outcomes Tools in this Setting

a. Introduction

Validity is a concept used and defined in many complex and different ways. In Outcomes research it is generally taken to mean the degree to which an indicator measures the desired underlying concepts (Jenkinson, 1994). This project has aimed to explore a range of aspects of validity, both quantitatively (concurrent validity, predictive validity) as well as by examining the content validity of assessment items in relation to qualitative descriptors that Indigenous consumers and carers themselves use to assess the consumers' mental health status. This chapter addresses the following research questions posed in Chapter 1:

- How valid are the assessments in relation to the standard definitions of mental health status of people with chronic and recurring mental illness?
- Do these tools measure aspects of mental health that are important to indigenous consumers and carers – are they socially and culturally valid as well as medically valid measurements of mental health?
- Can a set of consumer-rated mental health Outcome measures be developed which captures the perspectives of the consumer and is able to be implemented alongside the clinician rated measures?
- Can the results of the Health of the Nation Outcome Scales (HoNOS) and Life Skills Profile (LSP) and consumer-rated measures be effectively communicated by the clinician to consumers and carers to enhance each parties' understanding of the illness and its management?

This chapter first examines the question of validity of HoNOS and LSP data in relation to the application of the Principles, especially Principle One (section b), reviewing and consolidating the findings presented in Chapters 7 through 9. It then presents qualitative data exploring the

content validity of the scales in relation to the indicators of wellness and illness that Indigenous consumers' and carers' use themselves.

b. Validity of assessments with and without application of Principle One

One important psychometric property of assessment scales, such as HoNOS and LSP, is internal validity, which is usually assessed by Chronbach's alpha statistic. As presented in Chapter 7, relationships between items comprising HoNOS and LSP scores collected with Indigenous consumers in the Cairns Network of Far North Queensland mirrored patterns observed in broader mainstream data sets. This suggests there is no unique inter-relationship between the various items being scored for Indigenous consumers compared to non-Indigenous consumers. For example, the scores for items that comprise a subscale measure of social aspects of mental health (accommodation, relationships, activities of daily living and occupation and leisure activities) interrelate amongst Indigenous consumers in similar ways to non-Indigenous consumers.

Consultations and existing documents in Indigenous mental health assessment support approaches that engage family/carers and Indigenous Mental Health workers, to bridge the gap between consumer and non-Indigenous clinician and between clinical consultations and everyday life in the community. Adherence to this principle is fundamental for compliance with the Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research (NHMRC 2003) to acknowledge cultural difference and individual and collective identity in all aspects of working with Indigenous people. Principle One developed in this project through the First Wuchopperen Workshop aimed to ensure that clinicians working with Indigenous consumers would capture the strength of a partnered approach to assessment and Outcomes ratings as proposed by Gulash et al. (1999).

Furthermore, major differences in ratings for most HoNOS and LSP items in occasions completed with versus without a family member/carer and/or a local practitioner, as detailed in Chapter 8. Notably ratings completed without these informants were markedly lower than ratings that did include their information. Differences associated with the absence or presence of these informants were greater for consumers under 30 years of age compared to older consumers and for collection occasions in the community, compared to those taking place in the in-patient hospital setting.

These findings raise questions of fundamental importance to the evaluation of reliability and validity of scores and the guiding Principles, namely:

- Does inclusion of informants systematically overestimate scores?
- Does their absence lead to systematic underestimation of scores?
- Does the difference reflect differential availability of informants in situations linked to the severity of consumers' problems?

A challenge for this project was to ascertain the most plausible answer to the questions above. There are several possible explanations for the higher scores (representing greater severity) associated with the presence of informants, including:

1. greater communication of the experience and meaning of the consumers' problems by informants led to greater recognition of severity and inclusion in the ratings with the inference that those made without informants are underestimated (inclusion would enhance validity);
2. a tendency for consumers to under-report their own mental health issues to clinicians due to communication gaps or other issues with the inference that those made without informants are underestimated (inclusion would enhance validity);
3. that families would exaggerate severity of problems in order to have the consumer admitted to hospital or otherwise influence services (inclusion would reduce validity).
4. an increased likelihood that carers would accompany consumers with more severe illness or lack of interest or ability to engage with the clinician with the inference that scores are accurately capturing lower severity of problems among those occasions that did not include informants (inclusion would reflect rather than influence validity);
5. the inclusion of family hardship (which is not meant to be included) in ratings made where the clinician has received family input with the inference that scores made with informants are over-estimating the severity of problems experienced by the consumer (inclusion would reduce validity).

The first two explanations, which indicate that the use of these outcome measures with Indigenous consumers in the absence of informants systematically and substantially underestimate the severity of mental health problems, are consistent with the understandings that led to the collaborative identification of Principle One. This principle highlights the importance of including family members and a local practitioner as the most important

condition for making ratings with Indigenous consumers. These explanations are also consistent with the experience and understandings gained by psychiatrists whose careers have focussed on the mental health of Indigenous people and who are well aware of the tendency for Indigenous consumers to downplay their problems and 'put on a brave face' (Nagel and Hunter, personal communication 2006). Indigenous members of the Steering Committee have emphasised communication problems between consumers and non-Indigenous clinicians. The crucial need for informants when making any psychiatric assessments due to vast gaps in communication effectiveness across Indigenous consumers and non-Indigenous clinicians was first brought to the attention of Queensland mental health clinicians by Gulash et al. (1999).

Further support for the suggestion of underrating without informants as being the most important explanation of differences in scores was found through analysis of the 2004/2005 database of HoNOS and LSP scores, additional questions added for this project of Indigenous consumers across a range of comparisons and consistency with other mental health data. These arguments are detailed below.

Argument 1. Data collected in this project and examined in Chapter 6 have provided evidence from clinicians' perspective of benefits to their rating of involving families/carers and local health practitioners together with consumers in the assessment process. Cross-tabulations demonstrated statistically significant positive links between involvement and levels of engagement with consumer, carer and local practitioner, and clinicians' views of the validity and ease of the assessment.

Argument 2. Comparison with a 'gold standard' study: A randomised control trial involving Indigenous consumers in Northern Territory community settings that used strictly controlled approaches to outcomes assessment using the principles from this project (including full adherence to Principle 1 with both local health practitioner and family/carer informants) and conducted by a highly informed and experienced clinician, revealed an average HoNOS score of 23.6 (Nagel, unpublished findings). This compared to average scores of 12.1 overall, 10.1 without informants and 14.0 with family or local practitioner only and 19.0 with both types in the Far North Queensland setting. Although some variation in the patterns and severity of mental health problems across the two locations would be expected, it is considered unlikely that Indigenous consumers in the NT experience over twice the severity of problems compared to those in FNQ. Thus the extreme difference is likely to reflect underestimation of severity in the latter settings that are most marked without informants in comparison with 'gold standard' rating conditions in the NT.

Argument 3. Greater severity of problems among younger consumers (clearly evident in hospitalisation data) was only evident in outcomes occasions that included informants: As explained in the Chapter 9, a number of large differences have been observed in other indicators of mental health status (hospitalisation rates per population, average lengths of stay, suicide rates) between younger (<30) and older (30 years and over) Indigenous consumers. However, age-related differences were only seen in mental health outcome scores where informants were included in the assessment process (refer to Tables 40 and 41). Without informants, the HoNOS and LSP scores between younger and older consumers did not differ. This supports the explanation that additional informants systematically assisted in identifying the actual higher severity of mental health problems among younger, compared to older consumers.

The markedly long average length of stay that typified young (<30 years) Indigenous psychiatric admissions to Cairns Base Hospital in 2004/05 argues against the suggestion of explanation 3, i.e. that family members/carers exaggerate the severity of problems to achieve admission to hospital. Given the very high demand on beds in the Psychiatric Unit in 2004/2005, every day there was pressure to discharge patients whose acuity was less severe than others, including patients in crisis awaiting admission. Thus it is unlikely that scores made by clinicians that included informants were systematically exaggerated.

Many other mental health indicators show similar age-related patterns. It is also notable that the majority of Indigenous male suicides (age-stratified data on Indigenous female suicides has been suppressed due to small numbers in some groups) in Queensland have involved men under the age of 35 years, which is in contrast to the dual age-patterns observed for non-Indigenous men (de Leo et al., 2002; 2005). Examination of Far North Queensland suicide data between 1999 and 2004 has confirmed the high risk of Indigenous suicides at younger ages of males and probably females (Haswell et al., work in progress). Statistics on injuries reaching medical attention and incarcerations have revealed very high rates among young Indigenous men and a close association between injuries and with alcohol consumption (Gladman et al., 1997; Shannon et al., 2001; Krieg, 2006).

It is important to note that in this analysis, it is not being suggested that older Indigenous consumers do not experience extreme severity of illness – other influences on their hospitalisation rates and outcomes assessments are suspected, such as imprisonment and early mortality. However, there may be also cohort effects, such as has been suggested for the striking emergence of suicides among generations whose childhood was profoundly affected by the introduction and subsequent impact of alcohol (Hunter, Reser, Baird & Reser

1999). Differential use of illicit drugs among younger versus older consumers has also been suggested as a possible reason for the markedly higher hospitalisation rates and longer lengths of stay and worsening severity of cognitive problems and social circumstances reported through HoNOS within 2004/05. These severity patterns are also consistent with general trends of psychotic illnesses, where episodes in younger people are frequently of greater acuity as recognition of early signs of illness, coping skills and health seeking behaviour have not yet emerged.

Argument 4. Least difference where clinician has direct observation – pattern of differences consistent with items specified in original Principle Four. As shown in Chapter 8, scores most likely to systematically involve clinicians' direct observation of the consumers' greatest severity of problems (i.e. at hospital admission) were least affected by informant inclusion. It is worth pointing out (refer to Figure 15) the three items for which different average scores recorded between inpatient occasions in with and without informants approached statistical significance ($p \leq 0.10$), namely Item 2 (non-accidental self-injury, lower with informants) and Item 6 (hallucinations) and Item 8 (Other problems) (higher with informants). These are items which were highlighted in the original Principle Four as not to be rated if consultations with informants revealed that the behaviours, beliefs and experiences were consistent with socially and culturally accepted practices. Thus this is consistent with the need to achieve greater adherence with Principle One, most particularly when applying Principle Four.

Argument 5. Difference associated with informants observed even where consumer was considered well enough to be engaged in the assessment and within diagnostic groups: Analysis did not reveal evidence supporting the influence of the third explanation mentioned above that the higher ratings associated with informants are simply reflective of their likelihood of being more available in more severe circumstances (hence the higher ratings). In fact, the greatest differences in scores between the two situations (with and without informants) were found in occasions where the clinician reported that the consumer was partly to fully interested and engaged in the assessment process (see Tables 24 and 25 in Chapter 8). In contrast, smaller, rather than larger, differences were associated with informants where the consumer was not interested or engaged, in hospital, or not well enough to be involved in the assessment. Differences associated with informants were also found within diagnostic groups that had sufficient numbers of test (psychotic disorders and unrecorded diagnosis); hence trends were not simply reflecting more frequent involvement of informants in more severe types of illnesses (see Table 29).

Argument 6. No evidence that family/carer informants influenced scores more than local practitioner informants, suggesting lack of inappropriate inclusion of family burden. The fourth explanation suggests that clinicians are inaccurately influenced by informants to over-rate the severity of the consumer's problems through the inclusion of family distress, which is meant to be measured in other outcomes measures, but not in the HoNOS and LSP. This explanation is supported by research with non-Indigenous consumers comparing ratings made by clinicians versus family members, whereby family members asked to make their own outcomes ratings for the consumer are thought to reflect their own distress, parental psychopathology or 'family burden' in the scores (Parker, 1993; Trauer and Callaly 2002; Davidson 2005).

It is worth noting that the randomised control trial in the Northern Territory mentioned above also provided evidence of very high Kessler 10 scores among the family and carers of consumers (Nagel, personal communication). The extent to which this is associated with undiagnosed mental disorders among family, the overwhelming burden of responsibility for the consumer especially with such extreme severity of problems (HoNOS scores averaging over 20) or reflecting background levels of overwhelming stress associated with living in a remote Indigenous community needs to be determined. Whatever the reasons, however, this finding further indicates the degree to which serious mental health issues are currently underestimated and not being addressed.

However there are notable differences in the methodology of these mainstream studies and that of this study whereby informants provide information to the clinician but did not independently rate the consumer. There is also evidence that clinicians in this setting took care to distinguish independent distress of the family members and that associated with the severity of problems experienced by the consumer. Tables 23, 27 and 28 show that the elevation in scores associated with the inclusion of a family member/carer was no greater than those associated with the inclusion of local practitioners. Furthermore the patterns of elevation across sub-scale scores by informant type were reflective of expected knowledge – i.e. family members appeared to highlight severity of behaviour and symptoms while local practitioners' involvement was linked to higher ratings on the disability and social subscales.

Thus even against a background of probably severe family distress, no evidence emerged to indicate that aspects of family burden that are independent of the consumers' mental health problems led in higher HoNOS or LSP scores. Furthermore the very high scores that emerged in the small number of occasions where Principle One was fully adhered to (both family and local practitioner, Tables 23, 27 and 28) in this study and that of Nagel et al (2005)

as well as the different patterns of sub-scale score elevation between the two types of informants, suggests that both types of informants are required to fully understand the level of severity across all HoNOS items.

To summarise these arguments, the findings suggest that carers/ family members and local practitioners provide the clinician with knowledge of the extent and nature of problems experienced by the consumer which they may be unable to collect without such informants. This incomplete understanding appears to be associated with substantial underrating of severity on both HoNOS and LSP. Although other explanations may theoretically contribute to the observed differences, this study did not reveal any evidence of these occurring in a systematic fashion.

c. Content Validity - Are the tools socially and culturally meaningful?

A fundamental aspect of validity that is of particular importance when a scale developed in one social and cultural paradigm is used with people who live in another socio-cultural world, is known as 'content' or 'face validity'. Content Validity refers to the meaning of the items being measured in relation to what is important and of relevance to the consumers, carers and communities with whom it is being applied. It is often easy for those belonging to the dominant culture to underestimate the importance of other worldviews – both in the way assessments are delivered, and in the way they are responded to across cultures. It is a particular challenge to all involved in Outcomes assessment to deeply consider the influence that working across cultures has on their ability to question the tools they use, and on the significance and meaning of items assessed for other cultural groups.

These kinds of understandings are also important as mental health care changes focus on helping people move toward greater control of their illness, a sense of recovery and reclamation of “the journey toward a new and valued sense of identity, role and purpose outside the parameters of mental illness...” (Queensland Health, 2005). Many efforts are being made within the mental health system to support the consumer to gain a more empowered role in the therapeutic process (Schizophrenia Fellowship NSW Inc., 2005).

As these concepts of recovery-orientation become more relevant to mental health care (Queensland Health, 2005), it is increasingly necessary for clinicians to value and support the perspectives and roles of both consumers and the people who surround and support consumers in daily life. The fundamental process of supporting recovery of consumers is to help them work from the strengths that they have and build hope for a different future, in addition to 'fixing' the parts that may be 'broken'. Thus, it is important to note the overall

social and cultural meaning (and limitations) of HoNOS and LSP in the contemporary mental health paradigm.

This more complex task was addressed in multiple ways. Initially, during the first Wuchopperen workshop, the assessment items on HoNOS and LSP were discussed in detail, and potentially problematic items were identified. A range of problems were identified, as summarised by the following comments from participants:

“Indigenous people don’t particularly value that quantity [of some of the items on the HoNOS and LSP] within their perspectives”;

“Non-indigenous people are not often equipped to make measurements on that item [referring to items on HoNOS] because of the complexity of meaning it has for Indigenous people”;

“People are often influenced by what they see everyday – where some things are common, even when they are severe, there is a tendency for people to underrate... where severity is common.”

While the Wuchopperen conference was well received and it gave the project a clear direction, it was vital for the research to continue to find ways to hear Indigenous voices. This occurred in four ways:

- Exploring issues through in-depth interviews with Indigenous consumers and carers;
- Examining reports and arguments of Indigenous Australian academics and researchers (Gulash et al., 1999; Westerman, 2004), and comparing approaches of an active group in another Indigenous population (New Zealand) who are facing similar issues (Levy & Kingi, 2003; Levy et al., 2005a; Levy et al., 2005b).
- Attempting to provide a comfortable space for Indigenous colleagues to voice their views and guide the conduct and interpretations from the project (see Appendices 2 and 9);
- Continued reflection by the non-Indigenous academics and researchers involved in this project about their own cultural biases in light of the learnings from the above activities.

The next section provides data collected from consumer and carer interviews.

d. Consumer and Carer Interviews

Fourteen consumer and fifteen carer interviews were conducted in remote Cape York communities. As part of these interviews, a relatively simple set of questions were designed to elicit information from consumers and carers about the traits they recognise in themselves or in the consumer they care for, in relation to level of wellness. These questions were:

- What are you like when you are... well, getting ill, definitely crook [sick], getting better? (consumers question)
- What is the person you care for like when he or she is ... well, getting ill, definitely crook, getting better? (carers question)

As can be seen in Table 42, when respondents were describing the consumers' wellness, they highlighted the positive emotions, their social interactions, their activities and, to a small extent, their self care.

Signs of emerging illness or of being ill mentioned by the interviewees focused on feelings of anger and aggression, and while sadness and depressed feelings were mentioned often, mostly this occurred after prompting from the interviewer. A number of mental symptoms were mentioned, but these also required prompting at times. According to interviewees, social interactions deteriorate for some, but not all, consumers, and this deterioration may be indicated by withdrawal or by aggressiveness. Many references were made to the consumers' withdrawal from activities they normally enjoy, and to actions that further enhance consumers' isolation from others. Interestingly, in a number of cases, interviewees indicated little difference in drinking and substance use behaviour across the time points, although some indicated increased use of alcohol and substances during illness. Changes in self-care activities were spontaneously mentioned by a small number of interviewees, but were more frequently identified after prompting.

Responses made to describe consumers 'getting better' included a return to improved feelings and mood and a reduction or disappearance of symptoms [for some but not all consumers], as well as increasing social interactions and enjoyment in being with others, and a return to usual activities. Interviewees offered little description of increased or decreased self-care activities, even when prompted.

In general it can be argued that these descriptions of wellness and illness around the mental health status of the consumers and carers do not differ markedly from those that HoNOS and LSP aim to measure. Using both HoNOS and LSP enables the clinician capture data relating

to both the consumer's presentation and their functioning, and responses made by the interview sample describe both these aspects. Descriptions of the illness phase provided by consumers and carers through this relatively superficial inquiry appeared consistent with the perceptions of mental health clinicians and dimensions measured by the HoNOS and LSP scales.

The following are responses made by consumers and carers about “What are you [the person you care for] like in three situations – well, getting ill and getting better. Numbers in brackets indicate the number of respondents who mentioned the item without prompting. Numbers with letter P indicate those who affirmed the item was relevant when prompted.

When I'm well	When I'm getting ill or definitely ill	When I'm getting better
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How I'm Feeling

<p>Happy inside, feeling good, good mood (15)*</p> <p>Confident (1)</p> <p>Energetic, motivated, alive, active (6)</p> <p>Happy go lucky, not worrying (4)</p> <p>Relaxed and calm (4)</p>	<p>Depressed, sad (2, 16P)</p> <p>Angry and frustrated (9, 2P)</p> <p>Aggressive (8, 7P)</p> <p>Sick, dirty on inside (2)</p> <p>Slack, lazy, unmotivated, drowsy, sleepy (7, 2P)</p> <p>Overactive, agitated (2, 7P)</p> <p>Stressed, need to relax (4)</p> <p>Upset over little things (3)</p> <p>Needing peace and quiet (1)</p>	<p>Happy, feeling good/better inside (5)</p> <p>Better mood (2)</p> <p>Start to feel alive, liven up, more energy (4)</p> <p>Relaxed (1)</p>
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What's Going On in My Head

<p>Thinking straight (1P)</p> <p>Suicidal thoughts (3P)</p> <p>Hearing voices (1P)</p>	<p>Lose control (1P)</p> <p>Not thinking straight (7P)</p> <p>Having strange thoughts</p> <p>Thinking about killing myself (3, 7P)</p> <p>Hearing voices, fighting voices (7, 9P)</p> <p>Voices command me to hurt/kill myself (2P)</p> <p>Confused, cognitive problems (2,6P)</p> <p>Memory loss (2P)</p> <p>Catastrophic thinking (1, 1P)</p> <p>Thinking of bad things, like I'm going to die (3)</p> <p>Seeing spirits, cultural (1, 2P)</p> <p>Looking and Seeing things in sky (2P)</p> <p>Get paranoid about everything (6)</p>	<p>Thinking straight (1P)</p> <p>Suicide thoughts (3P)</p> <p>Hear voices (1P)</p>
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Being with Other People

<p>Being sociable, friendly, get on w/ people (4)</p> <p>Visiting, spending time with family (5)</p> <p>Sharing smokes (1)</p>	<p>Want more attention, be cared for (2)</p> <p>Less social (1)</p> <p>Complaining, cranky, argue, pick fights (6)</p> <p>Walk away, stay alone, withdraw (5, 2P)</p> <p>Angry, short tempered, getting wild (2)</p> <p>Avoiding/stressing at children, partner (5)</p> <p>Swearing at family, wanting to fight them (2)</p>	<p>Interact (1), More friendly, socialise (2)</p> <p>Talking peacefully, stop looking for fight (2)</p> <p>Less argumentative, avoid arguments (2)</p> <p>Visit/ Spend time with family, talk more (7)</p> <p>Enjoy sitting down, yarning, laughing (2)</p> <p>Make jokes (2)</p> <p>Like having the kids around, spending time (3)</p>
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What I'm Saying

Making jokes with friends (2)	Saying strange things (2, 2P), shrieking (1) Stop talking, won't answer questions (2) Talking to myself (1) Not making jokes (2)	Talking peacefully (2) Making jokes with friends (2)
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What I'm Doing

Walking around, getting out and about (5) Laughing, smiling (4) Playing sports, swimming, lifting (3) Art, music (2) Fishing, hunting (5) Feel like bush tucker (1) Helping in the house and yard (4) Drinking weekly (2P) Drinking (3, 5P) Smoking (1P) Using yandi [marijuana] (5P) Violent (1)	Won't do nothing, shutting down (1P) Sleeping more (5, 2P) Staying/resting at home more (8, 3P) Staying around community (2) Not walking around (1) Being very quiet (1) Laying down, laying around, can't stand up (5) Cover myself with blankets (1) Walking a lot alone (3, 1P) Throwing things, Banging things (2) Staying Away from Home (4, 8P) Stop doing recreational activities (1, 3P) Stop working (4P) Drinking same (5, 9P) or more (4, 5P) Smoking more (2P) Using yandi [marijuana] same (6P) or heavy (10P) Hurting myself (4, 2P), attempting suicide (1) Being violent (2, 1P), Setting fires (1) Hiding (2)	Get out of bed (1) Walking around, getting out & about (3) Doing sports (1) Art, music (2) TV, video games (2) Go bush, fishing (4) Helping more in the house (1) Goes to CDEP [Community Development Employment Program], working, TAFE [Tertiary and Further Education] (3) Drinking same amount (2, 5P) Drinking less (1) Using yandi [marijuana] sometimes or a lot (6P) Violent (1)
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Taking Care of Myself

Sleeps and eats (1) Dresses well (1) Self-medicating: smoking, drinking, yandi [marijuana] to stay well (2P)	Stop caring for self (1, 2P) Having difficulty coping, need help (2) Don't pay attention to appearance (10P) Stop eating, eat less, don't feel like eating (3, 17P) Losing sleep (1) Go to clinic (4, 2P) Won't go to clinic, won't cooperate (7P) Stop taking medications, refuse needle (1, 4P)	Bathes, toilets (1) Eats a lot (1) Don't want to take meds (1P)
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Table 42

Several considerations emerge from this table that, while not presented as criticisms of the tools themselves, could facilitate improved application of Mental Health Outcomes measured with Indigenous consumers.

