Child and Youth Outcome Measures: Examining current use and acceptability of measures in mental health services and recommending future directions

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Executive summary

Introduction

In order to measure the effectiveness of treatment in the mental health sector, District Health Boards are expected to start the process of establishing routine outcome measurement. To do that, the most reliable valid and acceptable measures need to be used. This project addresses the use and acceptability of child and youth mental health outcome measures in New Zealand.

There is a need to measure the effectiveness of child and youth mental health services in a coordinated way across the country. To date there has been no information on measures currently in use, nor on the acceptability of standardised measures to clinicians and consumers. If outcome measures are to be introduced, it is important to ensure that both the mental health professionals and the users of services, including children, adolescents and their families see these as acceptable and credible. Moreover, consumers should be treated as genuine participants in, rather than simply the “subjects” of, outcome measurement.

Purpose of the report

This report details a project aimed to gain information on what measures (if any) are used; what measures are acceptable to consumers, families and clinicians; and what are the issues for Māori and Pacific peoples. The study had three phases: (1) specific questionnaire asking clinicians for their views on the issue; (2) face-to-face consultations with child and youth consumers; (3) face-to-face consultations with family members. The aims of the project were to produce recommendations for a practical way forward in the implementation of routine assessment using standardised measures in day-to-day clinical practice in New Zealand.

This project is a part of the New Zealand Health Research and Development Strategy, which aims to use research and development to identify ways that will improve the planning, purchasing and delivery of mental health services in New Zealand, consistent with the Treaty of Waitangi and with the needs of consumers and their families.

Method

Phase One: Clinician Survey and Telephone Interviews

A questionnaire was sent to all Child and Adolescent Mental Health Services (“CAMHS”) clinicians through an email distribution list to gather data on clinicians’ knowledge and views of outcome measures.

CAMHS team leaders/service coordinators were invited to participate in brief telephone interviews to obtain more in-depth information regarding their survey responses and practical implementation issues.

Phase Two and Three: Focus Groups

Focus groups of child and youth consumers and their family/whānau members were held in Auckland, Dunedin, New Plymouth and Wellington. Specific groups were organised for children aged eight to twelve years, and for Māori and Pacific young people and their whānau.
Results

Phase One: Clinician Survey and Telephone Interviews

Most of the clinicians believed that outcome assessment in CAMHS was important in supporting service delivery and clinical work. An overwhelming majority were supportive of the introduction of a routine outcome measurement system. Most practical concerns and anticipated problems related to staff’s willingness and ability to undertake additional work and lack of resources to support data collection and analysis. Over three quarters of participants were familiar with the Health of the Nation Outcome Scales for Children and Adolescents (“HoNOSCA”) (discussed on page 9), and less than half were familiar with the Strengths and Difficulties Questionnaire (“SDQ”) (discussed on page 10). HoNOSCA was the most frequently recommended clinician-rated measure. The Child Behaviour Checklist (“CBCL”) (discussed on page 11) was suggested as a child- and family-rated measure.

Phase Two and Three: Focus Groups

Young consumers and their families were largely supportive of outcome measurement and believed that it would allow them to better identify their needs and allow for tracking of progress. Reservations about the introduction of routine assessment included concerns about the limitations of standardised measures, impact on well-being, treatment planning and ability to access and/or continue services.

The actual process of assessment was seen as more important than the measures used. Young people wanted to establish a trusting relationship with their clinician prior to the introduction of measures and wanted to feel more in control of the process by being better informed and consulted with. Families wanted to be assured that the measures would be utilised in case management and that appropriate feedback would be presented. Privacy and confidentiality were seen as crucial factors.

Participants wanted the measures to be brief, easy to complete and holistic. Feedback about specific measures suggested that SDQ was the most accepted measure because of its positive focus, brevity, ease of completion and the way in which sensitive questions were asked.

A number of culturally specific issues to Māori and Pacific people were identified including the need for cultural awareness and sensitivity in mental health measurement.

Conclusions

There is widespread support for the introduction of outcome measures amongst clinicians, young consumers and their families. However, although we have had feedback from a good cross section of clinicians and most consumer groups, despite our best efforts we have had little feedback from Pacific consumers due to difficulties in recruiting participants. This gap will need to be addressed.

There was agreement that HoNOSCA is a worthwhile measure and a there was great deal of support for its introduction from clinicians and consumers. Clinicians favoured the CBCL and Youth Self Report (“YSR”) (discussed on page 11) as self or family rated measures, partly because they had some experience with these measures which are widely used internationally. However they were not well regarded by the young consumers and their families in New Zealand who found them overly long and found some of the individual questions strange. They preferred the SDQ which compares well with the CBCL and YSR psychometrically, covers the
same symptom domains, is quick to complete and collects information on strengths as well as weaknesses.

Other measures identified covered specific domains such as depression and would not provide the comprehensive assessment of mental health needed for overall assessment of services.

The way in which outcome measures are collected and used will be critical to their acceptability and care will need to be taken over setting, timing and context, with trust in the person who introduces the measure a critical component for success. Access to information and feedback of results need special care as the information is personal and creates a feeling of vulnerability in young consumers. Clinicians also expressed concern that the measures may be used to monitor their performance in a negative way. Clinicians and consumers were concerned that the measures would be used to limit access to services. Introduction of routine outcome measures should take into account these concerns.

It is acknowledged that there are no ideal outcome measures and that compromise will be necessary. A process of regular review to allow incorporation of improved measures is needed. Particular areas that will need addressing in the near future are the establishment of a short outcome measure to assess drug and alcohol use, abuse and dependence and the revisiting of issues for Pacific people.

A Note about Language

There are no universally agreed definitions of terms such as "child", "young person", and some terms are used virtually inter-changeably. Unless the context indicates otherwise, in this report:

- ‘Child’ (or ‘children’) means a person (or people) aged between six and 12 years inclusive;
- ‘Family’ and ‘parents’ include whānau / extended family;
- Young person’ (or ‘young people’), ‘adolescent’ and ‘youth’ all mean a person (or people) aged between 13 and 19 years inclusive;
- ‘Taitamariki’ and ‘rangatahi’ mean Māori young people;
- ‘Tamariki’ means Māori children, and
- ‘Young consumers’ means both children and young people who have used Child and Adolescent Mental Health Services.

Recommendations

We recommend the introduction of HoNOSCA and the SDQ as routine outcome measures in CAMHS provided that:

- They are used in partnership with young consumers and their families;
- They are introduced after a therapeutic relationship is established;
- They are considered highly confidential;
- Young consumers are given feedback about the results in a way that does no harm and takes into account the possible negative effect of low scores;
- Families are informed and included in the process but that care is taken over specific information provided by individual informants;
- The measures are used to ensure monitoring of the effectiveness of services not individual clinicians;
- Adequate systems are put in place to make routine outcome measurement practical, and
- Further research is completed to establish the validity and reliability of the HoNOSCA and SDQ with the New Zealand population.
Section 1: Background

1.1 A brief overview of this project

This study was initiated under the New Zealand Mental Health Research and Development Strategy (MHRDS), which is funded by the Ministry of Health, administered by the Health Research Council and supported by the Mental Health Commission. One of the objectives of the MHRDS is to develop measures of outcomes for consumers of mental health services (Health Funding Authority, 1998).

All District Health Boards (DHBs) are expected to establish routine outcome measurement in services in the near future. To date there is a limited understanding of the effectiveness of New Zealand CAMHS (Mental Health Commission, 1999) and outcome research has been carried out only by those with an interest in the area. This project addresses this gap in knowledge and based on the findings, several recommendations are proposed for a practical way forward in the implementation of a routine outcome measurement system in CAMHS.

1.2 The need for outcome measurement in mental health services

Recently interest in how to measure the effectiveness of mental health services has grown. Given the increasing focus on accountability of mental health care delivery, it follows that clinicians, providers, and administrators have a vested interest in being able to determine the effectiveness of mental health care delivered to children and adolescents reliably and precisely. Those who fund services and those who receive care want to know whether treatments provided are of value.

One way to measure the quality of health care is to assess the effect of a given intervention on the well-being of an individual (or group of individuals) to identify whether the desired changes in health and quality of life have been achieved. This may be achieved using outcome measures that consist of standardised instruments (typically questionnaires or rating scales) designed to measure identifiable symptoms affected by an intervention. To assess the effect of services a comprehensive system of routine outcome measurement is needed.

The target of most health outcome measurement is a reduction in symptoms over time. Repeated measurements of symptoms and functioning can be used to evaluate the clinical benefit of a particular intervention by determining the extent to which symptoms decrease and functioning increases (Lambert, Salzer, & Bickman, 1998). Methods that are less intensive on resource and time include ad hoc measurement of improvement and consumer satisfaction. However, Lambert et al., (1998) compared the methods on a sample of treated adolescents and found no correlation between satisfaction and pathology change, which suggests that satisfaction cannot be used as a proxy for measuring mental health outcome. A comprehensive outcome assessment should therefore include measures with a quantitative score sensitive to change in the well-being of consumers.

Data on health outcomes provide information on which decisions and judgements can be made to improve the performance of health services. For the clinician and the consumer, data on outcome can serve as an indication of the progress made during service delivery, allowing the clinician to monitor whether a treatment plan is working. Outcome data can help clinicians and local managers decide which treatment model works best for particular consumers and whether it needs modification. Measurement systems can be used to match consumers to clinicians who are known to be especially effective in treating a particular problem. Finally, policy makers can use the data to make rational decisions concerning service planning and resource distribution.
1.3 Outcome measurement in children and adolescents

Hoagwood, Jensen, Petti and Burns (1996) have proposed a dynamic and interactional model of outcome measurement to encompass five domains, namely symptoms/diagnosis, functioning, consumer perspectives, environments, and systems. However, while numerous standardised instruments are available to assess mental health in children and adolescents, few measures exist that are suitable for measuring global outcome in clinical settings (Jensen, Hoagwood, & Petti, 1996). After a systematic and comprehensive review of the literature and consideration of the existing symptom questionnaires, Hunter, Higginson and Garralda (1996) concluded that at the time of their research none was suitable for routine use in clinical practice.