1. The lack of positive direction in the HoNOS and current LSP (LSP-16) does not allow the scores to indicate not only an absence of problems, but sources of strength and resilience. Thus a 0 on either scale would represent 'no problem' but is not sensitive to an enhancement of positive impacts of the consumer's mental health. This appears to be particularly important in the recovery phase where a range of positive signs are recognised and may predict the consumers' continued pathway toward wellness or a relapse back into illness. It is acknowledged that the clinician may employ alternative means to focus on positive signs, and that this capacity is built into the consumer-rated mental health inventory (MHI).

It is noteworthy that the positive direction of the LSP ratings was removed by Commonwealth Government during modifications instigated by the Mental Health – Classification and Service Costs (MH-CASC) project and the National Mental Health Strategy. The original authors of the LSP were not consulted about this change, and did not endorse it, but they accepted it subsequently as a *fait accompli*.

2. The continuity of some symptoms (voices and suicidal thoughts) and drinking and substance use behaviours at all phases was identified by some consumers and carers in both wellness and illness phases. Clinicians may need guidance in considering both the absence or presence of such behaviours and the degree of distress caused by them as instructed in the glossary for these items.

3. The need for prompting of some items to elicit non-volunteered but agreed responses related to the HoNOS and LSP items. For example, while only 2 respondents identified depressed and sad feelings of the consumer as an indicator of being "definitely crook [sick]", 16 responded that this was a part of the illness when prompted. In contrast, 9 offered descriptions of anger and frustration and 7 mentioned 'slackness' and sleepiness without the need for prompting which elicited only two further affirmative responses. Thus clinicians may need to be careful not to overlook some aspects of illness which are not immediately recognised by consumers and carers as important dimensions of unwellness.

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Discussion: Key Findings and Findings in Relation to Proposed Project Outcomes

To remind the reader, this study utilised an action research approach and was conducted through an actual health systems improvement process (the Outcomes Initiative), rather than within a controlled research context. As expected, there were missing values in a number of these analyses and possibly a lack of clarity in clinicians understanding of some of the possible choices for response, as described in Chapter 6. It is possible that this may have introduced bias into the data that may have influenced the observed associations. Generally however, the associations presented in this Report were relatively strong, showed high levels of statistical significance and were consistent with expectations of what is known about involvement of informants, engagement and communication between clinicians and consumers.

This chapter presents the original aims of this project (in italics), along with a discussion of relevant findings from the research.

Evaluation of the reliability and repeatability of HoNOS and LSP as Mental Health Outcomes measures among Indigenous consumers, with modifications if necessary

The Steering Group recommended that the research team focus on exploring the validity of HoNOS and LSP, rather than focusing on inter-rater reliability or repeatability.

This research project has provided a range of comprehensive information on the implementation of the modifications over the previous 12 months. Interim reports submitted to Queensland Health (Appendix 8) have included recommendations to assist certain aspects of the implementation. Some of these have been successful (e.g. dramatic reduction in the numbers of occasions where Indigenous status was unspecified) but others have been less so (e.g. proportion of occasions following Principle One (involving additional informants in the assessment process) did not increase over the 12 month period).

The analysis has shown that where neither family nor local practitioners provided additional information, the mean total and subscale scores of both HoNOS and LSP were markedly

lower than in cases where these informants were involved, calling into question issues of validity. Chapter 10 details a range of analyses exploring possible reasons for the difference. These support the explanation that the presence of additional informants was necessary for the clinician to gain full understanding of the severity of problems experienced by the consumer. This explanation is also consistent with the views of highly experienced psychiatrists who have decades of experience working with Indigenous consumers, families and communities, and National Health & Medical Research-endorsed ethical guidelines for research and data collection in Indigenous health.

These results are also consistent with the views of Lambert et al. (2001) who examined the involvement of informants in mainstream situations and stated, *“If these measures are to provide a valid reflection of client functioning and change, clinicians will be required to access a range of information sources. To do otherwise would likely result in assessments that are based either on inadequate or inaccurate information”*. While there is a clear argument that informants may be needed to ensure valid outcomes ratings with all clients, this would be even more important in cross cultural situations. Between the non-Indigenous clinician and the Indigenous consumer, there are enormous differences in culture and worldview, language, mannerisms, lifestyle and power, on top of historical and ongoing legacy of loss and trauma experienced by the consumers’ cultural group. Mental health clinicians need a very high level of skill and understanding to work effectively to support Indigenous consumers across this difference – those that do invariably recognise the importance of listening to and involving informants in all aspects of care. A recent report has highlighted problems in communication and understanding in delivering mental health care in trans-cultural situations where fundamental aspects of cultural safety are not adequately addressed (Johnstone & Kanitsaki 2006).

Although further research is needed to better understand how additional informants influence clinician ratings in collection occasions with both Indigenous and non-Indigenous consumers, this study has made it clear that adherence to Principle One (involvement of family/carer and local health practitioner) is likely to be crucial for valid measurement of Indigenous Mental Health Outcomes.

Assessment of the social and cultural validity of HoNOS and LSP as general measures of mental health Outcome across diagnostic categories and severity of mental illness.

“Aboriginal essence lies at the heart of cultural well-being. It is shaped and expressed in the web of physical, spiritual, political, environmental, economic and ideological inter-relations. Cultural well-being is the outcome of the integrity and harmony of these inter-relations. These inter-relations operate at the individual, family, community and societal levels” (Collins, 1994, cited in Commonwealth Department of Health and Aged Care, 2000a, p.83).

It is important to note that Principle One, Involvement of Family Members, Carers and Local Practitioners, was considered a fundamental component of culturally appropriate care by all of our Indigenous informants and this view is emphasised in many Indigenous health policy documents in Australia and New Zealand. (Swan & Raphael, 1995; Queensland Health, 1996; Commonwealth Department of Health and Aged Care, 2000a, Kingi & Durie, 2000; Ministry of Health, New Zealand, 2002; Social Health Reference Group, National Aboriginal and Torres Strait Islander Health Council and National Mental Health Working Group, 2004; Levy et al., 2005a). Outcomes assessment forms a part of the broader mental health care process. Although the focus of this study was the assessment process, the findings concerning the importance of engagement of consumer, family and local Indigenous health workers are likely to be critical to the success of all aspects of care for most Indigenous consumers. The concept of effective engagement with key people is also a fundamental component of the principles to guide practice in using Outcomes measurements developed by the Maori Monitoring and Review Group of New Zealand’s MH-SMART initiative (Levy et al., 2005a).

In-depth interviews with consumers and carers living in remote Cape York communities revealed six key categories of indicators which this group used to describe “what the consumer is like when s/he is ... ‘well’, ‘getting ill’, ‘definitely crook [sick]’ and ‘getting better’”. These categories were ‘how I’m feeling’, ‘what’s going on in my head’, ‘being with other people’, ‘what I’m saying’, ‘what I’m doing’, and ‘taking care of myself’. In many cases, the responses provided by the consumers and carers reflected items that HoNOS and LSP endeavour to measure. This qualitative analysis supported the argument that the HoNOS and LSP measure aspects of the consumer’s mental health status that are also deemed to be important indicators by the consumers themselves and by their families and carers.

It is not possible to provide a meaningful analysis of change in scores in the inpatient or community setting with provision of treatment due to the small numbers of occasions where consumers were measured more than once. Thus it isn’t impossible to comment on the performance of these scales in measuring outcomes associated with service provision. However, the findings described in the above paragraph across levels of wellness and illness

and the degree of agreement with the items being measured on the scales suggest a useful degree of social and cultural validity in Outcomes measurement.

A better understanding of the strengths and limitations of these two tools in assessment of Mental Health Outcomes for Indigenous consumers and how weaknesses can be minimised through modification of the training process, instructions or tools.

The implementation process, by its design, sought to minimise the limitations of the HoNOS and LSP applied with Indigenous consumers in a number of ways. First and foremost, the partnership between the researchers, the stakeholders attending the Wuchopperen meetings, the Steering Group involving Indigenous and non-Indigenous experts, and the Queensland Health staff involved in implementation of the measures, was a powerful mechanism for working towards improving the assessment process and minimising weaknesses. The creation of the original modifications document (see Appendix 6) and its translation into an extended training process (delivered to all clinicians initially, and later through refresher sessions) raised awareness of relevant issues and provided guidance to clinicians rating Outcomes measures with Indigenous consumers. The modifications document provided guidelines which aimed to reduce variation in the ways that clinicians made ratings, with particular attention paid to potentially problematic issues identified in the Wuchopperen workshops.

The main limitation of the assessment process identified through this research project related to the finding of low adherence to Principle One. Further, there was a demonstrated association between fulfilment of the principle's recommendations and lower Outcomes scores. These findings call into question the social and cultural validity of the data collected when using these measures, and the accuracy of the measures when additional informants are not engaged in the assessment process. The validity of Outcomes measures was explored in relation to patterns in length of stay at the Acute (Inpatient) Mental Health Unit at Cairns Base Hospital.

The HoNOS and LSP scales do not attempt to provide information about the consumers' progress towards recovery, which is increasingly being seen as a process consumers, families and services should be contributing to and working towards (Andresen et al. 2003; 2006; Queensland Health 2005). There is little understanding at present about Australian Indigenous views of recovery, and this needs to be explored further if there is to be an effective consumer-rated measure of recovery that is relevant to Indigenous consumers to enhance the current suite of measures within the Mental Health Outcomes Initiative.

Documentation of the effectiveness of engagement and feedback protocols aimed at enhancing the understanding of Mental Health Outcomes measurements among consumers, carers and clinicians.

This project aim was explored largely through the leadership of the Zonal Outcomes Coordinator and the Indigenous Mental Health Coordinator. Following the success of a request for funding, a pamphlet simplifying the mainstream Outcomes information leaflet was developed and produced for Indigenous consumers. In addition, two Health Worker forums were held, at which Indigenous Mental Health Workers learned more about the Outcomes process and discussed ways in which their role could be enhanced.

The findings from the Health Worker forum, combined with the clinicians' responses to the questions on the Outcomes Information System regarding the degree of engagement achieved with local practitioners, indicate that this workforce is interested, supportive and engaged (when consulted) in the Outcomes assessment process. Similar findings were found regarding family engagement – when family members were involved in Outcomes assessment, their level of engagement was most frequently perceived to be 'mixed' or 'full'.

It was clear from the analyses that some consumers who were 'well enough' were not involved in the Outcomes assessment and family members and local practitioners were often not invited to be involved in the assessment process. Thus, more work is needed to enhance both involvement and engagement of consumers, family members and local practitioners. Outcomes provide a valuable opportunity for consumer and carer involvement in care recovery to be enhanced. It is anticipated that greater awareness of the importance and value of the Outcomes process in the community, among family members and among local practitioners will lead to greater levels of involvement and engagement. This view was supported by the comments of Indigenous Mental Health Workers in the forums and by Indigenous stakeholders in this research project.

A range of attractive and immediate feedback report formats have been developed by the Outcomes Information Team of Queensland Health and made easily available to clinicians wanting to share their assessments with consumers and families. An analysis of the association between these tools, and levels of engagement and involvement, was outside the scope of this research project.

Continued monitoring of clinicians' impressions of undertaking Outcomes with Indigenous consumers, and continued discussion with consumers, carers and local health workers would

be helpful as this consultation adds to the validity, reliability and usefulness of Outcomes measurement.

Collection of an initial set of Mental Health Outcomes data that will begin to provide multiple benefits to mental health service delivery, ideally including:

- *Enhancement of the communication process between clinician, consumer and carers about consumers' progress over time*

Finding the most effective ways to achieve this is a key national objective – while focus has been on systems implementation and improvement, there is now strong focus on achieving the greatest gains in Outcomes from this enhanced level of data collection. Indigenous Mental Health Workers and other Indigenous primary health care workers interested in mental health are well placed to enhance and support the role of the clinician in communicating progress.

- *A reflection of the impact of management and treatment protocols on the consumers' wellbeing and functioning;*

Mental health resources, including perhaps most critically, mental health service providers' time, are precious and it is important to direct resources most wisely for maximum gain. While maximum gain is often shown by Outcomes as a product of fewer, or less lengthy, inpatient admissions, more modest, less traumatic, less expensive and more sustainable improvements through time are likely to be shown through high quality community care. This has been a guiding principle in broad changes to mental health services over the past few decades.

One of the most surprising findings of this study is the increase in severity of some items on HoNOS within the 12 month period among young Indigenous consumers; which is consistent with a marked increase in the length of stay and occupied bed days of this same group in the Mental Health Unit of the Cairns Base Hospital (Haswell et al., 2006). It is hope that these findings will stimulate greater understanding of the collective nature of Indigenous mental health. Community care involving local community health workers and other sectors is most appropriately placed to offer effective responses to the need for community-focussed rather than individually-focussed care. This can support the concept of “at risk communities” rather than focus on “at risk individuals” and orients clinicians to think in a “working from strengths” rather than a deficits approach. These perspectives also support concepts of recovery orientation as is now being promoted by Queensland Health where data is used as a tool to

promote shared responsibility for recovery (Queensland Health, 2005). Involving Indigenous mental health workers in the understanding of, interpretation and use of data, and further developing their role, is integral to promoting recovery for Indigenous consumers.

- *A basis for comparing Outcomes for Indigenous and non-Indigenous consumers;*

While this report has not provided a comparison of Outcomes for Indigenous and non-Indigenous consumers, there is clearly an outline and basis (see Chapter 8) for such a comparison to occur. We would like to emphasise that the most appropriate comparisons to be made at this time would be with non-Indigenous consumers from within the various districts of the Cairns Network where geography, local conditions and access to services are most closely aligned.

However, it is also important to state that in the course of this project, Indigenous views were frequently expressed which questioned the appropriateness and usefulness of comparisons between Indigenous and non-Indigenous consumers without there being specific beneficial purpose in mind. The sensitivity of this issue for Indigenous people should be respected and comparisons that are of useful purpose should be made through mutual, acceptable participation of Indigenous and non-Indigenous people.

Further, broader comparison of these data with non-Indigenous Outcomes across the state needs to be made cautiously, and may be less relevant. Such comparisons are likely to be dominated by trends in the more populous, metropolitan areas of Queensland where both Indigenous and non-Indigenous lives may be very different from those of consumers living in the Cairns network. The data collected in this project are representative only of Aboriginal and Torres Strait Islanders living in Far North Queensland and should not be considered representative of other Indigenous people living elsewhere. Additional data from areas outside the Cairns network would be helpful in gaining a fuller picture of challenges facing Indigenous consumers.

A long term goal for broader understanding of the use and findings from HoNOS and LSP may be to replicate the enhanced training and support of clinicians throughout the state. It would also be advantageous to include at least some of the additional questions on the OIS for consumers who are Indigenous, and preferably for non-Indigenous consumers as well. The analysis framework developed here will be useful for analyses conducted in other networks.

- *Assessment of the impact of efforts to improve mental health service delivery in remote areas.*

Lower Outcomes scores for HoNOS and LSP and fewer hospitalisations and shorter stays in the Mental Health Unit (Haswell et al., 2006) were observed for consumers from Cape York District compared to the other Districts in the Cairns Network. There are many possible reasons why this may have occurred. One of the possibilities is that subtle improvements in community-focussed care (combined with various family and community strengths in each setting), while continuing to face many challenges in its operation, may be contributing to both better outcomes and lower hospitalisation (Hunter et al., 2003; Brownlie et al., 2005). In 2004/05, the care provided in these settings involved a Mental Health clinician based in Weipa, Indigenous Mental Health Workers in some communities, generalist Indigenous Health Workers and nursing staff in all communities, and specialist psychiatrists visiting 3 to 4 times per year. This service model was supported from Cairns by a Remote Area Team Leader.

The analysis of outcomes scores have also been useful in guiding investigation of the increased admissions and lengths of stay in the Mental Health Unit at Cairns Base Hospital of Indigenous consumers under age 30 in 2004/05 (Haswell et al., 2006). Prior to the implementation of the Mental Health Outcomes Initiative, there was no rapid way to systematically examine patterns in the problems that consumers experience. With this system, services have an increased capacity to become more responsive.

Recommendations and a proposal for the development and validation of consumer rated outcome measures

The Mental Health Inventory (MHI) has been implemented on a small scale with some Indigenous consumers in the Cairns Network. However, its problems are many and, as discussed in the Health Worker Forums, include excessive length, lack of clarity, some irrelevant questions, and failure to capture a range of relevant issues. Further development or improvement of these existing tools may be helpful, however, neither HoNOS, nor LSP nor the MHI, have a clear focus on recovery.

Given the expanding literature on empowerment and recovery in mental health (Schizophrenia Fellowship NSW, 2005) and recent documents by Queensland Health (2005) and the National Mental Health Strategy outlining the rationale and implementation of recovery-orientation in existing services, there is an opportunity for the Outcomes Information System to adapt a capacity to monitor and support such changes. This may be long and

relatively slow process, as it requires shifts in the culture of mental health services and in the expectations and involvement of consumers and their families, carers and communities, as well as in society in general. Though the recovery processes of Indigenous consumers are likely to differ from that of non-Indigenous consumers, adopting a recovery focus is important for both non-Indigenous and Indigenous consumers.

A recent document (MH-Smart, 2005) examined the concept of recovery among a group of Maori consumers who have identified and documented what 'recovery' means to them. Recovery was strongly identified as not only relating to the individual consumer, but also to the entire family, clan group and community of the consumer. The researchers were unaware of similar documentation of the meaning of recovery for Indigenous Australian consumers, although they had been privileged to hear a number of personal oral accounts at conferences and workshops. It is possible to predict from the shared basis of strength with family, clan group and community, the broader concepts of mental health, the histories of disempowerment through colonisation and the resulting social, health, educational and economic disadvantage, that Aboriginal and Torres Strait Islander consumers have culturally-linked concepts of recovery.

An important mainstream tool (Stages of Recovery Instrument (STORI); Andresen, Oades and Caputi 2003; 2006) has arisen from emerging themes and phases described in the stories of recovery from a number of non-Indigenous consumers. This tool may be a useful starting point to inform the development of an Indigenous consumer-rated Outcomes measure that focuses not just on mental health and wellbeing, but also progress towards a self-defined recovery.

Variations on the Kessler 10 scale of distress are increasingly being adopted for use among Indigenous people and populations. Nagel et al. (2005) have found that the Kessler 10 scale supplemented with appropriate pictures has been well received as an additional measure of consumer distress in the Northern Territory. The questions and pictures have been well understood and have provided an opportunity for clients to reveal more about their internal experience that earlier discussion had left untapped.

An Indigenous-specific tool aiming to measure empowerment is being developed through a collaboration between the University of Queensland research team involved in this project (Haswell) and researchers at James Cook University who have been working to understand and promote Indigenous individual, group and community empowerment for many years (Tsey et al., 2003; 2005). The development of the tool involves identification and

quantification of attributes of empowerment from in-depth interviews with participants of the Family Well Being Empowerment Program. In the course of examining these stories of empowerment experiences, there are emerging parallels in the process and definition of empowerment and of mental health recovery. Thus the tool that is being developed to measure empowerment may be a useful starting point for Indigenous consumer-rated measures of recovery. The effectiveness of such a tool in identifying stages of recovery for Indigenous consumers will need to be validated using a range of methods and settings in a similar manner to that described in this report for HoNOS and LSP.

12

Conclusions and Recommendations

Key Findings and Recommendations

The findings of this research have substantial implications in the delivery, analysis and interpretation of Mental Health Outcomes data with Indigenous consumers. As in most applied research efforts, the findings require follow up research to substantiate causal relationships (as opposed to associations), to confirm observations with a larger sample, when coverage rates increase and possible sources of bias decrease, and to assess transferability of lessons learned to a broader range of Indigenous groups and environments.

Despite these limitations, this study has demonstrated usefulness and validity of HoNOS and LSP, as well as the need for significant improvement in their application with Indigenous consumers in the Cairns Network. The improvement most needed is the promotion of, and recommended improvements to, the guiding principles used in routine Outcomes assessment with Indigenous consumers. The project's findings particularly support continued engagement of Indigenous Health Workers (Mental Health and Primary Health), consumers and their families throughout the assessment process and in the interpretation and use of the data that is collected by clinicians.

Data has been presented which support the following recommendations in order to maximise the future benefits of Mental Health Outcomes assessments with Indigenous consumers.

1 To continue the use of HoNOS and LSP with Indigenous consumers, together with the four Principles, as tools that have the capacity to capture important information for the consumer, carer and clinician and reflect many of their expectations of assistance from mental health care providers.