The measures required for children and adolescents are often more complex than those used with adults. The reasons for this include the need to take developmental level into account, multiple informants are required, and the context and settings in which children and adolescents live and receive services differ from those of adults (Bickman et al., 1998). The developmental level of the child or adolescent affects both the range of normal behaviours and the level and quality of symptoms that indicate problems with mental health. Furthermore, children and adolescents require instruments adapted to their reading ability and level of understanding. Data on outcome should be gathered from multiple informants; while children are believed to be better informants regarding their own internalising problems and covert actions, parents are better suited to report children’s externalising behaviours (Achenbach, McConaughy, & Howell, 1987).

Overall, outcome measurement should be part of a system in which data are systematically collected, recorded, scored, interpreted and fed back to consumers, clinicians, managers and policy makers. A standardised outcome measurement system is designed to improve clinical services through regular monitoring of changes in the health and well-being of consumers. A system of regular monitoring of changes in the health and well-being of the consumers of mental health services should be of benefit them and their families.

1.4 The Australian initiative

The regular assessment of consumer outcomes has been an objective of Australia’s National Mental Health Strategy since 1992 (Australian Health Ministers, 1992). In order to improve the quality and the accountability of mental health services, the assessment of consumer outcomes has become a major focus of policy development.

In 1994, a study was initiated by Australian researchers (Andrews, Peters, & Teeson, 1994) to consider and recommend outcome measures applicable to adult mental health services. A few years later in 1997, a consultancy team led by Professor Barry Nurcombe was commissioned to review outcome measures in child and adolescent mental health. The team was asked to recommend measures that would be useful in routine clinical practice to monitor progress of individual clients and to provide information about outcomes at the broader service level. The resulting report “Consumer Measurement Systems for Child and Adolescent Mental Health” was authored by Professor Bickman (1998).

Bickman and his colleagues proposed that the following factors should be considered in deciding on outcome measures. They should be:

- **Feasible.** This is the extent to which a measure is applicable, acceptable, and practicable. Instruments should be easy to administer in clinical settings and take little effort and time for respondents to complete (adapted after Andrews et al., 1994). Little or no training should be required for administration, and the data yielded should
be easy to analyse and interpret. Timely information is required at specific points in the clinical process, for example at baseline (initial severity, complexity and likelihood of change, treatment planning), concurrent assessment (progress, feedback), discharge (short-term outcome, discharge planning), and follow-up (long-term outcome, discharge planning).

- **Comprehensive.** The measurement system should address all the outcome domains that stakeholders consider important.
- **Flexible.** Service delivery organisations are at different levels of development and vary in their receptiveness to measurement. A modular system would allow each organisation to select modules that are best suited to their unique needs.
- **Capable of improving clinical effectiveness.** Variables such as satisfaction with services and the quality of the therapeutic relationship should be encompassed to allow clinicians to maximise the effectiveness of their interventions.
- **Psychometrically sound.** Measurement systems must be reliable, valid and sensitive to the kind of change initiated by treatment.
- **Developmentally sensitive.** The measurement system should take into account variations in normal development and be capable of distinguishing it from developmental delay.
- **Culturally sensitive.** Measurement system should take into account cultural influences, values and beliefs that may impact on concepts of mental illness and health and affect responses on outcome measures. A measurement system designed for use in a particular country should ideally have norms from that country.

### 1.4.1 Bickman et al.’s (1998) recommendations

As a starting point, it was proposed that the outcome measurement should follow the Baseline-Follow-up Model whereby the information is collected at entry to services and at specified follow-up points. It was recommended that this baseline-follow up module take “less than 30 minutes to complete, involve the clinician minimally, and address the following domains: functional impairment, symptom severity, symptom acuity, parent-child relationship; quality of life and satisfaction with services” (Bickman et al., 1998, p. 6). Outcome information should be triangulated and collected from the young person, their family/carers and the clinician. In addition, it was suggested the instrument be available at no cost.

Bickman et al.’s (1998) report recommended the Ohio Youth Problems, Functioning and Satisfaction Scales (Ogles, Davis, & Lunnen, 1998) be the core of the measurement system in the Australian CAMHS due to the instrument’s brief administration time and multiple informant forms. However, since the measure is generally unknown and untried in Australia, they also suggested that extensive work was needed to ascertain reliability, validity, and cultural appropriateness of the instrument and that the range of normal values be established in an Australian population.

Subsequent to Bickman et al.’s (1998) review, two new measures of general symptom severity emerged, which have received considerable attention. One of these measures is designed to obtain ratings from parents, teachers or adolescents (SDQ) (please see below – page 10 for a review) and the other is a clinician rated measure, HoNOSCA (please see below – page 9 for a review). During a series of meetings of experts in the area it was resolved that HoNOSCA and the SDQ be recommended for adoption nationally. Work on practical implementation is underway in Australia.
Section 2: Measures examined in this study

The clinician survey (Phase 1) identified the main outcome measures used or recommended by clinicians in New Zealand. Consumer feedback on those instruments was sought in focus groups. The following section provides information about the reviewed measures.

2.1 Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA)

The HoNOSCA (Gowers & Bailey, 1999) is a brief global outcome measure modelled on the Health of the Nation Outcome Scales (HoNOS). HoNOS was originally developed by the Royal College of Psychiatrists in the United Kingdom (UK) as a tool to be used by clinicians in their routine work to measure adult mental health outcomes.

In response to similar needs that drove the development of the HoNOS, the UK Department of Health funded the Department of Child and Adolescent Psychiatry at the University of Manchester to develop a brief rating instrument for application by Child and Adolescent Mental Health Services. The resulting instrument is a 15-item clinician-rated measure designed specifically for use in the assessment of child and adolescent consumer outcome in mental health services (Gowers et al., 1999). It is a general measure of severity of mental disorder and covers a range of behavioural, symptomatic, social and impairment domains within the generally accepted knowledge of child psychopathology (Gowers et al., 1999).

<table>
<thead>
<tr>
<th>Table 1: The 15 HoNOSCA sub-scales.</th>
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<tbody>
<tr>
<td>1. Disruptive, antisocial or aggressive behaviour</td>
</tr>
<tr>
<td>2. Problems with over-activity, attention or concentration</td>
</tr>
<tr>
<td>3. Non-accidental self injury</td>
</tr>
<tr>
<td>4. Alcohol, substance or solvent abuse</td>
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<tr>
<td>5. Problems with scholastic or language skills</td>
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<tr>
<td>6. Physical illness or disability problems</td>
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<tr>
<td>7. Problems associated with hallucinations, delusions, or abnormal perceptions</td>
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<tr>
<td>8. Problems with non-organic somatic symptoms</td>
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<tr>
<td>9. Problems with emotional and related symptoms</td>
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<tr>
<td>10. Problems with peer relationships</td>
</tr>
<tr>
<td>11. Problems with self-care and independence</td>
</tr>
<tr>
<td>12. Problems with family life and functioning</td>
</tr>
<tr>
<td>13. Poor school attendance</td>
</tr>
<tr>
<td>14. Problems with lack of knowledge or understanding about the nature of the child or adolescent’s difficulties</td>
</tr>
<tr>
<td>15. Problems with lack of information about services or management of the child or adolescent’s difficulties</td>
</tr>
</tbody>
</table>

Items 1-13 require assessment of a specific aspect of the young person’s mental health, while the remaining two items concern environmental aspects related to lack of information or access to services.
Each HoNOSCA subscale is rated on a five-point scale (0=no problem, 1-4 minor to very severe problem) referring to the preceding 2-week period. In assigning ratings, the clinician should use a special glossary describing each anchor point for each item (please refer www.rcpsych.ac.uk.cru/honosca/supplies.htm). The measure takes between 2 to 20 minutes to complete, with an average of 8.5 minutes reported by Gowers et al., (1999).

As this is a relatively new instrument, a limited number of studies have examined the measure’s feasibility and psychometric properties. In three field trials in the U.K. the HoNOSCA demonstrated satisfactory reliability and validity and was found to be sensitive to change (Gowers et al., 1999). Yates, Garralda and Higginson (1999) examined the sensitivity of HoNOSCA and other clinician- and consumer-rated measures in describing the clinical profiles of children and adolescents at intake to mental health services. Correlations of moderate intensity ($r>0.6$) were found between total HoNOSCA scores and the Children’s Global Assessment Scale, C-GAS, (Schaffer et al., 1983) and other measures of clinical complexity. Garralda, Yates and Higginson (2000) assessed the validity of HoNOSCA in assessing outcome when used routinely in CAMHS. The researchers found modest correlations between change in HoNOSCA and C-GAS ($r=0.51$, $p<0.001$). Furthermore, the scale was deemed feasible and sensitive to change at the 6-month follow-up.

Brann, Coleman and Luk (2001) evaluated the HoNOSCA with a sample of Australian CAMHS patients and found moderate to good reliability and sensitivity to change over a 3-month period. In addition, HoNOSCA correlated with clinicians’ views of change and the total score appeared to be a useful proxy measure of symptom severity.

To date there are no published reports on the feasibility and usefulness of HoNOSCA in New Zealand. However, HoNOSCA was used in the recent Mental Health Classification and Outcomes Study (CAOS) and found to be an effective tool for the prediction of resource use (Gaines et al., 2003).