2 To continue the training and support to clinicians to continually enhance their skills in applying the Principles when rating Indigenous consumers. These principles, since they assist in enabling the clinician to understand the complexity and severity of the consumers' mental state and illness, should be applied to all assessments.

3 To develop and validate consumer-rated tools that capture the more fundamental and culturally determined aspects of Indigenous mental health that HoNOS and LSP do not attempt to measure. Such tools should adopt a positive direction to support a 'working from strengths' approach.

4 To interpret ratings made without adherence to Principle One cautiously, as such assessments may under-estimate the severity of problems experienced by the Indigenous consumer. To continue to allow identification of these occasions, it is recommended that clinicians continue to routinely indicate the presence or absence of additional informants in their assessments as a routine component of Mental Health Outcomes completion.

5 To ensure that clinicians are made fully aware of the importance of working in collaboration with family/carer and a local practitioner, preferably an Indigenous mental health worker, in all mental health assessments that guide diagnosis, care planning and outcomes assessment (including initial and outcomes assessments) that they complete with Indigenous consumers **regardless of the degree of engagement or understanding they feel they have with the consumer.**

6 To support more research on the relationship between involvement of informants and HoNOS and LSP scores for consumers from similar and different cultural background as their clinicians using a design which can clarify cause and effect associations.

7 To adjust Principle Four to instruct clinicians to ensure that consumers' beliefs, experiences and behaviours are consistent in form, intensity and duration with accepted local norms before considering them as culturally valid, and hence excluded, from rating in items 2 (self harm) and 6 (hallucinations and delusions). The modification should also guide clinicians to include mental health problems that result from such experiences in their ratings, even if the experience itself is determined to be within social and cultural norms and not a symptom of mental illness.

8 To provide continued encouragement and support of district management and clinicians to increase the level of coverage according to the Outcomes Initiative protocols. In the inpatient setting, this particularly includes routine occasions at discharge as well as admission; in the community setting this means increasing coverage of all consumers at the recommended intervals for standard reviews.

9 To adjust Principle One to explicitly state that while recognising the right of the consumer to refuse involvement of additional informants in their assessment and care, clinicians and

services should continually reflect on how opportunities for meaningful involvement of consumers, families, carers and Health Workers can be increased.

10 To provide opportunities for clinicians to become better prepared and supported to work with consumers, families and Indigenous Health Workers in completing Outcomes ratings. Making this a key component of training and professional development may increase clinicians' confidence and skill in working with multiple informants.

11 To encourage services to adopt a positive and pro-active approach to achieving successful collaboration with Indigenous Health and Mental Health Workers who can in turn empower consumers and families to actively guide the mental health assessment and care pathways.

12 To ensure that population level analysis and dissemination of Outcomes data be completed in a timely and locally relevant manner to maximise its use, not only between clinicians and consumers, but also in informing service planning to increase responsiveness to the varied and changing needs of the consumer population.

13 To disseminate this project's findings to key stakeholders of other regions, and encourage a collaborative approach inclusive of local Indigenous stakeholders to play a leading role in achieving the use of the guiding principles, the enhanced training and tools, and the resulting data within their locations.

14 To ensure that the following considerations are made when conducting comparisons between Indigenous and non-Indigenous Mental Health Outcomes Data: recognition of the heterogeneity of Indigenous Australian peoples (thus avoiding overgeneralisation), recognition of differences within and between regions, use of appropriate age-stratification reflecting age-related trends in Indigenous mental health indicators and documenting the presence or absence of additional informants in assessments.

Additional General Suggestions for Continuation of the Process

For the Cairns Network, we encourage:

- Wider acknowledgement and effort to ensure that accurate Outcomes assessment, reaches its potential as a useful engagement and communication tool involving Indigenous Mental Health Workers;

- Continued monitoring and analysis of Mental Health Outcomes data and continued use of the additional questions on the OIS (particularly the additional informant question);
- Continued sharing of this research project's findings at a local level, in conjunction with the use of other data sets (such as hospitalisation and CESA data) to assist in planning and evaluating both standard & innovative mental health care interventions;
- Advocating more appropriate approaches to enhance the involvement of Indigenous Health Workers (Mental Health and Primary Health), consumers, families, peers and communities in all aspects of mental health care including Outcomes assessment
- Considering the potential value of wider implementation of the additional questions on the Outcomes Information System trialled within this research project. The routine inclusion of additional informants may offer many advantages (as demonstrated by this project amongst Indigenous consumers) in the wider population.
- Considering the implications of variation between assessments of Indigenous consumers with and without additional informants observed here as a potential confound when comparing assessment scores over time. This may be similarly true for non-Indigenous consumers.

For Queensland and the Northern Territory

It is suggested that wider Queensland and Northern Territory mental health networks gain a clear understanding of the methods and findings of this project to enhance their activities by:

- Disseminating project findings amongst Mental Health and Indigenous Mental Health stakeholders in Queensland and the Northern Territory, and encouraging the adoption of similar consultation, training and implementation activities to enhance Wider Mental Health Outcomes use. It is imperative that these activities involve Indigenous Mental Health stakeholders;
- Considering application of the five additional questions on the OIS to enable similar monitoring in other Mental Health networks;
- Implementing tools (e.g. the modified pamphlets and reporting capacities built into the OIS) and processes (e.g. Indigenous Mental Health Worker Forums) to address barriers to enhanced local practitioner, consumer and carer involvement in assessment;
- Exploring the choice, modification and/or development of consumer and carer rated tools that capture developing strengths and progress towards recovery. Such tools can

enhance discussion between consumers, clinicians and carers about the meaning of recovery to consumers and carers, and in goal setting and planning for recovery.

Nationally

Finally, we encourage the national leadership in the Mental Health Outcomes initiative (in policy and in education of Australian mental health service providers) to prioritise responsiveness to culturally diverse groups and disadvantaged groups as an essential step toward correcting mental health inequalities.

13

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APPENDICES

- 1 Selected Outputs of the Australian Integrated Mental Health Initiative Indigenous Stream in Far North Queensland and Northern Territory:** List of Reports, Communications and Publications that have complemented this Project.
- 2 Systematic Literature Search Summary Table:** Numbers of citations identified through relevant keyword combinations. Conducted on Clinicians Knowledge Network, Queensland Health website (www.qheps.health.qld.gov.au).
- 3 Mental Health Outcomes Measures for use with adults and older persons utilised by the Queensland Health Mental Health Outcomes Initiative:** Details surrounding the collection occasion (Diagnosis, Mental Health Legal Status, Focus of Care), HoNOS/HoNOS 65+, RUG-ADL, LSP-16, Mental Health Inventory and the Outcomes Initiative Collection Protocol for Adults and Older Persons. All items downloaded from www.qheps.health.gov.au/hssb/mhu/system_and_outcomes/elearning/key.htm, Aug 06.
- 4 Summary of the First Wuchopperen Workshop.**
- 5 Timeline of Project Activities.**
- 6 Principles Document and Additional Questions added to the Outcomes Information System.**
- 7 Additional Engagement, Training and Evaluation Tools:** Outcomes Initiative Information Sheet 5 Role of Zonal Outcomes Coordinator, Outcomes Initiative information pamphlet for Indigenous communities, Principles for rating Adult Indigenous Consumers, HoNOS Guidelines for Indigenous Adults, Refresher session Powerpoint and the Health Worker Forum Evaluation Sheet.
- 8 Summary of the Second Wuchopperen Workshop and the Local Forum.**

Appendix 1. Selected Outputs of the Australian Integrated Mental Health Initiative Indigenous Stream in Far North Queensland and Northern Territory: List of Reports, Communications and Publications that have complemented this Project

PAPERS AND REPORTS

Far North Queensland

Six year review of statistics from the Mental Health Unit, Cairns Base Hospital 1999/2000 to 2004/2005. M Haswell-Elkins, R Wargent, F Tulip, T Wheeler, M Baird, A Brownlie, L Gardiner and K Heath. Cairns Health District, Queensland Health, 2006.

Protocols for the delivery of mental health services in Far North Queensland Indigenous communities: guidelines for health workers, clinicians, consumers and carers. AIMhi Indigenous Stream, North Queensland listed alphabetically: Brenda Hall, Melissa Haswell, Ciaran O'Higgins, Ernest Hunter, Rachael Wargent, Roy West. Commissioned by Queensland Health Northern Zone Management Unit, 2005.

The management of mental health information in Far North Queensland: Considerations around the integration of mental health information within primary health care systems. Melissa Haswell. Paper commissioned by Queensland Health, Northern Area Health Service, 2005.

Strengthening Families, Carers and Communities: Hope Vale Project Final Report. Brenda Hall and Melissa Haswell. Final report to Queensland Health Prevention and Early Intervention Initiatives, 2005.

Social and emotional well-being of Aboriginal and Torres Strait Islander people within the broader context of the social determinants of health. Literature review prepared for the Co-operative Research Centre for Aboriginal Health. G Henderson, C Robson, L Cox, C Dukes, K Tsey, M Haswell, 2005.

Indigenous Mental Health Workforce: Questionnaire Results for the Northern Zone, Queensland. Brenda Hall and Melissa Haswell, 2005.

Cape York District Mental Health Services Clinical Audit Report #2. A Brownlie, M Haswell, R Wargent, E Hunter, B Hall, 2005.

Cape York District Mental Health Services Audit #1. E Hunter, A Brownlie, M Haswell, R Wargent, B Hall, 2003.

Northern Territory

AIMHI NT care planning package. AIMHI NT 2006.

Grow Strong Stay Strong. T Nagel, The Chronicle, April 2006

AIMHI NT Auseinet On line recovery tool kit 2006 (auseinet.flinders.edu.au/toolkit/). Tricia Nagel.

Mental illness can be something chronic. T Nagel. The Chronicle, 2005; 8 (4)

Mental Problem Story. T Nagel, C Thompson. The Chronicle, 2005; 7 (6)

AIMHI NT 2003 Base line Measures Discussion Paper One. Darwin, Menzies School of Health Research. Institute of Advanced Studies. T Nagel. Charles Darwin University, 2005.

AIMHI NT Integrating Mental Health into Primary Care. Discussion Paper Two. Darwin, Menzies School of Health Research. Tricia Nagel, Institute of Advanced Studies. Charles Darwin University, 2004

AIMHI NT Learning about Indigenous Mental Health Promotion. Discussion Paper Four. Tricia Nagel and Jenny Judd. Darwin, Menzies School of Health Research. Institute of Advanced Studies. Charles Darwin University, 2004.

Compliance and Mental Health. T Nagel. The Chronicle, 2004; 8 (5)

FLIP CHARTS, INFORMATION SHEETS AND RADIO SPOTS FOR THE NT

- *5-minute therapy? No worries!* 2004
- *Mental Problem Story* 2004
- *Yakka Worries* 2005
- *Keep Family Strong* (Animated electronic resource) 2004
- *What is depression? What is psychosis? What is mania?* (Laminated Information sheets) 2005
- *Making a pictorial story with AIMHI* (Flip chart) AIMHI NT 2005
- *Grow strong mental health* (Flip chart) AIMHI NT 2005
- *Sadhearted* (radio spot and CD) AIMHI NT with Larrakia FM and CRCAH, 2005

Selected Publications in 2005/2006

- Nagel T: **Rural news.** Australasian Psychiatry, 2005; 12 (4): 425-427
- Haswell-Elkins M, Hunter, E, Nagel T, Thompson C, Hall B, Mills R, Wargent R, Tsey K, Knowles L, Wilkinson Y, **Reflections on integrating mental health into primary care services in remote indigenous communities in Far North Queensland and the Northern Territory.** Australian Journal of Primary Health, 2005; 11(2) p. 62-69
- Nagel T. **Remotely interested in Depression.** O&G Magazine, 2005; 7(4)
- Tsey, K., Travers H., Gibson, T., Whiteside, M., Cadet-James, Y., Haswell-Elkins, M., McCalman, J., Wilson, A. (2005) **The role of empowerment through life skills development in building comprehensive primary health care systems in Indigenous Australia.** Australian Journal of Primary Health, 11, 16-25.
- Nagel T and Thompson C. **Aboriginal mental health workers improve communication in inpatient setting.** Australasian Psychiatry, 2006 14(3)
- Nagel, T. **The need for relapse prevention in NT remote communities,** Australian e-Journal for the Advancement of Mental Health (AeJAMH), 2006. 5(1): p. 1446-7984.

Appendix 2. Systematic Literature Search Summary Table

Numbers of citations identified through relevant keyword combinations. Conducted on Clinicians Knowledge Network, Queensland Health website (www.qheps.health.qld.gov.au) in August 2006.

Keywords	No. of Psychinfo Citations (1985 to 29/8/06)	No. of PubMed citations (to 29/8/06)	No. of Medline citations (1996 to 29/8/06)	No. of directly relevant publications on issues important to the use of standard Mental health outcomes measures with Indigenous Australians
Indigenous	2178	10045	5048	nd
Aboriginal	696	3035	1560	nd
Mental health + health outcomes	733	203	486	nd
Mental health + health outcomes + Indigenous	3	11	3	0
Mental health + health outcomes + Aboriginal	1	3	1	0
Mental health + assessment	6451	8490	5540	nd
Mental health + assessment + Indigenous	36	21	16	3
Mental health + assessment + Aboriginal	6	12	10	1
HoNOS	92	102	70	nd
HoNOS + Indigenous	0	0	0	0
HoNOS + Aboriginal	0	0	0	0
Life Skills Profile	50	147	40	nd
Life Skills Profile + Indigenous	0	0	0	0
Life Skills Profile + Aboriginal	0	0	0	0

nd = not done (abstracts were not examined for relevance)

Appendix 3. Mental Health Outcomes Measures

Mental Health Outcomes Measures for use with adults and older persons utilised by the Queensland Health Mental Health Outcomes Initiative: Details surrounding the collection occasion (Diagnosis, Mental Health Legal Status, Focus of Care), HoNOS/HoNOS 65+, RUG-ADL, LSP-16, Mental Health Inventory and the Outcomes Initiative Collection Protocol for Adults and Older Persons. All items downloaded from www.qheps.health.gov.au/hssb/mhu/system_and_outcomes/elearning/key.htm, Aug 06.



First Name: _____
 Last Name: _____
 Sex: Male Female Unknown
 Date of Birth: / /
 (affix patient label here)

Outcomes: Adult and older person's measures

Outcomes details

Age group: (choose 1 only) Adult Older persons

Collection date: / /
 (NB: must be the date of the event prompting the reason for collection)

Episode service type: (choose one only)

<input type="checkbox"/> Acute mental health inpatient	} The <i>current</i> HBCIS UR number must be entered here: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="checkbox"/> Extended treatment-campus based	
<input type="checkbox"/> Extended treatment-non-campus based	
<input type="checkbox"/> Community / ambulatory	

Consumer's treating unit: _____

Measures completed by: _____ (Print name) _____ (Signature)
 (Tick if PSP)

Reason for collection

→ Choose one only
 → Date of collection (noted above) must be the same as the event prompting the reason for collection

Assessment Only
 New episode: new referral
 New episode: referred from other mental health service type within network
 Review: standard 3 month (91 day)
 Review: ad-hoc
 End of episode: no further care
 End of episode: movement of consumer to new service type
 End of Episode: lost to follow-up
 Death

Diagnosis and mental health legal status N/A

→ To be completed at review and discharge
 → Not required on admission
 → Note the diagnosis chiefly responsible for occasioning the patient treatment in the preceding period of care

Diagnosis (ICD-10-AM):

Principal	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	_____
Additional	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	_____
Additional	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	_____

Mental health legal status: Was the consumer an involuntary patient under the Mental Health Act 2000 at *some point* during the preceding period of care?
 Yes
 No

Focus of care N/A

→ Please refer to glossary when completing

<input type="checkbox"/> 01. Acute	<input type="checkbox"/> 04. Maintenance
<input type="checkbox"/> 02. Functional gain	<input type="checkbox"/> 05. Not applicable
<input type="checkbox"/> 03. Intensive extended	<input type="checkbox"/> 06. Not stated / missing

OUTCOMES: Adult and older persons measures



First Name: _____
 Last Name: _____
 Sex: Male Female Unknown
 Date of Birth: / /
 (affix patient label here)

OUTCOMES: Adult and older persons measures

HoNOS / HoNOS 65+

- Always refer to the full HoNOS glossary in your clinician's reference manual when making the rating
- Please use the standard HoNOS glossary when making ratings of Adults under 65 years of age
- Please use the HoNOS 65+ glossary when making ratings of older persons, defined as those aged 65 years or older
- Complete the ratings for new episodes only after the comprehensive clinical assessment has been completed
- Only use code 9 if you are definitely unable to make the rating

1. Overactive, aggressive, disruptive or agitated	0	1	2	3	4	9
2. Non-accidental self-injury	0	1	2	3	4	9
3. Problem drinking or drug-taking	0	1	2	3	4	9
4. Cognitive problems	0	1	2	3	4	9
5. Physical illness or disability problems	0	1	2	3	4	9
6. Problems with hallucinations and delusions	0	1	2	3	4	9
7. Problems with depressed mood	0	1	2	3	4	9
8. Other mental and behavioural problems	0	1	2	3	4	9
Specify problem or disorder A, B, C, D, E, F, G, H, I or J <input type="checkbox"/>						
9. Problems with relationships	0	1	2	3	4	9
10. Problems with activities of daily living	0	1	2	3	4	9
11. Problems with living conditions	0	1	2	3	4	9
12. Problems with occupation and activities	0	1	2	3	4	9

RUG - ADL N/A

- Always refer to the full RUG-ADL Glossary in your Clinician's Reference Guide when making the ratings.
- Only complete for Older persons (those aged 65 or older)
- Codes for Items 1, 2 & 3

<ul style="list-style-type: none"> 1. Independent or supervision only 3. Limited physical assistance 4. Other than two person physical assistance 5. Two person physical assistance 7. Unable to rate 	<ul style="list-style-type: none"> → Codes for Item 4 1. Independent or supervision only 2. Limited assistance 3. Extensive assistance / total dependence / tube fed 7. Unable to rate
--	---

1. Bed Mobility (ability to move in bed after the transfer is completed)	1	3	4	5	7
2. Toileting (includes mobilising to the toilet, adjustment of clothing before and after toileting and maintaining perineal hygiene without the incidence of incontinence or soiling of clothes).	1	3	4	5	7
3. Transfer (includes the transfer in and out of bed, bed to chair, in and out of shower or bath tub)	1	3	4	5	7
4. Eating (includes the task of cutting food, bringing food to the mouth and chewing and swallowing of food. Does not include preparation of the meal)	1	2	3		7

Mental Health Inventory (MHI) N/A

→ If this measure is required, give the *Outcomes: Mental Health Inventory* form to the patient with the appropriate explanation

If the MHI is required and is not attached to this form, state the reasons why here:



First Name: _____
 Last Name: _____
 Sex: Male Female Unknown
 Date of Birth: / /
 (affix patient label here)

OUTCOMES: Adult and older persons measures

LSP - 16 <input type="checkbox"/> N/A	
→ Refer to glossary when completing → Assess the patient or client's general functioning over the past 3 months.	
1. <i>Does this person generally have any difficulty with initiating and responding to conversation?</i> 0 <input type="checkbox"/> No difficulty with conversation 1 <input type="checkbox"/> Slight difficulty with conversation 2 <input type="checkbox"/> Moderate difficulty with conversation 3 <input type="checkbox"/> Extreme difficulty with conversation	9. <i>Does this person generally maintain an adequate diet ?</i> 0 <input type="checkbox"/> No problem 1 <input type="checkbox"/> Slight problem 2 <input type="checkbox"/> Moderate problem 3 <input type="checkbox"/> Extreme problem
2. <i>Does this person generally withdraw from social contact?</i> 0 <input type="checkbox"/> Does not withdraw at all 1 <input type="checkbox"/> Withdraws slightly 2 <input type="checkbox"/> Withdraws moderately 3 <input type="checkbox"/> Withdraws totally or near totally	10. <i>Does this person generally look after and take their own prescribed medication (or attend for prescribed injections) on time ?</i> 0 <input type="checkbox"/> Reliable with medication 1 <input type="checkbox"/> Slightly unreliable 2 <input type="checkbox"/> Moderately unreliable 3 <input type="checkbox"/> Extremely unreliable
3. <i>Does this person generally show warmth to others ?</i> 0 <input type="checkbox"/> Considerable warmth 1 <input type="checkbox"/> Moderate warmth 2 <input type="checkbox"/> Slight warmth 3 <input type="checkbox"/> No warmth at all	11. <i>Is this person willing to take psychiatric medication when prescribed by a doctor ?</i> 0 <input type="checkbox"/> Always 1 <input type="checkbox"/> Usually 2 <input type="checkbox"/> Rarely 3 <input type="checkbox"/> Never
4. <i>Is this person generally well groomed (eg. neatly dressed, hair combed) ?</i> 0 <input type="checkbox"/> Well groomed 1 <input type="checkbox"/> Moderately well groomed 2 <input type="checkbox"/> Poorly groomed 3 <input type="checkbox"/> Extremely poorly groomed	12. <i>Does this person co-operate with health services (eg. doctors and / or other health workers) ?</i> 0 <input type="checkbox"/> Always 1 <input type="checkbox"/> Usually 2 <input type="checkbox"/> Rarely 3 <input type="checkbox"/> Never
5. <i>Does this person wear clean clothes generally, or ensure that they are cleaned if dirty ?</i> 0 <input type="checkbox"/> Maintains cleanliness of clothes 1 <input type="checkbox"/> Moderate cleanliness of clothes 2 <input type="checkbox"/> Poor cleanliness of clothes 3 <input type="checkbox"/> Very poor cleanliness of clothes	13. <i>Does this person generally have problems (eg. friction, avoidance) living with others in the household ?</i> 0 <input type="checkbox"/> No obvious problems 1 <input type="checkbox"/> Slight problems 2 <input type="checkbox"/> Moderate problems 3 <input type="checkbox"/> Extreme problems
6. <i>Does this person generally neglect their physical health ?</i> 0 <input type="checkbox"/> No neglect 1 <input type="checkbox"/> Slight neglect of physical problems 2 <input type="checkbox"/> Moderate neglect of physical problems 3 <input type="checkbox"/> Extreme neglect of physical problems	14. <i>Does this person behave offensively (includes sexual behaviour) ?</i> 0 <input type="checkbox"/> Not at all 1 <input type="checkbox"/> Rarely 2 <input type="checkbox"/> Occasionally 3 <input type="checkbox"/> Often
7. <i>Is this person violent to others ?</i> 0 <input type="checkbox"/> Not at all 1 <input type="checkbox"/> Rarely 2 <input type="checkbox"/> Occasionally 3 <input type="checkbox"/> Often	15. <i>Does this person behave irresponsibly ?</i> 0 <input type="checkbox"/> Not at all 1 <input type="checkbox"/> Rarely 2 <input type="checkbox"/> Occasionally 3 <input type="checkbox"/> Often
8. <i>Does this person generally make and / or keep up friendships ?</i> 0 <input type="checkbox"/> Friendships made or kept up well 1 <input type="checkbox"/> Friendships made or kept with slight difficulty 2 <input type="checkbox"/> Friendships made or kept with considerable difficulty 3 <input type="checkbox"/> No friendships made or none kept	16. <i>What sort of work is this person capable of (even if unemployed, retired or doing unpaid domestic duties) ?</i> 0 <input type="checkbox"/> Capable of full-time work 1 <input type="checkbox"/> Capable of part-time work 2 <input type="checkbox"/> Capable of only sheltered work 3 <input type="checkbox"/> Totally incapable of work



First Name: _____
 Last Name: _____
 Sex: Male Female Unknown
 Date of Birth: / /
 (affix patient label here)

Outcomes: Mental health inventory (MHI)

→ Please read each question and tick the box by the ONE statement that best describes how things have been FOR YOU during the past month. There are no right or wrong answers.