### 2.2 Strengths and Difficulties Questionnaire (SDQ)

The SDQ is a brief behavioural screening questionnaire designed for 3-17 years olds developed by Goodman et al., (1997) in the United Kingdom (please refer www.doh.gov.uk/pdfs/qpstrengths.pdf). The SDQ provides a profile of child and adolescent behaviour, emotions and relationships. There are parent and teacher versions which are identical. The adolescent version is a self-report for 11-17 year olds and differs only in that it is written in the first, instead of the third person.

Each version includes between one and three of the following components:

- 25 items on psychological attributes: all versions of the SDQ ask about 25 attributes, some positive and others negative.
- These 25 items are divided between 5 scales:
  - Emotional symptoms (5 items);
  - Conduct problems (5 items);
  - Hyperactivity/inattention (5 items);
  - Peer relationship problems (5 items), and
  - Prosocial behaviour (5 items).

Scales 1-4 are summed up to generate a Total Difficulties Score. For each clinical scale, the score can range from 0 to 10. The resultant score can range from 0 to 40. The SDQ takes only five minutes to complete, and scoring is straightforward.
SDQ comes in several versions either one- or two-sided. Two-sided versions of the SDQ are available with the 25 items on strengths and difficulties on the front page and an impact supplement on the back. The extended version of the SDQ asks whether the respondent thinks the young person has a problem, and if so, enquires further about chronicity, distress, social impairment, and burden to others.

Respondents use a three-point scale to rate items as either “not true”, “somewhat true”, or “certainly true”. The basic 25-item version can be completed in 5 minutes by the parents or teachers of children aged 4-10 and 10 to 17.

Follow-up versions of the SDQ are available and include not only the 25 basic items and the impact questions, but also two additional follow-up questions for post intervention use: “Since coming to the service are your child’s problems…” followed by a 5-point Likert scale ranging from “much worse” to “much better”, and “Has coming to the service been helpful in other ways, e.g. providing information or making the problems more bearable?”

The SDQ has been shown to have a satisfactory cross-informant agreement, which compares favourably with that usually found for the Child Behaviour Checklist (CBCL) and other behavioural screening measures (Goodman, 2001). The SDQ has satisfactory internal reliability with a mean Cronbach alpha of 0.73 across scale scores and informants in a large community sample of 5- to 15-year-olds (Goodman, 2001). The SDQ also has satisfactory test-retest stability (0.62 after 4-6 months) (Goodman, 2001).

The SDQ has been found to have a respectable validity. When administered to multiple informants, the SDQ was shown to identify approximately two thirds of children and adolescents with psychiatric disorders in the community (specificity=94.6%; sensitivity=63.3%) (Goodman, Ford, Simmons, Gatward, & Meltzer, 2000). In a psychiatric clinic sample, diagnostic predictions based on the SDQ agreed well with clinical diagnosis (Goodman, Renfrew, & Mullick, 2000a). The parent and teacher’s versions of SDQ have been found to discriminate between psychiatric and non-psychiatric cases, and detect internalising and externalising problems as well as CBCL (Goodman & Scott, 1999).

The SDQ’s psychometric properties have not been confirmed with either an Australian or a New Zealand population. However, Mathai, Anderson and Bourne (2002) evaluated the usefulness of SDQ as a routine measure on a sample of 130 consecutive new attendees of an Australian CAMH service. They found moderate inter-rater correlations for the total difficulties score and small to moderate correlations for the clinical scales, which compared well with other studies (e.g. Achenbach et al., 1987). The authors also found moderate inter-test correlations ($r=0.363$ to 0.463, $p<0.01$) between the SDQ and HoNOSCA scores.

Studies are needed to ensure reliability and validity of the use of the SDQ in New Zealand and establish clinical and non-clinical norms.

2.3 Child Behaviour Checklist (CBCL)

The Child Behaviour Checklist, CBCL (Achenbach, 1991) is a parent, teacher (Teacher Report Form, TRF) and youth reported measure (Youth Self Report, YSR). It has been extensively researched and is one of the most widely used general symptom measures.
The CBCL investigates problem behaviour in children over the past 6 months. It incorporates:

- Externalising and internalising scales, and
- Additionally there are up to 15 other scales (depending on the version) that describe specific types of behaviour problems (e.g. depression, somatic complaints, social competency, delinquent behaviour, attention problems, aggressive behaviour etc.).

The CBCL is normed by gender for children aged 4 to 18 years and has been normed in Australia (Achenbach, Hensley, Phares, & Grayson, 1990b). Respondents are instructed to circle a ‘0’ if the item is not true of the child, a ‘1’ if the item is somewhat or sometimes true, and a ‘2’ if it is very true or often true.

The standard CBCL form takes 15-17 minutes to complete. Furthermore, the CBCL problem scale is supposed to be administered along with the CBCL social competence (approximately 5-10 minutes) making the measure lengthier.