1 How happy, satisfied, or pleased have you been with your personal life during the past month? (tick one)

- 1 Extremely happy, could not be more pleased or satisfied
- 2 Very happy most of the time
- 3 Generally, satisfied, pleased
- 4 Sometimes fairly satisfied, sometime fairly unhappy
- 5 Generally dissatisfied, unhappy
- 6 Very dissatisfied, unhappy most of the time

2 How much of the time have you felt lonely during the past month? (Tick one)

- 1 All of the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 None of the time

3 How often did you become nervous or jumpy when faced with excitement or unexpected situations during the past month? (Tick one)

- 1 Always
- 2 Very often
- 3 Fairly often
- 4 Sometimes
- 5 Almost never
- 6 Never

4 During the past month, how much of the time have you felt that the future looks hopeful and promising? (Tick one)

- 1 All of the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 None of the time

5 How much time, during the past month, has your daily life been full of things that were interesting to you? (Tick one)

- 1 All of the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 None of the time

6 How much time, during the past month, did you feel relaxed and free from tension? (Tick one)

- 1 All of the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 None of the time

7 During the past month, how much of the time have you generally enjoyed the things you do? (Tick one)

- 1 All of the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 None of the time

OUTCOMES: Mental Health Inventory (MHI)



First Name: _____
 Last Name: _____
 Sex: Male Female Unknown
 Date of Birth: / /
 (affix patient label here)

8 *During the past month, have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel or of your memory? (tick one)*

- 1 Not at all
- 2 Maybe a little
- 3 Yes, but not enough to be concerned or worried about
- 4 Yes, and I have been a little concerned
- 5 Yes, and I am quite concerned
- 6 Yes, and I am very much concerned about it

9 *Did you feel depressed during the past month? (tick one)*

- 1 Yes, to the point that I did not care about anything for days at a time
- 2 Yes, very depressed almost every day
- 3 Yes, quite depressed several times
- 4 Yes, a little depressed now and then
- 5 No, never felt depressed at all

10 *During the past month, how much of the time have you felt loved and wanted? (tick one)*

- 1 All of the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 None of the time

11 *How much time, during the past month, have you been a very nervous person? (tick one)*

- 1 All of the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 None of the time

12 *When have you got up in the morning, this past month, about how often did you expect to have an interesting day? (tick one)*

- 1 Always
- 2 Very often
- 3 Fairly often
- 4 Sometimes
- 5 Almost never
- 6 Never

13 *During the past month, how much of the time have you felt tense or "high strung"? (tick one)*

- 1 All of the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 None of the time

14 *During the past month, have you been in firm control of your behaviour, thoughts, emotions or feelings? (tick one)*

- 1 Yes, very definitely
- 2 Yes, for the most part
- 3 Yes, I guess so
- 4 No, not too well
- 5 No, and I am somewhat disturbed
- 6 No, and I am very disturbed



First Name: _____
 Last Name: _____
 Sex: Male Female Unknown
 Date of Birth: / /
 (affix patient label here)

15 *During the past month, how often did your hands shake when you tried to do something? (tick one)*

- | | |
|---|---|
| 1 <input type="checkbox"/> Always | 4 <input type="checkbox"/> Sometimes |
| 2 <input type="checkbox"/> Very often | 5 <input type="checkbox"/> Almost never |
| 3 <input type="checkbox"/> Fairly often | 6 <input type="checkbox"/> Never |

16 *During the past month, how often did you feel that you had nothing to look forward to? (tick one)*

- | | |
|---|---|
| 1 <input type="checkbox"/> Always | 4 <input type="checkbox"/> Sometimes |
| 2 <input type="checkbox"/> Very often | 5 <input type="checkbox"/> Almost never |
| 3 <input type="checkbox"/> Fairly often | 6 <input type="checkbox"/> Never |

17 *How much of the time, during the past month, have you felt calm and peaceful? (tick one)*

- | | |
|---|---|
| 1 <input type="checkbox"/> All of the time | 4 <input type="checkbox"/> Some of the time |
| 2 <input type="checkbox"/> Most of the time | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time |

18 *How much of the time, during the past month, have you felt emotionally stable? (tick one)*

- | | |
|---|---|
| 1 <input type="checkbox"/> All of the time | 4 <input type="checkbox"/> Some of the time |
| 2 <input type="checkbox"/> Most of the time | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time |

19 *How much of the time, during the past month, have you felt downhearted and blue? (tick one)*

- | | |
|---|---|
| 1 <input type="checkbox"/> All of the time | 4 <input type="checkbox"/> Some of the time |
| 2 <input type="checkbox"/> Most of the time | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time |

20 *How often have you felt like crying, during the past month? (tick one)*

- | | |
|---|---|
| 1 <input type="checkbox"/> Always | 4 <input type="checkbox"/> Sometimes |
| 2 <input type="checkbox"/> Very often | 5 <input type="checkbox"/> Almost never |
| 3 <input type="checkbox"/> Fairly often | 6 <input type="checkbox"/> Never |

21 *During the past month, how often have you felt that others would be better off if you were dead? (tick one)*

- | | |
|---|---|
| 1 <input type="checkbox"/> Always | 4 <input type="checkbox"/> Sometimes |
| 2 <input type="checkbox"/> Very often | 5 <input type="checkbox"/> Almost never |
| 3 <input type="checkbox"/> Fairly often | 6 <input type="checkbox"/> Never |

22 *How much of the time, during the past month, were you able to relax without difficulty? (tick one)*

- | | |
|---|---|
| 1 <input type="checkbox"/> All of the time | 4 <input type="checkbox"/> Some of the time |
| 2 <input type="checkbox"/> Most of the time | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time |

23 *How much of the time, during the past month, did you feel that your love relationships, loving and being loved, were full and complete? (tick one)*

- | | |
|---|---|
| 1 <input type="checkbox"/> All of the time | 4 <input type="checkbox"/> Some of the time |
| 2 <input type="checkbox"/> Most of the time | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time |



First Name: _____
 Last Name: _____
 Sex: Male Female Unknown
 Date of Birth: / /
 (affix patient label here)

- 24** *How often, during the past month, did you feel that nothing turned out for you the way you wanted it to? (tick one)*
- | | |
|---|---|
| 1 <input type="checkbox"/> Always | 4 <input type="checkbox"/> Sometimes |
| 2 <input type="checkbox"/> Very often | 5 <input type="checkbox"/> Almost never |
| 3 <input type="checkbox"/> Fairly often | 6 <input type="checkbox"/> Never |
- 25** *How much have you been bothered by nervousness, or your "nerves", during the past month? (tick one)*
- | |
|---|
| 1 <input type="checkbox"/> Extremely so, to the point where I could not take care of things |
| 2 <input type="checkbox"/> Very much bothered |
| 3 <input type="checkbox"/> Bothered quite a bit by nerves |
| 4 <input type="checkbox"/> Bothered some, enough to notice |
| 5 <input type="checkbox"/> Bothered just a little by nerves |
| 6 <input type="checkbox"/> Not bothered at all by this |
- 26** *During the past month, how much of the time has living been a wonderful adventure for you? (tick one)*
- | | |
|---|---|
| 1 <input type="checkbox"/> All of the time | 4 <input type="checkbox"/> Some of the time |
| 2 <input type="checkbox"/> Most of the time | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time |
- 27** *How often, during the past month, have you felt so down in the dumps that nothing could cheer you up? (tick one)*
- | | |
|---|---|
| 1 <input type="checkbox"/> Always | 4 <input type="checkbox"/> Sometimes |
| 2 <input type="checkbox"/> Very often | 5 <input type="checkbox"/> Almost never |
| 3 <input type="checkbox"/> Fairly often | 6 <input type="checkbox"/> Never |
- 28** *During the past month, did you think about taking your own life? (tick one)*
- | | |
|---|---|
| 1 <input type="checkbox"/> Yes, very often | 4 <input type="checkbox"/> Yes, at one time |
| 2 <input type="checkbox"/> Yes, fairly often | 5 <input type="checkbox"/> No, never |
| 3 <input type="checkbox"/> Yes, a couple of times | |
- 29** *During the past month, how much of the time have you felt restless, fidgety, or impatient? (tick one)*
- | | |
|---|---|
| 1 <input type="checkbox"/> All of the time | 4 <input type="checkbox"/> Some of the time |
| 2 <input type="checkbox"/> Most of the time | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time |
- 30** *During the past month, how much of the time have you been moody or brooded about things? (tick one)*
- | | |
|---|---|
| 1 <input type="checkbox"/> All of the time | 4 <input type="checkbox"/> Some of the time |
| 2 <input type="checkbox"/> Most of the time | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time |
- 31** *How much of the time, during the past month, have you felt cheerful, lighthearted? (tick one)*
- | | |
|---|---|
| 1 <input type="checkbox"/> All of the time | 4 <input type="checkbox"/> Some of the time |
| 2 <input type="checkbox"/> Most of the time | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time |

OUTCOMES: Mental Health Inventory (MHI)



First Name: _____
 Last Name: _____
 Sex: Male Female Unknown
 Date of Birth: / /
 (affix patient label here)

- 32** *During the past month, how often did you get rattled, upset or flustered? (tick one)*
- | | |
|---|---|
| 1 <input type="checkbox"/> Always | 4 <input type="checkbox"/> Sometimes |
| 2 <input type="checkbox"/> Very often | 5 <input type="checkbox"/> Almost never |
| 3 <input type="checkbox"/> Fairly often | 6 <input type="checkbox"/> Never |
- 33** *During the past month, have you been anxious or worried? (tick one)*
- 1 Yes, extremely to the point of being sick or almost sick
 2 Yes, very much so
 3 Yes, quite a bit
 4 Yes, some, enough to bother me
 5 Yes, a little bit
 6 No, not at all
- 34** *During the past month, how much of the time were you a happy person? (tick one)*
- | | |
|---|---|
| 1 <input type="checkbox"/> All of the time | 4 <input type="checkbox"/> Some of the time |
| 2 <input type="checkbox"/> Most of the time | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time |
- 35** *How often, during the past month, did you find yourself trying to calm down? (tick one)*
- | | |
|---|---|
| 1 <input type="checkbox"/> Always | 4 <input type="checkbox"/> Sometimes |
| 2 <input type="checkbox"/> Very often | 5 <input type="checkbox"/> Almost never |
| 3 <input type="checkbox"/> Fairly often | 6 <input type="checkbox"/> Never |
- 36** *During the past month, how much of the time have you been in low or very low spirits? (tick one)*
- | | |
|---|---|
| 1 <input type="checkbox"/> All of the time | 4 <input type="checkbox"/> Some of the time |
| 2 <input type="checkbox"/> Most of the time | 5 <input type="checkbox"/> A little of the time |
| 3 <input type="checkbox"/> A good bit of the time | 6 <input type="checkbox"/> None of the time |
- 37** *How often, during the past month, have you been waking up feeling fresh and rested? (tick one)*
- | | |
|--|---|
| 1 <input type="checkbox"/> Always, every day | 4 <input type="checkbox"/> Some days, but usually not |
| 2 <input type="checkbox"/> Almost every day | 5 <input type="checkbox"/> Hardly ever |
| 3 <input type="checkbox"/> Most days | 6 <input type="checkbox"/> Never wake up feeling rested |
- 38** *During the past month, have you been under or felt you were under any strain, stress or pressure? (tick one)*
- | | |
|--|--|
| 1 <input type="checkbox"/> Yes, almost more than I could stand or bear | 4 <input type="checkbox"/> Yes, some, but about normal |
| 2 <input type="checkbox"/> Yes, quite a bit of pressure | 5 <input type="checkbox"/> Yes, a little bit |
| 3 <input type="checkbox"/> Yes, some more than usual | 6 <input type="checkbox"/> No, not at all |

Completion date: / /

Thank you very much for your help

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Outcomes Initiative Collection Protocol: Adults and Older Persons

Outcomes Collection Protocol for Adults

<i>Collection Occasion</i>	N	R	E	N	R	E	N	R	E	A	N	R	E
Adults													
HoNOS	o	o	o	o	o	o	o	o	o	o	o	o	o
LSP-16	x	x	x	o	o	o	o	o	o	x	x	o	o
MHI	x	x	x	o	o	o	o	o	o	x	o	o	o
Principal & Additional Diagnosis	x	o	o	x	o	o	x	o	o	x	x	o	o
Focus of Care	x	x	x	x	x	x	x	x	x	x	x	o	o
Mental Health Legal Status	x	o	o	x	o	o	x	o	o	x	x	o	o

Outcomes Collection Protocol for Older Persons

<i>Collection Occasion</i>	N	R	E	N	R	E	N	R	E	A	N	R	E
Older persons													
HoNOS 65+	o	o	o	o	o	o	o	o	o	o	o	o	o
LSP-16	x	x	x	o	o	o	o	o	o	x	x	o	o
RUG-ADL	o	o	x	o	o	x	o	o	x	x	x	x	x
MHI	x	x	x	o	o	o	o	o	o	x	o	o	o
Principal & Additional Diagnosis	x	o	o	x	o	o	x	o	o	x	x	o	o
Focus of Care	x	x	x	x	x	x	x	x	x	x	x	o	o
Mental Health Legal Status	x	o	o	x	o	o	x	o	o	x	x	o	o

Abbreviations and Symbols

N	New episode	o	Collection of data on this occasion is mandatory
R	Review of mental health care	x	No collection requirements apply
E	End of episode	n/a	There are no services of this type for children and youth
A	Assessment only		

Review Date: 21 September 2005

Appendix 4. Summary of the First Wuchopperen Workshop.**INDIGENOUS MENTAL HEALTH OUTCOMES WORKSHOP
Wuchopperen Aboriginal Health Service, Cairns
June 12 & 13, 2003****Meeting Report and Minutes****Background and rationale of the Workshop**

A key objective during the first year of the NH&MRC Indigenous CRMD project is to progress the implementation of appropriate outcome measures in Indigenous settings. There have been calls for the development of new mental health outcome measures for indigenous people, most notably from the report by Tracy Westerman for the NT, however, it remains unclear what value the existing measures can bring to Indigenous mental health at least in the short term. The Northern Territory has already begun a trial of HONOS in Indigenous communities which includes collection of comments from administering practitioners regarding the presence of cultural factors influencing the process. This is in the very early stages. In New South Wales discussions have been initiated with the Aboriginal Health and Medical Research Council (AH&MRC) about how to approach this issue but this is very preliminary.

Queensland Health, like all other jurisdictions in Australia, is currently embarking on the implementation of indigenous mental health outcome measures as part of the National Information Development Agreements. There are significant reasons to support exploring the utility of existing measures that may turn out to be useable, adaptable or informative by virtue of providing insight as to why and how they are not appropriate to providing information regarding outcomes.

With sites within the Northern Territory and Far North Queensland, the NH&MRC project provides an ideal opportunity to explore these issues with a large and diverse Indigenous population whose mental health needs are provided through a relatively small number of mental health care providers. Several options for proceeding were considered but all rely on defining an appropriate framework for evaluation of adopted measures. Consultants, Dr Tom Trauer (Melbourne) and Dr Alan Rosen (Sydney), who have significant experience in this field with HONOS and LSP respectively, were engaged to provide expert input into this process. On the basis of these and other discussions, a workshop was hosted by WuChopperen Aboriginal Medical Service in Cairns on June 12 and 13, 2003. This workshop brought together workers with expertise in mental health outcome measure implementation and evaluation, remote Aboriginal and Torres Strait Islander mental health service delivery and Indigenous mental health professionals.

The purpose of the workshop was to examine the feasibility of adaptation, implementation and evaluation of selected existing practitioner-completed outcome measures for use in Indigenous populations, and to suggest a strategy by which this may be undertaken. The following objectives were formulated:

- 1 to define for participants the current status of existing practitioner-completed mental health outcome measures used in the wider population;
- 2 to define for participants the evaluation framework utilised during implementation in the mainstream;

- 3 to identify the key cultural and contextual factors that will impact the evaluation process in Indigenous settings;
- 4 to suggest adaptation of the evaluation framework to accommodate cultural and contextual factors;
- 5 to suggest minor alterations to the instruments/implementation process to accommodate cultural and contextual factors;
- 6 to define a phased implementation and evaluation process.

Mechanism

To facilitate this process pre-readings identified by Tom Trauer and Alan Rosen, were made available to participants. Participation was kept relatively tight to facilitate outcomes within the limited timeframe available, however, there was ample time for exploring issues directly and in depth. WuChopperen AMS was an ideal venue for the workshop and their participating staff provide crucial input in relation not only to service provision but to culture and context. Although Apunipima representatives were not able to attend due to time constraints, follow-up consultations will aim to ensure matching of data collection with their objectives in community health and well being. An agenda was set in advance to facilitate and focus the workshop activities.

Participants Invited

Alan Rosen, University of Sydney, Tom Trauer, Melbourne University, Trish Nagel, Top End Mental Health Service and Carolyn Thompson, TEMHS, Leanne Knowles, Mark Wenitong and additional staff from Wuchopperen Health Service, Audrey Deemal from Apunipima – Cape York Health Council, Radhika Santhanam, Ernest Hunter, Melissa Haswell and Joanne Bambie University of Queensland, Yvonne Wilkinson, Trudi Sebasio, Mercy Baird and Tim Higgins QH (Northern Zone) Miguel Garcia, Townsville MH, Ruth Catchpoole, Diana Petrovich Scholes, QH (MH Outcomes, Northern Zone), Liz Wilson, QH (ATSI Mental Health), Andrew Brownlie, Bruce Gynther, Tallita Wheeler, QH (IMH), Robert Williams and Brod Osbourne, RFDS, Stuart Hart QH (Cape District) Alannah O'Brien ,QH (Cairns District) Michael Fletcher QH (Torres District), Phil Smith QH (Mt Isa District)

Day 1 Attendees

Queensland Health: Yvonne Wilkinson, Diana Petrovich Scholes, Ruth Catchpoole, Stuart Hart, Alana O'Brien, Michael Fletcher, Phil Smith, Miguel Garcia, Liz Wilson, Trudi Sebasio, Bruce Gynther. University of Queensland: Melissa Haswell, Ernest Hunter. WuChopperen: Leanne Knowles, Josie Creek. RFDS: Robert Williams, Brod Osbourne. NT Health: Trish Nagel, Carolyn Thompson. Consultants: Tom Trauer and Alan Rosen

Day 2 Attendees

Queensland Health: Yvonne Wilkinson, Diana Petrovich-Scholes, Ruth Catchpoole, Stuart Hart, Alana O'Brien, Miguel Garcia, Liz Wilson, Trudi Sebasio, Bruce Gynther, Andrew Brownlie. University of Queensland: Melissa Haswell, Ernest Hunter. WuChopperen: Leanne Knowles, Josie Creek, Tania Robinson. RFDS: Robert Williams. NT Health: Trish Nagel, Carolyn Thompson. Consultants: Tom Trauer and Alan Rosen

Proceedings**Thursday June 12**

10.30am	Introductions	
	Background and objectives for the workshop	EH
	Why outcome measures?	TT
	Principles informing outcome measurement	TT & AR
	Overview of the instruments	
	HoNOS	TT
	Life Skills Profile	AR
12.30pm	Lunch	
1.15pm	Experience from the Northern Territory	TN
	General discussion	
2.45pm	Afternoon tea	
3.00pm	Factoring in context / culture (preparation for tomorrow)	EH
	Is it necessary?	
	Content vs process	
	Implications for outcome measures AND evaluation of measures	
	Cultural relevance vs comparability ...	
	Evaluation considerations	TT
4.30pm	Summary and close	EH

Friday June 13

9.00am	The mainstream outcomes project in Queensland	RC / DP-S
9.30am	General discussion	
10.00	The instruments	
	1 HoNOS	TT
10.30am	Morning tea	
11.00am	2 LSP	AR
	General discussion	
12.00md	Lunch	
12.45pm	HoNOS & LSP – process adaptations	
	Evaluation considerations	
	Future directions	
3.00	Workshop close	

The following notes are a brief summary of the workshop proceedings. Comprehensive readings describing the LSP and HoNOS were distributed as pre-readings rough notes transcribed at the meeting follow these notes.

Order of materials:

- 1 Brief outline of the workshop proceedings
- 2 Minimal adaptations to the instruments
- 3 Tentative project outline
- 4 Rough notes from workshop: Day 1
- 5 Rough notes from workshop: Day 2
- 6 Powerpoints presented by Tom Trauer
- 7 Powerpoints presented by Alan Rosen

Summary of the workshop proceedings

Participants were welcomed to WuChopperen by Nancy Long, CEO of WuChopperen Medical Service.

EH outlined the background to this workshop – Commonwealth requirements for implementation of routine outcome measures (ROM) across all states. Common to all are HoNOS and LSP as clinician-rated measures. Each state has completed a suite of tools with consumer rated outcome measures varying across jurisdictions.

Development of Indigenous mental health instruments has long been problematic. In the early-1990s consideration was given to inclusion of an Indigenous survey within the National Mental Health Survey. That did not proceed due to what were perceived to be insurmountable political and practical obstacles. An Indigenous mental health workshop was arranged by the Commonwealth as a consequence and was held in Brisbane in the mid-1990s, but which failed to progress the agenda. Subsequently there have been a number of local initiatives. For instance, in Queensland in 1997, a project was undertaken by Alex Goulash working with the Queensland Centre for Schizophrenia Research, which set out to develop a culturally appropriate means for the assessment of psychosis. This was not achievable and the project ultimately focused on developing appropriate mechanisms for engagement around mental health assessment and intervention in Indigenous populations.

In 2001/2002 the Northern Territory coordinated a report on Indigenous mental health measures completed by Tracy Westermann from Western Australia who has undertaken extensive work in developing screening tools for use with Indigenous youth. That report focused primarily on the need for development of new measures. The question of the applicability of existing outcome measures thus remains unclear. As a consequence of the implementation of ROM in Queensland the FNQ service was approached to consider how to proceed. This workshop was convened in order to consider the feasibility of a trial of minimally adapted mainstream measures. To this end it was decided to focus on clinician administered ROM (because consumer ROM are clearly more complex and will demand a much more substantial consultation process which will, however, benefit from the outcomes of this project) for adults only (thus not for children and youth or older consumers).

This initiative, supported by Queensland Health proceeds in parallel to the mainstream implementation of ROM which will include Indigenous consumers. EH emphasised that this first initiative does NOT seek to demonstrate that HoNOS and LSP are appropriate for use in Indigenous populations. It simply aims to demonstrate IF these measures can be used, and in so doing to guide further initiatives (be it to begin from scratch to develop an entirely new set of measures, to further modify the approach to HoNOS and LSP, or to use this experience to proceed to consumer ROM). The benefits of utilising existing practitioner administered ROM (rather than Indigenous-specific) include:

- Enormous effort has already been expended in developing and testing the mainstream measures;
- Indigenous specific measures would require a similarly extensive process and, consequently a significant delay in time;
- Using mainstream measures preserves comparability with other populations in Australia (thus facilitating some of the ends to which application of ROM are used, such as resource allocation);
- The Indigenous population is itself extremely diverse and Indigenous specific ROM must then be responsive to this diversity;

- HoNOS has been used in certain other cultural settings.

This initiative is thus a tentative first step which will inform a much more substantial process. It does not presume that mainstream measures are appropriate or to force their application. It responds to the requirement on all service providers to ensure the quality of the services provided.

General principles of outcome measurement were discussed by TT. An outcome, pragmatically defined as:

The effect on a patient's health that is attributable to an intervention

This may be measured across a range of dimensions: symptoms, disability, service satisfaction, needs, quality of life ...

TT added that, for various reasons, his preference in terms of routine outcome measures (ROM) was for the following working definition which does NOT presume anything about cause:

The change in mental health status between two points in time

Generally accepted principles in assessing status (and change in status):

- Clinical judgements can be 'unstable' – need for shared criteria;
- 'Objective' judgements do not replace clinical judgements
- Multiple informants should be used
- Multiple specialised instruments should be used
- Instruments should be
 - Brief
 - Valid and reliable
 - Useful

The beneficiaries of this process should be broadly considered and include consumers, clinicians, carers, managers, funders, policy makers, ... In this process questions to consider include: Who receives what services, how are they provided, at what cost and to what effect. These activities, incorporating ROM, should be viewed as ongoing quality improvement.

TT and AR spoke at length about the HoNOS and LSP respectively, AR outlining the background, strengths and weaknesses of the 20 and 16 item versions of LSP by comparison to the original. There is now experience with HoNOS in other cultures but, for both HoNOS and LSP there is no experience with Indigenous populations.

Both TT and AR emphasised that both of these measures demands that the practitioner completing the instrument seek information from a range of sources. They similarly emphasised that neither instrument attributes causality – that is, they estimate status over a period of time and do not attribute it to mental disorder per se. Implementation of both includes development of appropriate methods by which to provide information not only to service users but to consumers and carers.

TN talked of the experience in the NT following the Westermann report. The NT has chosen to proceed with implementation of these measures including an item to allow practitioners to identify whether the practitioner felt that social or cultural considerations have influenced the assessment. At present the uptake (rate of implementation) has been slow and there is insufficient information to make any reasonable comment regarding that process. TN and CT both emphasised the need to be able to take into consideration cultural and spiritual issues.

Continuing from this AR spoke to the need to acknowledge and identify strengths rather than to implicitly emphasise pathology or disability. The importance of social disadvantage was discussed at length in terms of its impact both on mental health status and on the process of ROM. The range of appropriate informants for practitioners to seek input from was considered as was the importance of developing appropriate means and mechanisms for providing input back to consumers and carers. The work of Tarun Weeramanthi in the NT (in relation to mortality data feedback) was mentioned.

At the end of Day 1 TT gave a short presentation on factors informing evaluation, noting the following signs of a good evaluation:

- It did not become overly large and complex
- It did justice to everyone's views and ideas
- We learned things from it, it broke new ground
- What it came up with was useful
- It took time

At the beginning of Day 2 RC outlined the national context of implementation of ROM and, with DP-S described the status of the initiative in Queensland. RC emphasised that Commonwealth is very interested in understanding the limitations or inappropriateness of existing measures before proceeding to more radical approaches. TT described the Australian mental Health Outcomes Network, formed in late 2002, which will be taking up particular issues in relation to OM over the next three years under the guidance of an Expert Group.

TT and AR spoke to the HoNOS and LSP respectively in relation to training, process and content. Issues of informed consent were raised. In this regard it was noted that these tools simply attempt to standardise what is usual clinical practice – making an assessment about the status of an individual consumer on which to base judgements about clinical care. Most of the data obtained should already be being integrated into any comprehensive assessment and treatment planning.

There was considerable discussion of particular items on both scales, the impact and means of taking into account social disadvantage, culturally informed behaviours (such as particular patterns of self-harm of quasi-‘psychotic’ phenomena that may reflect traditional issues).

By the afternoon of Day 2 there was consensus that what would emerge would be step one in a phased process utilising HoNOS and LSP with minimal adaptation to content but with recommendations built in to the administration instructions (and thus into training for the HoNOS). The pros and cons of including an additional item to capture (and perhaps quantify) social adversity were discussed (it was noted that items 9-12 of HoNOS already capture some of these issues). AR stated his belief that measurement in the strengths direction was preferable and that the full or 20 item versions of LSP were also preferable (Queensland is currently using the 16 item).

With the decision to proceed with this initiative having been agreed on, the group then considered process issues including phases to the project, support from Queensland Health, possible auspicing organisations, formation of Steering Committee and retention of workshop participants as a wider Reference Group. The need to include a consumer and carer were stated and agreed to. TT and AR both indicated their willingness to remain involved and, potentially, to participate in a follow-up meeting in Cairns. There was also discussion of using information from Indigenous consumers from the ongoing implementation process in

Queensland to inform the ongoing process of adaptation. It was clarified that this was NOT a control group as that process will proceed regardless of this project. The size of the potential consumer population across FNQ and NT are such that data management should not be overly onerous.

Tentative minimal adaptation to HoNOS and LSP

Timeframe for each instrument to remain the same as for mainstream.

Within preamble / instructions

Need to emphasise to practitioner that assessment should be informed by an understanding of consumer's age and social context (including the periodicity of social circumstances in Indigenous communities). However, in completing HoNOS items should be scored as objectively as possible and the practitioner should understand that the scoring does NOT infer causality. In assessing issues of social disadvantage the wider context of disadvantage should be understood but should NOT reduce scoring which should remain objective (that is, scoring of adverse social circumstances in items 9-12 of HoNOS the practitioner should be aware of wider levels of social disadvantage but should not reduce scoring for the consumer being rated).

New box at beginning of instruments

For practitioner to identify whether application has involved consultation with a responsible family member or carer AND a relevant local informant (preferably an Indigenous health practitioner).

Content items

Within HoNOS attention given to providing caveats or guidance within instructions in relation to the following items (importance of the items in order):

- Items 9-12
- Items 1-3
- Item 6

Within LSP attention given to providing caveats or guidance within instructions in relation to the following items (importance of the items in order):

- Items 4 & 5
- Item 3

Following completion of instruments

Practitioner to fill in three items, the first two being boxes, the third being a space for comments:

- 1 How much difficulty have you had in completing this form (tick box or 4 item Likert scale).
- 2 How much does / do the scales reflect the underlying mental health problems (tick box or 4 item Likert scale).
- 3 Comments (what else should be considered)

Tentative project outline

PROM	Practitioner rated outcome measures
CROM	Consumer rated outcome measures

Phase 1: development of Indigenous PROM (version 1) / implementation of mainstream PROM measures

- 1) North Queensland and Northern Territory
WuChopperen MH Outcomes workshop
Circulation of:
 - minutes for outcome workshop – feedback requested
 - draft project proposal – feedback requested
 - draft Indigenous PROM – feedback requested
 Formation of Steering Committee
 First revision of draft Indigenous PROM
 Pilot Indigenous PROM (version 1) ready for implementation
- 2) Wider Queensland
Implementation of mainstream PROM

Phase 2: pilot implementation of Indigenous PROM (version 1)

- 1) NQ & NT
Pilot implementation of Indigenous outcome measures (version 1) NQ & NT
- 2) Wider Queensland
Examination of findings of mainstream PROM
- 3) Development of feedback / engagement protocols; consultation regarding consumer rated measures

Phase 3:

- 1) evaluation of pilot implementation and PROM adaptation
 - Collation and evaluation of findings from NQ / NT pilot implementation
 - Comparison with findings from mainstream PROM with Indigenous consumers
 - Adaptation and production of Indigenous PROM (version 2)
 - Implementation of Indigenous PROM
- 2) Trial of feedback / engagement protocols
- 3) Production of proposal for development of Indigenous CROM

Considerations for evaluation

Quantitative data – completion rates, item analysis, examination of test / retest and inter-rater reliability.

Qualitative data – examination of comments, user interviews.

Corollary data – relationship to diagnoses, mental health service utilisation, other relevant incidents (injuries, police involvement ...).

Appendix 6. Principles Document and Additional Questions added to the Outcomes Information System.**Final Version****Content for Enhanced Training for Clinicians Delivering HoNOS and LSP
with Aboriginal and Torres Strait Islander Consumers****Why is it important to use these instruments?**

The value and validity of using mental health outcomes assessments with Indigenous consumers has been discussed extensively. Some have argued that they are not culturally appropriate and a new set of tools and/or approaches to rating must be developed. However, with the adoption of a standardised outcomes-based approach to resource allocation, planning and service delivery assessment across mental health services, there would be serious disadvantages for any population group that is not included in the current outcomes measurement initiatives. Queensland Health has decided to implement the HoNOS and LSP scales in all communities, and to pay special attention to the evaluation of their reliability, repeatability and validity as outcomes measures among indigenous consumers.

It is clear from a number of studies that there are many potential pitfalls in asking the same set of direct questions regarding indigenous and non-indigenous consumers. However, some of the major pitfalls can be anticipated and serious breaches of reliability and validity may be avoided by incorporating additional guidance in training sessions and written instructions. The aim of this enhanced training is to ensure that clinicians administering these tools with Indigenous consumers have been given adequate direction to ensure a consistent and culturally valid approach to their ratings.

The major issues that need to be considered stem from the complexity of issues which may impact on Indigenous consumers to a greater degree than non-Indigenous consumers. Clinicians may be unclear whether they should or shouldn't take these issues into consideration in their ratings. Therefore, the following definitions and principles are provided to assist clinicians and increase the validity and reliability of the scores.

Basic Issues to Keep in Mind**Identification of Indigenous Status**

The correct identification of Aboriginal and/or Torres Strait Islander ethnicity when completing Outcomes measures is extremely important. This should not be determined by observation alone and should have been, but is not always, identified as part of the routine clinical information gathering. The clinician is reminded that while there are times when Indigenous status is incorrectly assigned (for example with South Sea Islanders or PNG nationals), a more common mistake is to assume the consumer is not Indigenous because of their appearance. It is always important to ask if the consumer is Aboriginal, Torres Strait Islander or both if the information is not already available or may not be reliable.

Assessment Rating Periods

The rating periods for both measures are the same as those established for the general population. These are the last two weeks for HoNOS with the exception following release from inpatient care or extended treatment, and the last three months for LSP.

Definition of Community

The term ‘community’ is used throughout this document. As is the case in the wider Australian society, for Indigenous people this term and the concept of community have multiple meanings. In addition to shared understandings, for Indigenous people community is also used to describe the site and residents of discrete Indigenous settlements many of which were the result of historically imposed bureaucratic expedience rather than common identity or purpose. Regardless, community will here refer to self-identified collectives of Indigenous people, be they in cities, towns or discrete Indigenous settlements who share interests and aspirations for the collective as a whole. This may or may not involve governance.

The term “Community/ambulatory” also has a specific meaning in the context of Outcomes as it describes a specific service type, that is: “mental health services provided to non-mental health in-patients and medical/surgical outpatients accessing ambulatory services provided in outpatient and emergency departments. For the purposes of the outcomes collection this service type only applies to those consumers accepted for on-going treatment or care by the mental health service (including consultation-liaison and assessment services).”

Basic Principles to Follow when Rating Indigenous Consumers

Principle 1. Although the clinician provides the final ratings for HoNOS and LSP, it is extremely important to involve ADDITIONAL INFORMANTS when applying them to Indigenous consumers. Whenever it is possible, please gather information for the assessments from a range of sources, including:

- at least one carer or family member involved in the consumers care **AND**
- one local practitioner (preferably an Indigenous Health Practitioner) who knows the consumer and the community well.

We acknowledge that this may already be part of your standard practice.

There are three major purposes for including additional informants, namely:

- to enable you to gather a comprehensive picture of the consumer’s experience over time
- to help ensure that Indigenous people will accept the ratings as being socially and culturally informed
- To clarify the complex interactions between cultural practices, social circumstances and community standards. The aim of Principles 2-4 is to provide guidance on how these should be taken into account in your ratings.

An extra item has been included which enables you to identify whether you were able to access additional informants while making your assessment.

Principle 2. Your scoring of all issues should objectively reflect underlying social disadvantage experienced by the consumer, and should not be influenced by the fact that similar disadvantage is also widely experienced by the entire community. The outcomes measurements should capture these prevailing levels of social disadvantage as well as any additional disadvantage experienced by the consumer as a result of the illness or disability.

Examples of issues that should be included in your rating if they are present: lack of adequate food supply to the community, overcrowding in households, lack of support services to be accessed, lack of opportunity for employment or other meaningful activity, weekly/fortnightly cycle of income and expenditure

Relevant items include:

HoNOS – Items 9, 10, 11, 12 – Social Problems Items

HoNOS – Item 8 – Other mental and behavioural problems

LSP – Items 4, 5, 9, 13, 16

Principle 3. Your scoring of behaviours that are socially and culturally unacceptable should not be influenced by how common such behaviours are in the community. That is, scoring should objectively reflect behaviours not sanctioned or accepted even if they are common.

Examples: excessive alcohol consumption, violence in the home or community, disruptive behaviour, self-harm which is clearly unconnected to cultural practices shared by others in the community

Relevant items include:

HoNOS – Items 1, 2, 3 – Behavioural Items and Item 8 – Other mental and behavioural problems

LSP – Items 4, 5, 7, 13, 14, 15, 16

Principle 4. Socially and culturally acceptable behaviours, experiences and beliefs associated with funerals, religious or traditional activities SHOULD NOT BE INCLUDED in any assessment items. Therefore you must identify whether the reported / observed findings are consistent with social or cultural practices that are recognised and accepted within the community. If your discussions with a family member/carer and the local practitioner indicate that the behaviours are socially and culturally acceptable, they should not be included in the scoring.

Examples:

- 1) non-accidental self-injury occurring as part of mourning rituals and paranormal phenomena (such as visions and beliefs) in the context of funeral, healing, religious or other traditional activities, where these are recognised and accepted in the community;
- 2) the reported / observed findings are deemed to be acceptable in light of prevailing expectations and standards in the community (for instance standards of grooming and dress such as going barefoot);
- 3) assessment of warmth and interpersonal interactions should take into account community standards, awareness of shame and considerations of privacy and confidentiality in the interview situation.

Relevant items include:

HoNOS – Items 2, – Behavioural Items; 6 - Symptomatic Problems Item, 10 – Social Problems, 8 – other mental and behavioural problems

LSP – Items 1, 2, 3, 4, 5

Feedback on Your Experience in using HoNOS and LSP

While HoNOS and LSP has been extensively trialed and validated for use among mainstream consumers in Australia and many other countries, there has not been a formal assessment of the tools with Indigenous Australians. The implementation of Mental Health Outcomes for Indigenous consumers is being carefully evaluated for its validity, repeatability and reliability in North Queensland. Changes may be made in the content or process in the future if necessary to make improvements. We therefore greatly value your feedback and reflections on the rating process. Five short items plus space for you to provide any additional feedback

have been added as part of the collection occasion to enable you to inform this process from your experiences. Kindly complete these items as the feedback will be greatly appreciated and used.

1 Some Sample Scenarios to add to the Outcomes Collection Protocol

SCENARIO	COMMON QUESTIONS	PROTOCOL REQUIREMENTS
Principle 1		
<p>You are in a hurry and an Indigenous consumer who is due for outcomes assessment arrives alone and late for her appointment. There is no phone at her house and it is across town. There is no vehicle free.</p>	<p>You have concluded there is no way to complete an outcomes assessment during this time that is informed by a family member or carer.</p> <p>Shall I carry out the assessment anyway?</p> <p>Shall I delay my assessment?</p> <p>What should I do?</p>	<p>Suggested pathway in order of preference</p> <p>1 : delay the assessment until both a carer and local practitioner can be consulted, as long as you can keep within an acceptable timeframe</p> <p>2 : if the time delay will be too long, seek the engagement of an indigenous local health practitioner who knows the consumer well</p> <p>3 : if the above is not available at the time, organise contact with the carer and practitioner at a later time (e.g. by phone) to complete the items.</p> <p>4: if none of the above is possible, conduct the assessment and appropriately mark the INPUT item near the end of the assessment.</p>
Principle 2		
<p>It is Friday of payweek. The consumer has shared his/her pension with family members and has no money left to buy food for the next 12 days.</p>	<p>How do I rate this person's social circumstances when I know that his/her lack of money for food is related to wider social disadvantage and not to the mental illness?</p>	<p>Rating should reflect the lack of resources only and NOT be influenced by the reasons underlying the lack of resources, or by how common the circumstance is in the community.</p>
<p>The consumer has not worked or participated in any work related program and has been living off his partner's child endowment funding.</p>	<p>How do I rate this person's occupation and activities, and capacity for work when all that is available in the community is CDEP (work for the dole) funding for two days per week?</p>	<p>Rating should reflect the lack of participation in available formal opportunities (in this case CDEP) or in subsistence activities (hunting and fishing). Score this item objectively, regardless of whether it is due to choice, lack of capacity or absence of opportunities.</p>

Principle 3		
The consumer is binge drinking after payday and frequently injured in fights.	How do I rate this person's behaviour that is common among young adult males in this community?	Regardless of commonality, community standards do not condone binge drinking or violence and rating should reflect this. The rating should NOT be influenced by how common such behaviours are within the consumer's peer group.
The consumer's self care and activities of daily living are extremely poor.	How do I rate this when prevailing social disadvantage is such that general levels of self-care are lower than in the mainstream?	Standards and expectations exist in all communities regardless of prevailing disadvantage. The clinician must find out from a local informant (e.g. indigenous health practitioner) to what extent the level achieved by the consumer meets local standards.
Principle 4		
The consumer has sustained cuts to her head which she states are "sorry cuts" following a recent death.	Should I rate this as deliberate self-injury when I am informed that this is a common and understood behaviour?	In such circumstances, the clinician is strongly advised to find out from a cultural informant to what extent the behaviour in question is recognised as understandable and acceptable by the community. If the cutting is recognised and understood within this community as a shared sign of grief, this behaviour should NOT be rated as non-accidental self-harm.
The consumer stabbed himself while intoxicated and attributes it to 'grief'.	Should I rate this as deliberate self-injury when I am informed that 'sorry cuts' are a real phenomenon? It is not clear if this young man's behaviour is considered acceptable cultural behaviour or if it is atypical and extreme.	In such circumstances, the clinician is strongly advised to find out from a cultural informant to what extent the behaviour in question is recognised as understandable and acceptable by the community. If a particular behaviour is not recognised within this community as an acceptable shared sign of grief, the behaviour SHOULD be rated as non-accidental self-injury.
The consumer has reported frequent 'visions' of a dead relative.	Should I rate this as disordered perception?	In such circumstances, the clinician is strongly advised to find out from a cultural informant to what extent the behaviour in question is recognised as understandable and acceptable by the community. If these visions have occurred following a death and there is consensual understanding and acceptance of its manifestation and duration, this should NOT be rated as a hallucination. If this is not the case, then the rating SHOULD reflect the experiences as hallucinations.

<p>The consumer has been housebound due to fears of <i>puri-puri</i> (sorcery)</p>	<p>Should I rate this as disordered ideation? How should I rate the consumer's isolation and withdrawal?</p>	<p><i>In such circumstances, the clinician is strongly advised to find out from a cultural informant to what extent the Beliefs are consistent with locally shared beliefs and customs. If they are consistent, the clinician needs to further assess if the behaviours have been consistent (in terms of duration and manifestations) with expectations based on those beliefs. If both belief and behaviours are consistent, then they should NOT be rated. If either the belief or the behaviour is NOT consistent, then rating SHOULD reflect the symptomatology.</i></p>
<p>The consumer has almost no eye contact with the rater with little warmth and limited communication.</p>	<p>How do I rate the consumer based on this first hand experience?</p>	<p><i>In such circumstances, the clinician is strongly advised to find out from a cultural informant to what extent the Shyness and lack of warmth displayed in this circumstance is considered understandable and acceptable by the community. The clinician needs to understand local norms for shyness and 'shame'. Assessment must take into account the consumer's general inter-personal capacities over the rating period.</i></p>

Comment included in the preamble of the HoNOS

In completing the HoNOS for an Indigenous consumer it is important that you maintain the integrity of the instrument by rating the consumer's health status and severity of symptoms (over the last two weeks except following release from inpatient care or extended treatment) in the same way as you would for the wider population. Do not modify these ratings to accommodate social disadvantage or common but socially unacceptable behaviour.