The CBCL has good validity and effectively discriminates between clinical and non-clinical samples (Achenbach, 1991). Its internal consistency is adequate; test-retest reliability is high and convergent validity with other measures of childhood psychopathology (e.g. Conner’s Parent Questionnaire, 1973) is generally adequate for many of its subscales.

The Child Behaviour Checklist (Achenbach, 1991) was reviewed by Bickman et al., (1998). The CBCL is generally considered to be one of the prime instruments to assess general symptom severity and is widely used in both clinical and epidemiological studies in Australia. However, Bickman et al.’s review deemed it too lengthy to be a part of a comprehensive assessment package and as such it would compromise the assessment of other domains. In addition, the CBCL is a proprietary instrument, which makes it a costly measure when used on a routine basis.

### 2.4 Conner's Rating Scales

The Conner’s Rating Scales (Conner's, 1989) are used frequently in clinical assessment and monitoring of treatment especially for young people with diagnoses of attention deficit hyperactivity disorder (ADHD). There are Conner’s Teacher Rating Scales (CTRS) and Conner’s Parent Rating Scales (CPRS) forms available in short and long versions.

The hyphenated number of the scale (e.g. CTRS-28) reflects the number of questions in the form. The original long Teacher version takes approximately 15-20 minutes while the short versions can be completed in 5 to 10 minutes. The long parent version takes approximately 30 minutes while the shorter version approximately 20 minutes.

Revised versions of the Conner’s Rating Scales are now available. However, the present study used the original rating scales as they were readily available at the time. In particular, we chose to present the CTRS-39 to the participants as the Teacher version (the Hyperactivity index subscale) is commonly used for the diagnosis of ADHD.
Table 2: Summary of Conner’s Rating Scales available and the subscales they cover.

<table>
<thead>
<tr>
<th>Teacher Scales</th>
<th>Parent Scales</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Short</strong></td>
<td><strong>Long</strong></td>
</tr>
<tr>
<td>CTRS-28</td>
<td>CTRS-39</td>
</tr>
<tr>
<td>Conduct Problem</td>
<td>Conduct Problem</td>
</tr>
<tr>
<td>Hyperactivity</td>
<td>Hyperactivity</td>
</tr>
<tr>
<td>Inattentive-Passivity scales</td>
<td>Anxious-Passive</td>
</tr>
<tr>
<td>Daydream-Attendance Problem</td>
<td>Learning Problem</td>
</tr>
<tr>
<td>Asocial</td>
<td>Psychosomatic</td>
</tr>
<tr>
<td>Emotional</td>
<td>Learning Problem</td>
</tr>
<tr>
<td>Overindulgent</td>
<td>Obsessional</td>
</tr>
<tr>
<td></td>
<td>Restless-Disorganised</td>
</tr>
</tbody>
</table>

Respondents are instructed to circle a ‘1’ for “not at all”, ‘2’ for “just a little”, ‘3’ for “pretty much” and ‘4’ for “very much”. Normal ranges on the scales have been established for both genders for ages 3 to 17 years.

The CTRS-39 reliability has been rated adequate and stable; the test-retest is considered good, and its construct validity was also assessed to be satisfactory (Trites, Blouin, & LaPrade, 1982). Consistent with its origins, the CTRS has also been utilized to measure the effects of medication treatment on classroom behaviour (Fisher & Newby, 1991); (Rapport, DuPaul, Stoner, & T, 1986). The CPRS has been used for assessing psychosocial, e.g. (Horn, Ialongo, Popovich, & Peradotto, 1987), and drug treatment outcomes in children with disruptive behaviour problems, e.g. (Fisher & Newby, 1991).

2.5 Global Assessment of Functioning Scale (GAF)

The Global Assessment of Functioning DSM-IV, Axis V (GAF), (American Psychological Association, 1994) is a quick and simple measure of overall psychological disturbance. It consists of a 100-point scale that measures a client’s overall level of psychological, social, and occupational functioning on a hypothetical continuum, where the higher score indicates better functioning. It has nine behavioural descriptors ranging from “superior functioning in a wide range of activities” through “moderate symptoms or moderate difficulty in one of the following: social, occupational, or school functioning” to “persistent danger of severely hurting self or others or persistent inability to maintain minimal personal hygiene or serious suicidal act with clear expectation of death”. Clients are rated between 0 (most severe) and 100 (least severe) and intermediate codes can be used. The final score is coded as ‘GAF Total’.

The GAF is designed to guide clinicians through a consideration of all aspects of a client’s symptoms and functioning to determine a patient’s GAF rating in less than 3 minutes. The GAF scale can be particularly useful for managed care-driven diagnostic evaluations to determine...
eligibility for treatment and disability benefits and to delineate the level of care required for patients.