Comment included in the preamble of the LSP

In completing the LSP for an Indigenous consumer, it is important that you maintain the integrity of the instrument by rating the consumer's general functioning and disability (over the last three months) in the same way as you would for the wider population. Do not modify these ratings to accommodate social disadvantage or common but socially unacceptable behaviour.

Amendments to items in HoNOS

SOCIAL PROBLEMS ITEMS

Item 9

Rate the consumer's most severe problem associated with active or passive withdrawal from social relationships and / or non-supportive, destructive or self-damaging relationships.

Rate the severity of impairment and do not be influenced by prevailing levels of social disadvantage.

Item 10

Rate the overall functioning in activities of daily living; eg problems with basic activities of self care such as eating, washing, dressing, toilet; also **complex skills** such as budgeting, organising where to live, occupation and recreation, mobility and use of transport, shopping, self-development, etc. Include any lack of motivation for using self-help opportunities since this contributes to a lower level of functioning. Do not include lack of opportunities for exercising intact abilities and skills rated at items 11 –12.

In rating, self care and complex skills (exclusive of living conditions and occupation / activities rated in 11 and 12) should not be influenced by prevailing levels of social disadvantage, but should take into account the standards and expectations of the community as a whole.

Item 11

Rate the overall severity of problems with the quality of living conditions and daily domestic routine. Are the basic necessities met (heat, light, hygiene)? If so is there help to cope with disabilities and a choice of opportunities to use skills and develop new ones? Do not rate the level of functional disability itself, rated at item 10.

NB rate the consumers usual accommodation – if in acute ward rate the home accommodation.

Rating should be objective and not influenced by prevailing levels of disadvantage in relation to living conditions.

Item 12

Rate the overall level of problems with quality of daytime environment. Is there help to cope with disabilities, and opportunities for maintaining or improving occupational and recreational skills and activities? Consider factors such as stigma, lack of qualified staff, access to supportive facilities. For example - staffing and equipment of day centres, workshops, social clubs etc.... Do not rate the level of functional disability rated at item 10.

NB rate the consumer's usual situation.

Rating should be objective and not influenced by prevailing levels of disadvantage in relation to resources and facilities.

BEHAVIOURAL PROBLEMS ITEMS

Item 1

Overactive, aggressive, disruptive or agitated behaviour. Include such behaviour due to any cause, e.g. drugs, alcohol, dementia, psychosis, depression, etc. Do not include bizarre behaviour rated at item 6.

Rating should be objective BUT should not include behaviours associated with funeral, religious or traditional activities that are sanctioned by the community.

Item 2

Non-accidental self-injury. Do NOT include accidental self-injury due, for example, to dementia or severe learning disabilities; the cognitive problem is rated at item 4 and the injury at item 5. Do not include illness or injury as a direct consequence of drug / alcohol use rated at item 3 (e.g. cirrhosis of the liver or injury resulting from drunk driving are rated at item 5).

Rating should be objective BUT socially sanctioned self-injury in the context of funeral or traditional activities should NOT be considered non-accidental self-harm.

Item 3

Problem drinking or drug taking. Do NOT include aggressive / destructive behaviour due to alcohol or drug use rated at item 1. Do NOT include physical illness or disability due to alcohol or drug use rated at item 5.

Rating should be objective and not influenced by the prevailing patterns and levels of consumption within the consumer's social environment or peer group.

SYMPTOMATIC PROBLEMS ITEM

Item 6

Problems associated with hallucinations and delusions. Include hallucinations irrespective of diagnosis. Include odd and bizarre behaviour associated with hallucinations or delusions. Do NOT include aggressive, destructive or overactive behaviours attributed to hallucinations or delusions rated at item 1.

Rating should be objective BUT should NOT include experiences and beliefs associated with funeral, religious or traditional activities that are sanctioned by the community.

Item 8

In assessing individual symptomatology, the same principles outlined above apply, e.g. include symptoms caused or aggravated by underlying social disadvantage and include symptoms that reflect behaviours or moods that fall outside the accepted social and cultural boundaries, but do NOT include symptoms that are manifestations of accepted social or cultural practices.

Rating should be objective according to the principles outlined for other items.

Amendments to items in LSP

SELF CARE SUBSCALE

Item 4

Is the person generally well groomed (e.g. neatly dressed, hair combed)?

Rate this item taking into account accepted community standards.

Item 5

Does this person wear clean clothes generally or ensure that they are cleaned if dirty?

Rate this item taking into account accepted community standards.

WITHDRAWAL SUBSCALE

Item 3

Does this person generally show warmth to others?

Rate this item taking into account accepted community standards and the fact that the assessment situation may provoke feelings of shame and shyness, and concerns about privacy and confidentiality that can appear as a lack of warmth.

Additional Screen in the Outcome Information System

When you are assessing an Aboriginal and/or Torres Strait Islander consumer, you will need to fill out six items on an additional screen before completion. On this screen, there will be five short questions about your experience in completing the ratings followed by a question asking you to write in any comments you have. The implementation of Mental Health Outcomes for Indigenous consumers is being carefully evaluated for its validity, repeatability and reliability in North Queensland so your insight and experience on the process is most welcome.

INPUT

1. In completing the outcome measures for this consumer, did your assessment include information from a family member/carer **AND** a local health practitioner (preferably an Indigenous health practitioner)? Please specify by selecting one choice below:

- 0 Neither
- 1 Family /Carer
- 2 Local health practitioner
- 3 Both

FEEDBACK

In order to assist in evaluation of the Indigenous Mental Health Outcomes Implementation process, we would be extremely grateful if you would provide the following feedback.

2. Compared to your experience with the mainstream measures, has there been additional difficulty in completing the measures with this Indigenous consumer?

- 0 no
- 1 some
- 2 moderate
- 3 substantial

3. How well do you feel the scales reflect the underlying mental health problems of this Indigenous client?
 - 0 good agreement
 - 1 reasonable
 - 2 inadequate
 - 3 poor

4. How interested and / or engaged do you feel the carer/family member(s) were in being involved in the assessment process?
 - 0 Uninterested or unengaged, or showed resistance
 - 1 mixed response
 - 2 interested and engaged
 - 9 I couldn't tell
 - 7 I could not access a carer or family member for the assessment

5. How interested / engaged do you feel the local practitioner was in being involved in the assessment process?
 - 0 Uninterested or unengaged, or showed resistance
 - 1 mixed response
 - 2 interested and engaged
 - 9 I couldn't tell
 - could not access a local practitioner for the assessment

6. We would be extremely grateful if you are able to provide any additional comments in relation to your own experience filling out these instruments and observations you made about the response of the consumer, other key informants you spoke with and the health centre or community to the use of these instruments.



First Name: _____
 Last Name: _____
 Sex: Male Female Unknown
 Date of Birth / /
 (affix patient label here)

Indigenous Consumer Survey Questions

In order to assist in evaluation of the Indigenous Mental Health Outcomes Implementation process, we would be extremely grateful if you would provide the following feedback.

<p>In completing the outcome measures for this consumer, did your assessment include information from a family member/carer AND a local health practitioner (preferably an Indigenous health practitioner)? Please specify by selecting one of the</p>	<p>Neither <input type="checkbox"/> Family/Carer <input type="checkbox"/> Local health practitioner <input type="checkbox"/> Both <input type="checkbox"/> Not stated/Missing <input type="checkbox"/></p>
<p>1. Compared to your experience with the mainstream measures, has there been additional difficulty in completing the measures with this Indigenous consumer?</p>	<p>No <input type="checkbox"/> Some <input type="checkbox"/> Moderate <input type="checkbox"/> Substantial <input type="checkbox"/> Not stated/Missing <input type="checkbox"/></p>
<p>2. How well do you feel the scales reflect the underlying mental health problems of this Indigenous consumer?</p>	<p>Good agreement <input type="checkbox"/> Reasonable <input type="checkbox"/> Inadequate <input type="checkbox"/> Poor <input type="checkbox"/> Not Stated/Missing <input type="checkbox"/></p>
<p>3. How interested and/or engaged do you feel the consumer was when you were conducting the assessment that informed the completion of the HoNOS and LSP-16?</p>	<p>Disinterested and unengaged, or resistant <input type="checkbox"/> Mixed response <input type="checkbox"/> Interested and engaged <input type="checkbox"/> Consumer was not well enough to be involved <input type="checkbox"/> I couldn't tell <input type="checkbox"/></p>

OUTCOMES: Adult and older persons measures – Indigenous Questions



First Name: _____
 Last Name _____
 Sex: Male Female Unknown
 Date of Birth / /
 (affix patient label here)

Indigenous Consumer Survey Questions (continued)

In order to assist in evaluation of the Indigenous Mental Health Outcomes Implementation process, we would be extremely grateful if you would provide the following feedback.

<p>4. How interested and/or engaged do you feel the carer/family members(s) were in being involved in the assessment process?</p>	<p>Disinterested and unengaged, or resistant <input type="checkbox"/></p> <p>Mixed response <input type="checkbox"/></p> <p>Interested and engaged <input type="checkbox"/></p> <p>I could not access a carer or family member for the assessment <input type="checkbox"/></p> <p>I couldn't tell <input type="checkbox"/></p>
<p>5. How interested/engaged do you feel the local practitioner was in being involved in the assessment process?</p>	<p>Disinterested and unengaged, or resistant <input type="checkbox"/></p> <p>Mixed response <input type="checkbox"/></p> <p>Interested and engaged <input type="checkbox"/></p> <p>I could not access a local practitioner for the assessment <input type="checkbox"/></p> <p>I couldn't tell <input type="checkbox"/></p>
<p>6. We would be extremely grateful if you are able to provide any additional comments in relation to your own experience filling out these instruments and observations you made about the response of the consumer, other key informants you spoke with and the health centre or community to the use of these instruments.</p>	
<p>_____</p>	
<p>_____</p>	
<p>_____</p>	
<p>_____</p>	
<p>_____</p>	
<p>_____</p>	
<p>_____</p>	
<p>_____</p>	
<p>_____</p>	

OUTCOMES: Adult and older persons measures – Indigenous Questions

Appendix 7. Additional Engagement, Training and Evaluation Tools: Outcomes Initiative Information Sheet 5 Role of Zonal Outcomes Coordinator, Outcomes Initiative information pamphlet for Indigenous communities, Principles for rating Adult Indigenous Consumers, HoNOS Guidelines for Indigenous Adults, Refresher session Powerpoint and the Health Worker Forum Evaluation Sheet.
(PLEASE NOTE THESE WERE BASED ON THE ORIGINAL PRINCIPLES ONE AND FOUR)



Zonal Outcomes Coordinator (ZOC)

The Zonal Outcomes Coordinator (ZOC) position was established to assist and support mental health managers, team leaders and clinical staff with the implementation of standardized outcome measures into all public mental health services.

1. Service Readiness

Initially, the ZOC role focussed on 'Service Readiness'. This involved the provision of support to networks/districts to develop their structural and organizational capacity to successfully implement the Outcomes Initiative. The ZOC's role and responsibilities in relation to service readiness activities have included:

- providing support to local network/district implementation committees to provide an organizational orientation to the Outcomes Initiative and identify risks and strategies for successful implementation
- meeting with individual mental health teams to provide clinicians with an orientation to the goals of the Outcomes Initiative and its potential to support clinical practice
- facilitating meetings with consumers, carers and other stakeholder groups to provide a general orientation to the Outcomes Initiative and its potential to improve the quality of mental health care received
- supporting the Outcomes Training Team with co-ordination of training including identification of training facilities and liaison with local implementation teams.


2. Support Post-Implementation

The ZOC role post implementation of the Outcomes Initiative has developed in partnership with networks/districts, however the role remains flexible to accommodate individual network/district needs. Examples of the ZOC role includes:

- encouraging and supporting clinicians to increase their confidence with Outcomes Initiative Collection Protocol
- assisting with Outcomes Information System report analysis and interpretation at the clinical level
- providing support and guidance to implementation groups to develop 'local' Outcomes Initiative business rules
- identification of practical issues associated with the Outcomes Information System and contribute to further enhancement priorities
- liaise with Systems and Outcomes Team, Mental Health Unit to review future information development needs for mental health clinical service delivery.

3. Clinical liaison and problem solving

The primary focus of the Outcomes Initiative is to ensure that the information developed is clinically useful and meaningful to the clinician, the treating team, consumers and carers. A key role of the ZOC is to work in partnership with networks/districts to find creative and innovative ways to embed outcome measures into day to day clinical practices.

 **Do I get to see the results?**

YES.

Your mental health worker will go through all the results with you.

If you have any questions about your results remember to ask ... your mental health worker will answer them for you.

Will my information be kept private?

YES.

All the information about you is kept strictly private and confidential.

Your mental health worker might need to talk to some others about your care. This could include:

- Your doctor
- A previous/current counsellor.

Your worker will need your "Ok" to do this.

Do I have to answer the questions?

No — it is YOUR choice.

But, please remember, it can really help you.

 **Got more questions?**

Please talk with your mental health worker or doctor.
For general information you can contact Queensland Health's Outcomes team at

Information Systems and Management Team
Mental Health Unit
Queensland Health
GPO Box 48

BRISBANE QLD 4001
Telephone: (07) 3234 0671
Facsimile: (07) 3234 1362
e-mail: outcomesinitiative@health.qld.gov.au

Other helpful service numbers.....

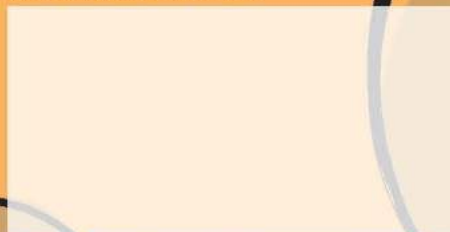
Lifeline
13 11 14
(24 hours / 7 days a week)

Health Information Line
Telephone: (07) 3236 4833



Health Rights Commission
Telephone: 3234 0272 or 1800 077 308 (regional Queensland)

**Information Systems and Management
Mental Health Unit**
Telephone: (07) 3234 0759
Facsimile: (07) 3234 1362
outcomesinitiative@health.qld.gov.au

Local Mental Health Service



The collection of Outcome measures is part of the National Mental Health Strategy approved by the Commonwealth and all Territory and State Health Ministers

 **Outcomes Initiative
Outcome Questions** 

Queensland Health would like to acknowledge the contribution and funding received from the Australian Government Department of Health and Ageing.



**Queensland
Government**
Queensland Health

This brochure is for YOU!

It will help to explain Outcome Initiative and how it can help you.



Introduction

Queensland Health wants to improve mental health services and the quality of life for people living with mental health problems and illness. We can do this by understanding your needs and by measuring our effectiveness in providing the care and treatment you need.



Why do we have Outcome questions?

The Outcome questions help us to understand you better.

They give us a good idea of things like

- How you are doing
- How you are feeling
- How you are coping with things

What are the questions?

There are 2 sets of questions: One is completed by you and the other by your mental health worker.

The questions aren't hard. Most are as easy as ticking a box.

You decide the answer that describes you the best.

Some examples are:

"How much of the time have you felt lonely during the past month?"

"How much time, during the last month, did you feel relaxed and free from tension?"

"During the past month, how much of the time have you been moody or brooded about things?"

Remember, you can ask your mental health worker for help filling out the questions.



When do I answer these questions?

You may be asked to answer these questions several times such as:

- On the first day you go to talk to the mental health worker
- Sometime during your care and treatment
- Just before you see your mental health worker for the last time
- Or, if you are in hospital, just before you go home.

Your worker might also ask you to fill it out more than once

This all helps you and your worker to check on your progress.

REMEMBER – you can also ask at ANY time during your treatment to answer the questions again.

What about the results?

They help us to work out the best way to help you.

- It might show us that things have changed for you
- It might mean that your helping plan needs to change so that it is right for you.



Principles for use of HoNOS and LSP-16 with Indigenous Consumers		
Principle	HoNOS	LSP-16
1. Although clinicians provide the final ratings for the HoNOS and LSP-16, it is extremely important to involve additional informants when applying these measures to indigenous consumers.		
2. The clinician's scoring of all issues should objectively reflect underlying any social disadvantage experienced by the consumer and should not be influenced by the fact that similar disadvantage is also widely experienced by the entire community.	8, 9, 10, 11, 12	4, 5, 9, 13, 16
3. The clinician's scoring of behaviours that are socially and culturally unacceptable should not be influenced by how common such behaviours are in the community.	1, 2, 3, 8	4, 5, 7, 13, 14, 15, 16
4. Socially and culturally acceptable behaviours, experiences and beliefs associated with funerals, religious or traditional activities should not be included in any assessment items.	2, 6, 8	1, 2, 3, 4, 5



outcomes



HoNOS Guidelines for Indigenous Adults

Use of Outcome Measures with Indigenous Adults

HoNOS

Scale 1 Overactive, aggressive, disruptive or agitated behaviour

Include such behaviour due to any cause, e.g. drugs, alcohol, dementia, psychosis, depression, etc.

Do not include bizarre behaviour rated at Scale 6.

Rating should be objective but not include behaviours associated with funeral, religious or traditional activities that are sanctioned by the community.

- 0 No problems of this kind during the period rated.
- 1 Irritability, quarrels, restlessness, etc. not requiring action.
- 2 Includes aggressive gestures, pushing or pestering others; threats or verbal aggression; lesser damage to property (e.g. broken cup, window); marked overactivity or agitation.
- 3 Physically aggressive to others or animals (short of rating 4); threatening manner; more serious overactivity or destruction of property.
- 4 At least one serious physical attack on others or on animals; destruction of property (e.g. fire-setting); serious intimidation or obscene behaviour.

Scale 2 Non-accidental self-injury

Do not include accidental self-injury (due e.g. to dementia or severe learning disability); the cognitive problem is rated at Scale 4 and the injury at Scale 5.

Do not include illness or injury as a direct consequence of drug/alcohol use rated at Scale 3 (e.g. cirrhosis of the liver or injury resulting from drunk driving are rated at Scale 5).

Rating should be objective but socially sanctioned self harm in the context of funeral or traditional activities should not be considered non-accidental self harm.

- 0 No problem of this kind during the period rated.
- 1 Fleeting thoughts about ending it all but little risk during the period rated; no self-harm.
- 2 Mild risk during period; includes non-hazardous self-harm, e.g. wrist-scratching.
- 3 Moderate to serious risk of deliberate self-harm during the period rated; includes preparatory acts, e.g. collecting tablets.
- 4 Serious suicidal attempt and/or serious deliberate self-injury during period.

Scale 3 Problem drinking or drug taking

Do not include aggressive/destructive behaviour due to alcohol or drug use, rated at Scale 1.

Do not include physical illness or disability due to alcohol or drug use, rated at Scale 5.

Rating should be objective and independent of prevailing patterns of consumption within the consumer's social environment or peer group.

- 0 No problem of this kind during the period rated.
- 1 Some over-indulgence but within social norm.
- 2 Loss of control of drinking or drug-taking; but not seriously addicted.
- 3 Marked craving or dependence on alcohol or drugs with frequent loss of control, risk taking under influence (e.g. drunk driving), etc.
- 4 Incapacitated by alcohol/drug problems.

Scale 4 Cognitive Problems

Include problems of memory, orientation and understanding associated with any disorder: learning disability, dementia, schizophrenia, etc.

Do not include temporary problems (e.g. hangovers) resulting from drug/alcohol use, rated at Scale 3

- 0 No problem of this kind during the period rated.
- 1 Minor problems with memory or understanding e.g. forgets names occasionally.
- 2 Mild but definite problems, e.g. has lost way in a familiar place or failed to recognise a familiar person; sometimes mixed up about simple decisions.
- 3 Marked disorientation in time, place or person, bewildered by everyday events; speech is sometimes incoherent; mental slowing.
- 4 Severe disorientation, e.g. unable to recognise relatives, at risk of accidents, speech incomprehensible, clouding or stupor.

Scale 5 Physical illness or disability problems

Include illness or disability from any cause that limits or prevents movement, or impairs sight or hearing, or otherwise interferes with personal functioning.

Include side-effects from medication; effects of drug/alcohol use; physical disabilities resulting from accidents or self-harm associated with cognitive problems, drunk driving etc.

Do not include mental or behavioural problems rated at Scale 4.

- 0 No physical health problem during the period rated.
- 1 Minor health problem during the period (e.g. cold, non-serious fall, etc.).
- 2 Physical health problem imposes mild restriction on mobility and activity
- 3 Moderate degree of restriction on activity due to physical health problem.
- 4. Severe or complete incapacity due to physical health problem.

Scale 6 Problems associated with hallucinations and delusions

Include hallucinations and delusions irrespective of diagnosis.

Include odd and bizarre behaviour associated with hallucinations or delusions.

Do not include aggressive, destructive or overactive behaviours attributed to hallucinations or delusions, rated at Scale 1.

Rating should be objective but not include beliefs and experiences associated with funeral, religious or traditional activities that are sanctioned by the community.

- 0 No evidence of hallucinations or delusions during the period rated.
- 1 Somewhat odd or eccentric beliefs not in keeping with cultural norms.
- 2 Delusions or hallucinations (e.g. voices, visions) are present, but there is little distress to consumer or manifestation in bizarre behaviour, i.e. clinically present but mild.
- 3 Marked preoccupation with delusions or hallucinations, causing much distress and/or manifested in obviously bizarre behaviour, i.e. moderately severe clinical problem.
- 4 Mental state and behaviour is seriously and adversely affected by delusions or hallucinations, with severe impact on consumer.

Scale 7 Problems with depressed mood

Do not include overactivity or agitation, rated at Scale 1.

Do not include suicidal ideation or attempts, rated at Scale 2.

Do not include delusions or hallucinations, rated at Scale 6.

- 0 No problems associated with depressed mood during the period rated.
- 1 Gloomy; or minor changes in mood.
- 2 Mild but definite depression and distress: e.g. feelings of guilt; loss of self-esteem.
- 3 Depression with marked physical or mental slowing, inappropriate self-blame, preoccupied with feelings of guilt.
- 4 Severe or very severe depression, with guilt or self-accusation.

Scale 8 Other mental and behavioural problems

Rate only the most severe clinical problem not considered at Scale 6 and 7 as follows: specify the type of problem by entering the appropriate letter: A phobic; B anxiety; C obsessive-compulsive; D stress; E dissociative; F somatoform; G eating; H sleep; I sexual; J other specified problem.

Ratings should be objective according to the principles outlined for the other items.

- 0 No evidence of any of these problems during period rated.
- 1 Minor non-clinical problems.
- 2 A problem is clinically present at a mild level, e.g. consumer/consumer has a degree of control.
- 3 Occasional severe attack or distress, with loss of control (e.g. has to avoid anxiety provoking situations altogether, call in a neighbour to help, etc.) i.e. moderately severe level of problem.
- 4 Severe problem dominates most activities.

Scale 9 Problems with relationships

Rate the consumer's most severe problem associated with active or passive withdrawal from social relationships, and/or non-supportive, destructive or self-damaging relationships

Rate the severity of the impairment and do not be influenced by prevailing levels of social disadvantage.

- 0 No significant problems during the period.
- 1 Minor non-clinical problems.
- 2 Definite problems in making or sustaining supportive relationships: consumer complains and/or problems are evident to others.
- 3 Persisting major problems due to active or passive withdrawal from social relationships, and/or to relationships that provide little or no comfort or support.
- 4 Severe and distressing social isolation due to inability to communicate socially and/or withdrawal from social relationships.

Scale 10 Problems with activities of daily living

Rate the overall level of functioning in activities of daily living (ADL): e.g. problems with basic activities of self-care such as eating, washing, dressing, toilet; also complex skills such as budgeting, organising where to live, occupation and recreation, mobility and use of transport, shopping, self-development, etc.

Include any lack of motivation for using self-help opportunities, since this contributes to a lower level of functioning.

Do not include lack of opportunities for exercising intact abilities and skills, rated at Scales 11-12

For Indigenous consumers, self care and complex skills (exclusive of living conditions and occupation/activities rated in Scale 11 and 12) should not be influenced by prevailing levels of social disadvantage, but should take into account the standards and expectations of the community as a whole.

- 0 No problems during period rated; good ability to function in all areas.
- 1 Minor problems only e.g. untidy, disorganised.
- 2 Self-care adequate, but major lack of performance of one or more complex skills (see above).
- 3 Major problems in one or more areas of self-care (eating, washing, dressing, toilet) as well as major inability to perform several complex skills.
- 4 Severe disability or incapacity in all or nearly all areas of self-care and complex skills.

Scale 11 Problems with living conditions

Rate the overall severity of problems with the quality of living conditions and daily domestic routine.

Are the basic necessities met (heat, light, hygiene)? If so, is there help to cope with disabilities and a choice of opportunities to use skills and develop new ones?

Do not rate the level of functional disability itself, rated at Scale 10.

N.B. Rate the consumer's usual accommodation. If in acute ward, rate the home accommodation. If information is not obtainable, rate 9.

Rating should not be influenced by prevailing levels of disadvantage in relation to living conditions.

- 0 Accommodation and living conditions are acceptable; helpful in keeping any disability rated at Item 10 to the lowest level possible, and supportive of self-help.
- 1 Accommodation is reasonably acceptable although there are mild or transient problems (e.g. not ideal location, not preferred option, doesn't like food, etc.).
- 2 Significant problems with one or more aspects of the accommodation and/or regime: e.g. restricted choice; staff or household have little understanding of how to limit disability, or how to help develop new or intact skills.
- 3 Distressing multiple problems with accommodation; e.g. some basic necessities absent; housing has minimal or no facilities to improve consumer's independence.
- 4 Accommodation is unacceptable: e.g. lack of basic necessities, consumer is at risk of eviction, or 'roofless', or living conditions are otherwise intolerable making consumer's problems worse

Scale 12 Problems with occupation and activities

Rate the overall level of problems with quality of day-time environment. Is there help to cope with disabilities, and opportunities for maintaining or improving occupational and recreational skills and activities? Consider factors such as stigma, lack of qualified staff, access to supportive facilities, e.g. staffing and equipment of day centres, workshops, social clubs, etc.

Do not rate the level of functional disability itself, rated at Scale 10.

N.B. Rate the consumer's usual situation. If in acute ward, rate activities during period before admission. If information not obtainable, rate 9.

Rating should not be influenced by prevailing levels of disadvantage in relation to resources and facilities.

- 0 Consumer's day-time environment is acceptable; helpful in keeping any disability rated at Item 10 to the lowest level possible, and supportive of self-help.
- 1 Minor or temporary problems e.g. late pension cheques, reasonable facilities available but not always at desired times etc.
- 2 Limited choice of activities; e.g. there is a lack of reasonable tolerance (e.g. unfairly refused entry to public library or baths etc.); or handicapped by lack of a permanent address; or insufficient carer or professional support; or helpful day setting available but for very limited hours.
- 3 Marked deficiency in skilled services available to help minimise level of existing disability; no opportunities to use intact skills or add new ones; unskilled care difficult to access
- 4 Lack of opportunity for daytime activities makes consumer's problems worse.

Refresher Session Powerpoint

AIMhi
outcomes

Utilising
Mental Health Measurements
with
Indigenous Adults

Refresher Session

Queensland Government

Why Collect Outcomes Measurements?

- The aspiration is to build an informed mental health system where information is available to guide decisions at all levels to:
 - Support clinicians in their treatment decisions
 - Strengthen the focus on consumer outcomes and inform consumers about the services they receive
 - Help managers manage
 - Improve understanding of population needs
 - Inform policy makers in planning for services

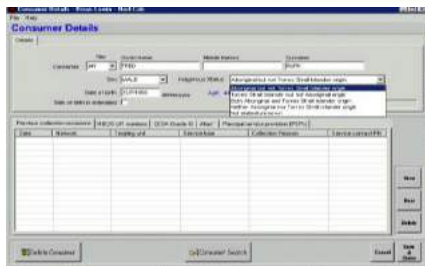
Why have Special Consideration for Measurement with Indigenous Consumers (and other Social and Cultural Groups)?

- it is of great importance that the whole population be effectively included in Outcomes Measurement
- rating of socially and culturally distinct groups may require further clarification to ensure the ratings are reliable, valid and accepted

Outcomes Assessment : Progress Statewide and Cairns Network

- Outcome Measures: HoNOS, LSP, MHI & FOC
- Pre-implementation statewide training program,
 - over 3,000 clinicians trained in 2003
- Go-Live implementation completed Dec 2003
- With supporting documentation, brochures, materials
- Electronic database developed for user-friendly access
- Statewide addition of Indigenous identifier question with encouragement to **ASK, Don't Assume**.
- Cairns Network selected for pilot/evaluation of Indigenous Outcomes Measurement
- Queensland, not first, but possibly most prepared state

Indigenous Identifier Screen



Indigenous Adult Mental Health Outcomes Evaluation Project: 2004

Set of principles and guidelines developed specifically to assist rating for Aboriginal and Torres Strait Islander consumers

Aims to maximise benefits of Outcomes Measurement by monitoring, exploring and promoting:

- Acceptability to the Community
- Validity & Meaning to Consumers
- Reliability and Repeatability of Ratings
- Sustainability through Utility

Four Areas of Focus Acceptability and Validity

- 1. Acceptability to the Community**
Develop/Evaluate Engagement protocols and materials for Health Centres and Clinicians to help inform about:
 - Why are outcomes assessments being done?
 - What are the benefits to consumer, carer, community?
 - What limitations - Is there any potential for harm?
- 2. Valid and Meaningful to Consumers**
In depth interviews with consumers and carers to find out:
 - Does what is being measured in HoNOS and LSP really capture what Indigenous consumers and carers feel is important in their lives and what they expect MH service delivery to assist in?

Four Areas of Focus Reliability and Utility

- 3. Reliability and Repeatability of Ratings**
 - Clinicians' measurements must be reliable to be of value – minimise inter-rater variation via enhanced training & support (e.g. ZOC, telehealth, case reviews)
 - Good communication about areas of difficulty to enable strategic improvement, retreat
- 4. Sustainability via Utility**
For Clinician/ Consumer/ Carer in communication, care planning, resource allocation
 - Supporting circular movement of information beyond clinical detail from consumer, carer, local practitioner to clinician to system and back from system to clinician to consumer, carer, local practitioner.

Four Areas of Focus
Reliability and Repeatability of Ratings

- Clinician Focus - Your Work is Very Important
- Using the same tools and general instructions for Indigenous and non-Indigenous consumers (HoNOS/LSP/MHI/FOC)
- But require additional assurance that ratings are done with the same set of considerations and similar scoring no matter who is the rater (similar or less variation than for non-Indigenous)
- Principles, scenarios, instructions, training and ongoing support to assist clinicians in rating

Four Principles of Rating Indigenous Consumers

- **SHOULD** involve additional informants wherever possible : Family member/carer **PLUS** a local health practitioner
- **SHOULD** reflect underlying disadvantage (even if common)
- **SHOULD** reflect socially and culturally unacceptable behaviour (even if common)
- **SHOULD NOT** reflect socially/culturally acceptable behaviours, experiences and beliefs

What am I rating against?

- Your rating should reflect both the degree of distress the problem causes and the effect it has on behaviour

HoNOS (5 point scale)	LSP (4 point scale)
0 if no problem	LSP 0
1 if minor problem, no formal action	LSP 1
2 if mild problem	LSP 1
3 if problem of moderate severity	LSP 2
4 if severe to very severe problem	LSP 3

- Try not to use 9: not known or not applicable

Principle 1.

- **Although the clinician provides the final ratings for HoNOS and LSP, it is extremely important to INVOLVE ADDITIONAL INFORMANTS when applying them to Indigenous consumers.**

Whenever possible, gather information from a range of sources, including: at least one carer or family member involved in the consumer's care **AND** one local practitioner (preferably Indigenous Health Practitioner) who knows the consumer and the community well.
We acknowledge this may already be part of your standard practice.

Three major purposes for including additional informants, namely to help: gather a comprehensive picture of the consumer's experience over time ensure Indigenous people accept ratings as socially & culturally informed clarify complex interactions between cultural practices, social circumstances and community standards and the consumers' own experiences (Principles 2-4)

PLEASE TELL US: Additional item at end of the instrument enables you to tell us if you were able to access additional informants while rating or not.

Scenarios – Principle 1

SCENARIO	COMMON QUESTIONS	PROTOCOL REQUIREMENTS
You are in a hurry and an Indigenous consumer who is due for outcomes assessment arrives alone and late for her appointment. There is no phone at her house and it is across town. There is no vehicle to get family member/carer.	You conclude there is no way to complete outcomes assessment during this time informed by family/carer... Shall I carry out the assessment anyway? Shall I delay my assessment? What should I do?	Suggested pathway in order of Preference: 1 : delay until both carer and local practitioner can be consulted, if you can keep acceptable timeframe (3 days) 2 : if the time delay will be too long, seek Indigenous local practitioner who knows the consumer well 3 : if above is not available, organise contact with carer and practitioner at a later time (e.g. by phone) to complete. 4: if none of the above is possible, conduct assessment and appropriately mark the INPUT item on assessment.

Discussion

- Your Experiences and Concerns...Principle 1

Please share experiences and the kinds of barriers you have faced in trying to access a family member or carer and/or a local practitioner.

Principle 2.

- **Your scoring of all issues SHOULD REFLECT UNDERLYING SOCIAL DISADVANTAGE experienced by the consumer even if it is widely experienced by the entire community.**

The outcomes measurements should capture prevailing levels of social disadvantage PLUS any additional disadvantage experienced by the consumer as a result of the illness or disability.

Examples to include if present: lack of adequate food supply to the community, overcrowding in households, lack of support services to be accessed, lack of opportunity for employment or other meaningful activity, weekly/fortnightly cycle of income and expenditure, etc.

Principle 2: Relevant HoNOS Items

8. Other mental and behaviour problems
9. Most severe problem associated with active or passive withdrawal from social relationships +/- or with damaging, self-destructive relationships
10. Overall functioning in activities of daily living
11. Problems with living conditions
12. Social Problems: occupation & activities

Principle 2 Relevant LSP-16 Items

Is/Does this person generally:

4. ...well groomed?
5. ...wear clean clothes or ensure that they are cleaned if dirty?
9. ...maintain an adequate diet?
13. ...have problems (friction, avoidance) living with others in the household?
16. What sort of work is this person generally capable of (even if unemployed, retired or doing unpaid domestic duties)?

First Scenario for Principle 2

SCENARIO	COMMON QUESTIONS	PROTOCOL REQUIREMENTS
It is Friday of payweek. The consumer has shared his/her pension with family members and has no money left to buy food for the next 12 days.	How do I rate this person's social circumstances when I know that his/her lack of money for food is related to wider social disadvantage and not to the mental illness?	Rating should reflect the lack of resources only and NOT be influenced by the reasons underlying the lack of resources, or by how common the circumstance is in the community.

Second Scenario for Principle 2 

SCENARIO	COMMON QUESTIONS	PROTOCOL REQUIREMENTS
The consumer has not worked or participated in any work related program and has been living off his partner's child endowment funding.	How do I rate this person's occupation and activities, and capacity for work when all that is available in the community is CDEP (work for the dole) funding for two days per week?	Rating should reflect the lack of participation in available formal opportunities (in this case CDEP) or in subsistence activities (hunting and fishing). Score this item objectively, regardless of whether it is due to choice, lack of capacity or absence of opportunities.

Discussion 

- Principle 2
Your Experiences and Concerns


Please share experiences and the kinds of difficulties you have faced or anticipate facing in applying Principle 2.

Principle 3. 

- Your scoring **SHOULD** include socially and culturally unacceptable behaviour even if it is common in the community.

In other words, you should not reduce your scoring of unacceptable behaviours even if others practice the same behaviour to a similar or greater extent.

Examples include excessive alcohol consumption, domestic or community violence, disruptive behaviour and self-harm which is unconnected to cultural practices that are shared by others in the community


Principle 3 Relevant HoNOS Items 

1. Overactive, aggressive, disruptive or agitated behaviour
2. Non-accidental self-injury
3. Problem drinking or drug taking
8. Other mental and behavioural problems

Principle 3 Relevant LSP Items 

Is/Does this person generally:

4. ...well groomed?
5. ...wear clean clothes or ensure they are cleaned if dirty?
7. ...violent to others?
13. ...have problems living with others in the household?
14. ...behave offensively?
15. ...behave irresponsibly?
16. What sort of work is this person generally capable of?

Scenario for Principle 3 


SCENARIO	COMMON QUESTIONS	PROTOCOL REQUIREMENTS
The consumer is binge drinking after payday and frequently injured in fights.	How do I rate this person's behaviour that is common among young adult males in this community?	Regardless of commonality, community standards do not condone binge drinking or violence, and rating should reflect this. The rating should NOT be influenced by how common such behaviours are within the consumer's peer group.
See Scenarios for Principle 4.		

Principle 4. 

- Your ratings **SHOULD NOT** reflect socially/culturally acceptable behaviours, experiences and beliefs associated with funerals, religious or traditional activities.

Therefore, you must consult with a family member/carer and the local practitioner to identify whether the reported/observed findings are consistent with social or cultural practices that are recognised and accepted within the community. If your discussions indicate that the behaviours are socially and culturally acceptable, they should not be included in the scoring.

Examples of things that should not be included in the ratings:
 -non-accidental self-injury occurring as part of mourning rituals and paranormal phenomena (e.g. visions, beliefs) in the context of funeral, healing, religious or other traditional activities, where these are recognised and accepted in the community;
 -reported/observed findings deemed acceptable within prevailing standards and expectations in the community (e.g. standards of grooming, dress, going barefoot);
 -reduced warmth and interpersonal interactions that are determined by community protocols, e.g. limiting expression to unfamiliar people and enhancing awareness of shame and concern for privacy and confidentiality in the interview situation.

Principle 4 Relevant HoNOS Items 

1. Overactive, aggressive, disruptive or agitated behaviour
2. Non-accidental self-injury
3. Problem drinking or drug taking
8. Other mental and behavioural problems

Principle 4 Relevant LSP Items 

Does/Is this person generally:

1. ...have any difficulty with initiating and responding to conversation?
2. ...withdraw from social contact?
3. ...show warmth to others?
4. ...well groomed?
5. ...wear clean clothes or ensure that they are cleaned if dirty?

Scenarios for Principle 4 

SCENARIO	COMMON QUESTIONS	PROTOCOL REQUIREMENTS
The consumer has sustained cuts to her head which she states are "sorry cuts" following a recent death.	Should I rate this as deliberate self-injury when I am informed that this is a common and understood behaviour?	In such circumstances, the clinician is strongly advised to find out from a cultural informant to what extent the behaviour in question is recognised as understandable and acceptable by the community. If the cutting is recognised within this community as a shared sign of grief, it should NOT be rated as non-accidental self-harm.
The consumer stabbed himself while intoxicated and attributes it to 'grief'.	Should I rate this as deliberate self-injury when I am informed that 'sorry cuts' are real? It isn't clear if his behaviour is acceptable cultural behaviour or if it is atypical and extreme.	In such circumstances, the clinician is strongly advised to find out from a cultural informant to what extent the behaviour in question is recognised as understandable and acceptable by the community. If the stabbing is not recognised in this community as an acceptable shared sign of grief, the behaviour SHOULD be rated as non-accidental self-injury.

Scenarios for Principle 4 

SCENARIO	COMMON QUESTIONS	PROTOCOL REQUIREMENTS
The consumer has reported frequent 'visions' of a dead relative.	Should I rate this as disordered perception?	In such circumstances, the clinician is strongly advised to find out from a cultural informant to what extent the behaviour in question is recognised as understandable and acceptable by the community. If these visions occurred after a death and there is consensual understanding and acceptance of its manifestation and duration, this should NOT be rated as hallucinations. If this is not the case, then rating SHOULD reflect the experiences as hallucinations.
The consumer has almost no eye contact with the rater with little warmth/limited communication	How do I rate the consumer based on this first hand experience?	In such circumstances, the clinician is strongly advised to find out from a cultural informant to what extent the shyness and lack of warmth displayed in this circumstance is considered understandable and acceptable by the community. The clinician needs to understand local norms for shyness and 'shame'. Assessment must take into account the consumer's general inter-personal capacities over the rating period.

Scenarios for Principle 4 

SCENARIO	COMMON QUESTIONS	PROTOCOL REQUIREMENTS
The consumer's self care and activities of daily living are extremely poor.	How do I rate this when prevailing social disadvantage is such that general levels of self-care are lower than in the mainstream?	Standards and expectations exist in all communities regardless of prevailing disadvantage. The clinician must find out from a local informant (e.g. indigenous health practitioner) to what extent the level achieved by the consumer meets local standards.

Scenarios for Principle 4 

SCENARIO	COMMON QUESTIONS	PROTOCOL REQUIREMENTS
The consumer has been housebound due to fears of <i>puri-puri</i> (sorcery).	Should I rate this as disordered ideation? How should I rate the consumer's isolation and withdrawal?	In such circumstances, the clinician is strongly advised to find out from a cultural informant to what extent the Beliefs are consistent with locally shared beliefs and customs. If they are consistent, the clinician needs to further assess if the behaviours have been consistent (in terms of duration and manifestations) with expectations based on those beliefs. If both belief and behaviours are consistent, then they should NOT be rated. If either the belief or the behaviour is NOT consistent, then rating SHOULD reflect the symptomatology.

Discussion 

- Principles 3 & 4
Your Experiences and Concerns....

Please share experiences and the kinds of difficulties you have faced or anticipate facing in applying Principle 3 & 4.

Your Experience 



Your Feedback 

- We would greatly appreciate your input into the evaluation process. Your experiences are important.
- There are a few additional questions, including a space for comments on the instrument to help you do that. We may also ask to interview you from time to time.
- The information you provide will be analysed carefully and used to improve the process.
- Many Many Thanks.

**Health Worker Forum for
MENTAL HEALTH OUTCOMES
EVALUATION SHEET 1**

1. Have you ever received any training or information about measuring health outcomes in any areas of health services, not just mental health?

- Never heard about measuring outcomes before
- Have heard about outcomes measurement, but not had any training about it
- Have received information and had some training in outcomes measurement

2. Have you heard about the Mental Health Outcomes Initiative in the Mental Health Services before today? (besides being invited to this forum)

- Nothing at all
- Little bit
- A lot

3. Do you think there is a role for Health Workers to explain to community members about the Mental Health Outcomes Initiative and to encourage participation by families and consumers of the service?

- No role at all
- A small and not so important role
- A major and important role

Any comments on the role

4. Have you ever been asked by a mental health service clinician to help explain to clients and carers what mental health outcomes are and why they are done?

- Never been asked to help
- Have been asked a few times
- Have been asked often

5. How confident would you feel to explain to community members and families and consumers of mental health services about the Mental Health Outcomes Initiative?

- Not confident at all
- Some confidence but still hesitant
- Very confident

6. Do you see any value in using measurements to describe how a mental health service consumer is doing at different points in time?

- Little or no value
- Some value but wouldn't be a high priority
- Very valuable and a high priority

7. How important do you think it is for mental health service clinicians to gain information from a Health Worker and a family member / carer when doing mental health outcomes assessments?

- Not important at all
- Would be helpful but not necessary
- Very important and necessary

Please explain:

8. Have you played any role in helping a mental health service clinician understand consumers' behavior or symptoms?

- No role at all
- A little bit
- Often

9. How confident would you feel in helping a mental health service clinician to measure mental health outcomes by providing information about a client in your community?

- Not confident at all
- Some confidence but still hesitant
- Very confident

10. How much has this training increased your understanding of mental health outcomes measurements?

- Not at all
- A little bit
- A lot

11. Do you see any problems in putting in to practice the things that you learned in the session?

- No problems at all
- A few problems that are easily solved
- Some problems that will be a challenge to solve
- Too many problems

Comments are welcome:

THANK YOU FOR PARTICIPATING!