Jones, Thornicroft, Dunn and Coffey (1995) have found satisfactory reliability for total GAF score in spite of raters having only one brief training session. Hilsenroth et al., (2000) also noted that GAF exhibited very high levels of inter-rater reliability and their findings also supported the validity of the GAF as a scale of global psychopathology. However, in a recent study of clients with psychiatric and substance disorders, no strong associations were found between GAF ratings and outcomes as assessed by clinician interview or by clients’ self-report at follow-up (Moos, Nichol, & Moos, 2002).

The GAF scale has been adapted by Schaffer, Gould and Brasic (1983) for use with children aged 6-17 and is called the Children’s Global Assessment Scale (C-GAS). Similarly, it is a 100-point rating scale measuring psychological, social and school functioning. However, the descriptions associated with each rating are more applicable to the behaviours and life situations of children and young people (e.g. participation in extracurricular activities, difficulty with school work, school refusal, or need for constant supervision). The C-GAS scale was not reviewed in this project as we did not find it to be used extensively by the clinicians (Phase 1); instead the GAF scale was shown to the participants during focus groups.

2.6 Beck Depression Inventory II (BDI II)

The Beck Depression Inventory-II (“BDI-II”) (Beck, Steer, & Brown, 1996) is a self-report measure of depressive symptoms. It has recently been revised to make the symptom content correspond more closely to the diagnostic criteria of the American Psychological Association’s (1994) Diagnostic and Statistical Manual of Mental Disorder (DSM-IV) for depressive disorders. It is designed for use in adolescents 13 years of age and older, as well as adults.

The BDI-II is composed of 21 questions most of which assess depressive symptoms on a Likert scale of 0-3. The two exceptions to this are questions that address directional changes in sleeping pattern and appetite. The symptoms of weight loss, body image change, work difficulty, and somatic preoccupation were eliminated and replaced by four new symptoms of agitation, worthlessness, concentration difficulty, and loss of energy.

The scoring is the same as the original BDI (Beck, Ward, & Mendelson, 1961). A four-point scale is used with scores ranging from 0 to 3. The time frame for the ratings is two weeks. Approximately 5-10 minutes is required for clients to complete the BDI-II. The BDI-II is scored by hand only.

The BDI-II has highly established psychometric qualities: the Alpha reliability for BDI-II was 0.92 for the outpatients and 0.93 for the college students (Beck et al., 1996). The same study also found BDI-II to correlates highly (r=0.71) with the revised Hamilton Psychiatric Rating Scale for Depression (Hamilton, 1960) providing evidence of the BDI-II’s construct validity.

2.7 Child Depression Inventory (CDI)

The Child Depression Inventory (“CDI”) (Kovacs, 1992) is a self-rated measure of current depressive symptoms in children and adolescents (ages 7-17 years). It is available as long (27 items) and short (10 items) versions. Each item consists of three choices, (e.g. “I am sad once in a while”, “I am sad many times”, and “I am sad all the time”). The child endorses the statement that best describes him/her during the past 2 weeks. Statements are scored 0, 1, or 2 to reflect symptom severity.
The CDI includes five subscales:

- Negative Mood;
- Interpersonal Problems;
- Ineffectiveness;
- Anhedonia, and
- Negative Self-Esteem.

CDI scores have been normed according to gender and age. The CDI has demonstrated satisfactory test-retest reliability, split-half reliability, and internal consistency with non-clinical samples (Kovacs, 1992; Saylor, Finch, Spirito, & Bennett, 1984). With an inpatient sample, CDI scores correlated moderately with an independent psychiatric diagnosis (Saylor et al., 1984). Other research suggests that the CDI is better able to distinguish normal from clinical populations and less able to distinguish between different clinical samples (Kovacs, 1992).

### 2.8 Hua Oranga – A Māori Mental Health Outcome Measure

Recently, significant work has been completed by Dr Te Kani Kingi and Professor Mason Durie at the School of Māori Studies at Massey University (2000) to design an outcome measure for Tāngata Whai Ora (Māori mental health consumers). The resulting measure, Hua Oranga, is based on Māori concepts of health and well being and reflects aspects of mental health outcome relevant to Tāngata Whai Ora /clients and their whānau. The scale covers four domains of the well accepted Māori health model Te Whare Tapa Whā (The Four Walls of a Meeting House) in which the meeting house walls symbolise the cornerstones of health:

- Te Taha Wairua (Spiritual Dimension);
- Taha Hinengaro (Mental Dimension);
- Te Taha Tinana (Physical Dimension), and
- Te Taha Whānau (Family Dimension).

Within each of these domains, four dimensions of outcome are assessed.