Appendix 8. Summary of the Second Wuchopperen Workshop and the Local Forum**Measuring Indigenous Mental Health Outcomes:
Sharing Stories of Achievement & Challenge****Indigenous Mental Health Outcomes Project****Report of the Second Workshop
at Wuchopperen Health Service, Cairns, Qld****Acknowledgements**

The team from the AIMhi – Indigenous Stream, North Queensland would like to thank the Maori Mental Health Professionals namely, Dr Te Kani Kingi, Michelle Levy, Materoa Mar, Ana Sokratov, and Dr Sylvia Van Altvorst for their interest and support in the Mental Health Outcomes project in North Queensland. The sharing of their knowledge and experiences in Maori mental health is highly valued and extremely appreciated. We hope to continue our partnership and friendship on the journey towards improving mental health outcomes for Indigenous consumers, carers and their families.

We would also like to acknowledge the support and resources from Queensland Health in particular the management and staff from the Mental Health Outcomes Team in Brisbane. We also express thanks to our consultants, Associate Professor Tom Trauer and Professor Alan Rosen, for the expertise and advice they provided in the Workshop. We also thank Anthea Duquemin for taking detailed notes throughout the two days.

Finally we give thanks to Wuchopperen Health Service for allowing us to use their wonderful Rainforest venue once again and to all of the presenters and participants in the Workshop that made it a rich experience for all.

Workshop Participants

Dr Te Kani Kingi	Post Doctoral Research Fellow	School of Maori Studies Massey University
Michelle Levy	Independent Consultant	Maori and Psychology Research Unit, University of Waikato
Materoa Mar	Director – Yesterday, Today & Tomorrow, Consultant	Maori MH-SMART Outcomes Initiative Health Research Council New Zealand
Ana Sokratov	Consumer Advisor	Waitemata District Health Board, Auckland
Dr Sylvia Van Altvorst	Consultant Psychiatrist and Clinical Head	Maori Mental Health Counties Manukau District Health Board
A/Prof Tom Trauer HoNOS Consultant	Consultant	University of Melbourne Monash University, Sydney
Professor Alan Rosen Life Skill Profile Consultant	Director Clinical Services Associate Professor, Dept of Psychological Medicine, Associate Professor, School of Public Health	Royal North Shore Hospital and Community Mental Health Services University of Sydney Associate Professor School of Public Health, University of Wollongong
Ruth Catchpoole	Team Leader	Systems & Outcomes Team Mental Health Unit Queensland Health, Brisbane
Luke Hatzipetrou	Team Leader Zonal Outcomes Team	Information Systems and Management Unit Mental Health Unit Queensland Health, Brisbane
Kathy Stapely	Northern Zonal Outcomes Coordinator	Information Systems and Management Unit Mental Health Queensland Health, Cairns
Mercy Baird	Indigenous Mental Health Coordinator	Integrated Mental Health Unit Queensland Health, Cairns
Phil Cammish	District Manager	Cairns Health Service District Queensland Health
Radhika Santhanam	Senior Lecturer	North Queensland Health Equalities Promotion Unit, University of Queensland
Dr Roy West	Consultant Psychiatrist	Integrated Mental Health Unit Queensland Health, Cairns
Andrew Brownlie	Nursing Director	Mental Health Unit, Cairns Base Hospital
Gregg Pratt	Male Counsellor, Social Health Program	Wuchopperen Health Service, Cairns
Yvonne Walker-Shipley	Coordinator, HACC	HACC Centre, Pormpuraaw Community, Cape York Peninsula

Tim Coombs	Training and Service Development Australian Mental Health Outcomes and Classification Network	New South Wales Institute of Psychiatry
Prof Philip Burgess	Professor, Mental Health Services Research	Qld Centre for Mental Health Research, University of Queensland, Brisbane
Dr Melissa Haswell	Chief Investigator (AIMhi) Senior Lecturer	NQHEPU University of Queensland, Cairns
Prof Ernest Hunter	Chief Investigator (AIMhi) Consultant Psychiatrist	NQHEPU University of Queensland, Cairns
Dr Tricia Nagel	Chief Investigator (AIMhi) Psychiatrist	
Rachael Wargent	Project Officer (AIMhi)	NQHEPU University of Queensland, Cairns
Brenda Hall	Project Officer (AIMhi)	NQHEPU University of Queensland, Cairns
Ciaran O'Higgins	Clinician Consultant (AIMhi)	NQHEPU University of Queensland, Cairns
Anthea Duquemin	Consultant (AIMhi)	Cairns
Kim Ward	Mental Health Clinician	Integrated Mental Health Unit, South Team, Queensland Health
Peta Romano	Indigenous Mental Health Worker	Integrated Mental Health Unit, South Team, Queensland Health

Indigenous Outcomes Project in Far North Queensland

History

Many questions have been raised about the use of mainstream measures of various aspects of mental health with Indigenous people. With the major efforts now in place nationally and internationally to use standard outcomes assessment tools for a wide range of purposes, it is particularly important to determine their validity and reliability for Indigenous consumers.

In 2003, Queensland Health was preparing to implement their mental health outcomes training initiative in the Cairns Network, which encompasses the districts of the Tablelands, Innisfail, Cairns, Cape York and Torres Strait and Northern Peninsula Area. Because of the relatively high percentage of Indigenous consumers in the region, the Mental Health Outcomes Unit was particularly interested in making links with local researchers, specifically the Indigenous Stream of the AIMhi project in North Queensland, to explore these questions. With Queensland Health funding, AIMhi hosted a workshop in June 2003 at Wuchopperen Health Service in Cairns to discuss these issues and formulate a plan.

This workshop brought together people with expertise in mental health outcome measure implementation, evaluation and in remote Aboriginal and Torres Strait Islander mental health service delivery and other Indigenous mental health professionals. The purpose of the workshop was to examine the feasibility of adaptation, implementation and evaluation of

selected existing practitioner-completed outcome measures for use in Indigenous populations and to suggest a strategy by which this may be undertaken. A report was produced following the workshop, which detailed the discussions and outlined a research proposal.

By the end of 2003, the AIMhi team in collaboration with the Mental Health Outcomes Unit and other members of a small Steering Group, had developed a set of principles designed to assist Mental Health Clinicians when making ratings for Indigenous consumers. A Business Case proposal was also finalised which detailed the methodology for project involving exploratory studies in tandem and in support of the training and implementation activities of the mental health outcomes process. Work commenced during 2004 and a number of activities have been completed.

With a planned completion of the project in August 2005, it was decided early in the year to hold this second workshop. The aims were to provide feedback of progress and findings so far and to gain further guidance on the remaining activities to the end of the project. In particular it was felt that more discussion and direction was needed from Indigenous stakeholders to assist in deciding how information should be released in publications and reports.

International Indigenous Collaborators

An important link between North Queensland, Northern Territory and New Zealand grew from initial contact between the AIMhi Team and Matoroa Mar at various presentations at the TheMHS conference in the Gold Coast in 2004. This led to a visit by five Maori Mental Health experts involved in the MH-SMART initiative in New Zealand to attend and contribute greatly to the depth and breadth of discussion of the 2nd Indigenous Mental Health Outcomes workshop. The visitors were Matoroa Mar, Te Kani Kingi, Ana Sokratov, Michele Levy and Sylvia Van Altvorst.

Sharing experiences working with Maori and Indigenous Australians suggested that the challenges for achieving better health outcomes were fundamentally similar in many ways.

The inclusion of the Maori team in the workshop enabled us to share perspectives on the big picture of Indigenous mental health outcomes research and services in New Zealand, north Queensland and Northern Territory. There were 2 components to the 2-day workshop. Day one was a full day meeting aimed specifically at focusing on Indigenous views on outcomes research. The second day aimed to provide feedback to the wider group about the progress and findings so far, to gain assistance in interpretation of data gathered so far, to enable workshopping of the remaining project activities and to formulate recommendations for the next steps.

We talked about the many similarities between the three cultures of Maori, Aboriginal and Torres Strait Islander peoples and the shared experiences of mental health practices that have dominated past practice. New ways of seeing and moving forward were also discussed which encompass positive, recovery-oriented and cultural strengthening approaches involving primary health care models that better reflect the needs of Indigenous consumers in Australia and New Zealand.

MH-SMART, Hua Oranga and Tuituia are three main documents presented by the Maori group and discussed at the workshop. The history and approach to outcomes assessment processes has been somewhat different across the three sites. However, a great deal of learning and valuable sharing was possible because of the shared challenges.

Agenda – Day 1Thursday 21st April 2005

Opportunities, Challenges and Approaches – A chance for sharing the big picture of mental health outcomes research and services among New Zealand, Far North Queensland and Northern Territory. This full day meeting aims to focus on Indigenous views on outcomes research as a prelude to more specific presentations and discussions on current projects on Day 2.

- 10.00am Workshop begins with morning tea/networking
- 10.30am Welcome and Introductions
- 11.30am Challenges to improving Indigenous Mental Health Outcomes
- What changes need to happen for consumers in order to achieve positive change in these three levels – Presentations by the Maori group:
- *Individual People: consumers and families/carers;*
 - *Tangata whaiora/consumer paper by Ana Sokratov & team*
 - *Training and Education in New Zealand*
 - *Hua Oranga, Te Kani Kingi*
 - *Approaches to Service Delivery & how they got there - NZ*
 - *Communities: structural change, organisational change*
 - *Services: services and inter-sectoral linkages*
- 12.30pm Lunch (provided)
- 1.30pm Discussion
- 2.00pm AIMhi – Universal Awareness Model of Care – Brenda Hall
- Addressing the challenges identified. What questions do we need to be asking to ensure we are moving towards meeting the challenges?
- 2.45pm Afternoon tea
- 3.00pm How can we use the data to help us address the challenges?
- *Lessons from History*
 - *Challenges for today in the Outcomes information system*
 - *Presentation by Tom Trauer of Data already collected in New Zealand followed by discussion and interpretation*
- 5.00pm End of Day**

Agenda – Day 2

Progress and Guidance for Outcomes Project. This full day meeting aims to provide a feedback from the 2003 Wuchopperen Workshop about the progress and findings so far, to gain assistance in interpretation of data gathered so far and to enable discussion of remaining project activities and formulate recommendations for the next steps.

- 8:30am Welcome, background and objectives for the workshop
- 8:45am Outcomes initiatives and perspectives
- *Australia/Queensland*
Ruth Catchpole, Phil Burgess, Tim Coombs
 - *Discussion*
- 10.00am Morning tea
- 10.20am Cairns Network Approach and Progress
- *Engagement Tools / Health Worker forum*
 - *HoNOS and LSP complementary tools*
 - *Modifications Document*
 - *Training Activity and Supports*
 - *Research Design and Work Completed*
- 11.30am PART ONE – Reflections on Consumer/Carer interview findings
- 12.00pm Lunch (provided)
- 1.00pm PART TWO - Reflections on process and interpretation of preliminary data collected so far in the Cairns network
- 2.00pm Remaining tasks for Cairns project (AIMHI)
- *Exploring consistency of clinician ratings, key areas of difficulty, contribution of the principles*
 - *Demonstrating validity – are we measuring meaningful things?*
- 3.30pm Pulling it together, Recommendations
- 5:00pm Close & Thank You to all Attendees, especially Maori group**

Key Events and Issues Emerging from the Meeting

A report was prepared that aims to capture the presentations and discussions at a two day workshop held at Wuchopperen Health Service in Cairns on April 21 and 22. The aim of the workshop was to explore benefits, challenges and preferred pathways in Indigenous mental health outcomes research. The workshop involved 3 main groups of participants, namely:

- some of the key Indigenous and non-Indigenous people working in Indigenous mental health around the Far North Queensland region,
- a group of national experts involved in mainstream mental health outcomes research, implementation and analysis, and
- a group of 6 Maori clinicians, researchers and managers leading responsiveness to Maori in New Zealand's mental health policies and practices.

The first day was formally opened by Aunty Rose Richards, a highly respected Aboriginal Elder whose efforts for greater community control helped to in health services in Cairns for decades. This was followed by a joint presentation by all of the Maori visitors that focused mainly on the Maori experience of opportunities, challenges and current approaches in their outcomes work. The talk also highlighted the exciting reality of Maori inclusion plus a recovery-oriented approach in all stages of development and implementation of New Zealand's MH-SMART initiative. A review of the findings from HoNOS and LSP applied with Maori consumers from the former initiative, CAOS, was presented by Tom Trauer.

The second day shifted focus to Australia's Mental Health Outcomes and Casemix Initiative, highlighting Queensland's flexible and innovative approach informed by experiences of other states and territories. This was followed by specific presentations on the developmental phases, the current understandings and the remaining challenges for the AIMhi Indigenous Mental Health Outcomes project. As the project was nearing completion, data analysis and interpretation was just beginning. The presentation of findings, followed by open discussions and sharing of experiences across both Indigenous groups, provided the North Queensland team with guidance on how to approach this phase of presentation and interpretation to the broader community.

Upon examining the minutes and reflecting on the in depth discussions that occurred over the two days, the following key issues emerged to guide in the collection, analysis, interpretation and presentation data concerning Indigenous people:

- To employ a positive orientation towards future change – where are we, where do we want to be, how do we get there - and avoid the presentation of a hopeless situation where nothing can be done which is never true and can be harmful to mental health
- To approach from a strengths/proactive model and not a deficits model, especially if comparing Indigenous and non-Indigenous data
- To have a recovery-oriented focus which is culturally defined (e.g. recovery for Maori is know to be different than that of non-Indigenous New Zealanders and the same is likely to be true for Aboriginal and non-Indigenous Australians)

- To be mindful towards exploring the whole story – statistics can only reveal superficially what is happening; stories or narratives are needed to understand complex issues such as Indigenous identity, well being and mental health
- To remember that socio-economic explanations of health status by themselves rarely explain the whole story – the legacies of dispossession, disempowerment, loss of cultural strength and grief linger on in community life and addressing these needs to be part of new initiatives
- To be aware of the limitations of the data – it is not perfect; there may be a range of underlying biases in the situation it suggests
- To not be limited by the data – knowing that it does not adequately reflect all aspects of the issue
- To allow for multiple explanations and flexible interpretations as Indigenous people see their mental health in complex inter-related ways that may not seem compatible to non-Indigenous people but are valid and should be respected as such
- To have a responsive approach to data collection – systems should be flexible and able to be adjusted in order to make the data it collects better and more useful
- To understand and honour collectivism, as opposed to individualism, as a key cultural component whenever health and mental health are addressed
- To ensure that data instruments in mental health are a routine part of quality enhancement in mental health services driving better care, and not just an addition to the workload that is unconnected to how people work.

The emergence of these shared themes was a very important and valuable outcome of the two days of presentation, discussion and sharing.

INDIGENOUS MENTAL HEALTH OUTCOMES PROJECT
LOCAL FORUM

18th January 2006
Wuchopperen Health Service
13 Moinard Street, Manoora Cairns

AGENDA

1.00pm	Welcome and Introductions	
1.10pm	Project Overview: Why we did the project, what we did and how we did it	Rachael and Melissa
2 pm	Afternoon tea	
1.30pm half hour 1 hr 1 hr	<p><u>Workshops</u></p> <ol style="list-style-type: none"> 1. Are we satisfied with the principles? Should we recommend adjustments - particularly to principle 4? 2. What have we learnt from the project? Examining the report – <ul style="list-style-type: none"> • Monitoring the Implementation of the OIS <ul style="list-style-type: none"> ○ Awareness of coverage (gender, districts, reasons) • Having additional questions about involvement and engagement of consumer, carer and local practitioner • Analysing HoNOS and LSP Data of Indigenous Consumers <ul style="list-style-type: none"> ○ Measurements with and without informants ○ Patterns by gender, age, district and diagnostic group ○ Focus on younger Indigenous consumers ○ Patterns across time within the year 3. What conclusions should we make from the findings? What recommendations should we propose for reporting, for services at the local, state and national level (if any) and for further research? 	
4.00pm	Conclusion and Close	

Brief overview of Indigenous Mental Health Outcomes Project

AIMHI (Indigenous Stream, North Queensland) recently completed a project to support and examine the implementation of the Queensland Health Outcomes Information System with Indigenous consumers in the Cairns Network. A draft final report has been prepared, reviewed by the project's expert consultants and now requires examination by local stakeholders.

This project emerged from an initial workshop held at Wuchopperen Health Service in July 2003 to discuss the benefits and potential pitfalls of using HoNOS and LSP with Indigenous consumers. Based on discussions and recommendations from this workshop, a Steering Committee was formed and four principles were developed to address the concerns raised and implemented as an extended module within the routine outcomes training of clinicians.

A proposal was also developed and funded by Queensland Health to monitor the implementation process and examine the reliability, validity and usefulness of measuring outcomes with Indigenous adult consumers. AIMHI hosted a second workshop in April 2004 to present a progress report and gain further guidance on the analysis of data as the study approached completion.

The anticipated outcomes from this third and final workshop will be to share the data among key local stakeholders, including representatives on the project's steering committee and other close associates, and to ensure that the final report and communications are informed by their knowledge and experience.

Local Forum – Summary

List of attendees

Trudi Sebasio, Principle Project Officer (Statewide), Indigenous Mental Health, Queensland Health

Ruth Fagan, Gurriny Yealamucka Health, Yarrabah Community

Joanne Brown, Alcohol, Tobacco and Other Drugs, Queensland Health, Cairns

Anthony Weller, Team Leader, Northern Area Health Service

Martine Slevin, Mental Health Quality & Safety Officer, Cairns Integrated Mental Health

Andrew Brownlie, Nursing Director, Mental Health, Cairns Base Hospital

Radhika Santhanam, Senior Lecturer University of Queensland/Team Leader Remote Area Child and Youth Mental Health

Greg Pratt, Male Counsellor, Wuchopperen Health Service, AIMhi Steering Committee Member

AIMhi Project Team: Melissa Haswell, Brenda Hall, Valmae Ypinazar, Tom Ogwang, Rachael Wargent

Apologies

Komla Tsey, Mercy Baird, Ernest Hunter, Leanne Knowles, Tallita Wheeler, Brod Osborne

Summary:

Melissa and Rachael presented core project findings using a powerpoint presentation detailing the background, methods and process, findings and questions to stimulate discussion of the key issues.

The presentation led to discussion of cultural bias in defining 'outcomes' – It was strongly argued that outcomes have thus far been culturally defined, which in turn influences how outcomes are measured. The following was raised without resolution:
How does consumer empowerment rate as an outcome?
How does consumer enablement become measurable?

The presentation discussed the results of the additional questions on OIS relating to Indigenous identity and ways the questions provide a clinician rating of tool efficacy with Indigenous consumers.

There was significant group discussion of possible factors leading to patterns of elevated admission of the under 30 age group to Cairns Base Hospital. A wide range of client related factors were offered to explain the patterns observed in the data – particularly around shared histories of drug amongst youthful consumers. Factors possibly explaining substantial elevation in <30 admissions:

- Seasonal spikes in drug production and supply
- The widespread abuse of newer, potent 'super strains' of marijuana among young people;

There was re-emphasis of a number of points arrived at during the second workshop, including:

- The need for strength-based perspectives and recognition of the existence and sources of resilience and recovery rather than merely the absence of illness;
- The need to recognise collectivism as a key component of wellbeing amongst Indigenous people;

Significant new points raised by participants included

- The most important aspect of principle 4 is principle 1- engaging a cultural interpreter is essential to understanding the distress surrounding culturally 'normalised' behaviours.

It was reiterated by participants that use of principle 1 has powerful and widespread benefits – it provides non-Indigenous clinicians opportunity to clarify uncertain points with a cultural interpreter and to distinguish between culturally appropriate and aberrant behaviour. This being acknowledged, issues around the implementation of principle one were discussed, including:

- There is a strong issue of confidentiality during assessment if the consumer's family member or an Indigenous Mental Health Worker is present.
- The likelihood of the consumer to allow the clinician to adhere to principle one was observed to be dependent on who the consumer first spoke to –

If the Indigenous Mental Health Worker was first point of contact for consumer, the consumer is more likely to express preference for their inclusion in the interview, however if the IMHW introduced by the clinician, typically the consumer expresses preference for their not being there.

It was unanimously agreed by participants of the third workshop that all things being said, effective recognition of cultural factors affecting the consumer is always predicated on the cultural competence of the worker. Given this, the ways that a service equips its workers with cultural competence were raised, as was the issue of how an Indigenous community works with a clinician to build their cultural competence. This led to the conclusion, also arrived at in workshop 2 by the Maori representatives, that cultural competence doesn't matter as much as the worker's ability to listen. The implication here is that open listening is analogous to cultural competence.

Discussion of Principle 4 - In the context of the project action orientation

During the second Wuchopperen workshop, participants recognised problematic aspects of the principle 4 assertion that socially and culturally acceptable behaviours associated with funeral rites, religious or traditional activities should not be included in any assessment items. Application of the principle caused concern where the behaviours, experiences and beliefs are **source of significant distress or danger** to the consumer and/or their family and community. In recognition of these issues, the Maori Monitoring and Review Group require inclusion of distress and potential harm even where underlying cause may be socially and culturally acceptable to the consumer's community. Reflection on this brought recommendation of similar modification of principle 4 to the third consultation workshop, and the project steering

group overwhelmingly endorsed the modifications to principle 4 shown below in underlined italics.

Socially and culturally acceptable behaviours, experiences and beliefs associated with funerals, religious or traditional activities [that are not associated with distress or harm to the consumer or to others] SHOULD NOT BE INCLUDED in any assessment items. *[However, when these behaviours, experiences and beliefs cause significant distress and/or danger to the consumer, their family or other people, they SHOULD BE INCLUDED in the ratings].*

Therefore the clinician must identify whether the reported / observed findings are consistent with social or cultural practices that are recognised and accepted within the community. *[The clinician should also determine how much distress or potential danger is associated with the behaviours, experiences or beliefs].* This is determined through discussions with a family member/carer, the local practitioner and other cultural informants.

Examples:

- Non-accidental self-injury occurring as part of mourning rituals and paranormal phenomena (such as visions and beliefs) in the context of funeral, healing, religious or other traditional activities, where these are recognised and accepted in the community *[and not associated with significant distress or danger]*;
- the reported / observed findings are deemed to be acceptable in light of prevailing expectations and standards in the community (for instance standards of grooming and dress such as going barefoot);
- Assessment of warmth and interpersonal interactions should take into account community standards, awareness of shame and considerations of privacy and confidentiality in the interview situation.

Relevant items include:

HoNOS – Items 2, – Behavioural Items; 6 - Symptomatic Problems Item,
10 – Social Problems, 8 – other mental and behavioural problems

LSP – Items 1, 2, 3, 4, 5