**Table 3: Domains and dimensions assessed by Hua Oranga.**

<table>
<thead>
<tr>
<th>Domains</th>
<th>Wairua</th>
<th>Hinengaro</th>
<th>Tinana</th>
<th>Whānau</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dimension 1</strong></td>
<td>dignity, respect</td>
<td>motivation</td>
<td>mobility/pain</td>
<td>communication</td>
</tr>
<tr>
<td><strong>Dimension 2</strong></td>
<td>cultural identity</td>
<td>cognition/behaviour</td>
<td>opportunity for enhanced health</td>
<td>relationship</td>
</tr>
<tr>
<td><strong>Dimension 3</strong></td>
<td>personal contentment</td>
<td>management of emotions, thinking</td>
<td>mind and body links</td>
<td>mutuality</td>
</tr>
<tr>
<td><strong>Dimension 4</strong></td>
<td>spirituality (non-physical experience)</td>
<td>understanding</td>
<td>physical health status</td>
<td>social participation</td>
</tr>
</tbody>
</table>
Hua Oranga is intended to be administered at five clinical endpoints (Assessment, Inpatient Treatment, Outpatient Treatment, Community Care and Community Support) providing a more comprehensive assessment of progress and the effectiveness of care. The end points allow for greater flexibility than “Discharge” especially for those with long-term treatment plans. More recently, however, it has been suggested that the tool could be used at any point where an outcome may be expected or where a culturally derived outcome is anticipated. A triangulated approach is used in the administration of Hua Oranga with views being obtained from the clinician, Tangata Whai Ora and whānau. It has been recommended (Kingi & Durie, 2000) that Tangata Whai Ora should be able to determine who in their whānau completes the questionnaire. At present Hua Oranga is intended for use in adult population. We consulted with the author, Dr Kingi about the current status of Hua Oranga as an outcome measure for children and adolescents. He reported that work was currently being undertaken to modify the schedules and to ensure that the instrument better met the needs of tamariki and taitamariki. This work is not yet complete, as a consequence, Hua Oranga is not currently suitable for inclusion as a routine outcome measure for tamariki and taitamariki.

2.9 Drug and alcohol measures

Individuals presenting with mental illness frequently have substance abuse and dependence problems, placing them at increased risk for poor treatment outcome (Cocco & Carey, 1998). In the United States it has been estimated that as many as 75% of drug-abusing adolescents have a co-morbid mental disorder, with conduct disorder, affective disorders, and ADHD being the most prevalent (Crowley, MacDonald, Whitmore, & Mikulich, 1998a). However, substance abuse disorders are often not detected in psychiatric settings, with one of the reasons being attributed a lack of validated and feasible screening procedures (Wolford et al., 1999).

Since the mid-1980’s a number of behavioural-based screening and assessment tools have been developed for use in the services that address adolescent drug and alcohol abuse (Leccese & Waldron, 1994). These efforts have benefited the specialty services and introduced greater standardisation allowing for a more objective screening and measurement of alcohol and drug outcomes. Self-reports are considered to be the most direct and accurate sources of information about an individual’s drug and alcohol use and related problems because of the difficulty in obtaining supporting information from other sources (Winters, Latimer, & Stinchfield, 2002). Parents tend to underreport their child or young person’s substance abuse and are not likely to provide meaningful details of their child or young person’s involvement with alcohol and drugs (Winters, Anderson, Bengston, Stinchfield, & Latimer, 2000). Despite some concerns about the validity of self-report and expectations that adolescents intentionally underreport their substance abuse, there is an empirical support for the validity in general of self-report alcohol and drug use scales. Furthermore, Wolford et al., (1999) carried out an extensive evaluation of detection methods (laboratory blood and urine tests, medical exam, collateral report, interviews and self-report instruments) on a sample of adult psychiatric patients and found that screens based on self-report were superior to the other approaches.

A clinically feasible drug and alcohol screening instrument should be simple for a range of health professionals to administer and score, and ideally taking 10-15 minutes (Winters et al., 2002). The measure should cover the severity of drug and alcohol use and the negative consequences associated with consumption. In addition, briefly screening for other problems associated with child and youth substance abuse such as legal problems, suicidality, sexual/physical abuse and HIV/STD risk may be incorporated (Winters et al., 2002).
2.10 Drug and Alcohol measures most commonly reported in this study

2.10.1 Alcohol Use Disorders Identification Test (AUDIT)

The Alcohol Use Disorders Identification Test (AUDIT; Saunders, Aasland, Babor, De La Fuente, & Grant, 1993) is a brief 10-item screening tool designed for use in primary medical care settings with adult patients which is easy to administer. The measure is designed to identify individuals whose use of alcohol places them at risk for alcohol problems or who are experiencing such problems. AUDIT has a high internal consistency (Barry et al., 1995), has been validated by showing moderate to high correlations with other alcohol and drug self-report instruments (Saunders et al., 1993) and has good sensitivity and specificity (Maisto, Carey, Carey, Gordon, & Gleason, 2000) but its utility for children and young people has not yet been established.

2.10.2 Drug Abuse Screening Test for Adolescents (DAST-A)

The Drug Abuse Screening Test for Adolescents ("DAST-A") (Martino, Grilo, & Fehon, 2000) was developed to quantify the severity of substance abuse among young psychiatric patients. The measure can be used to screen for illicit drug abuse within acute psychiatric settings to initiate dual diagnosis treatment. It is a brief 27-item self-report instrument. The validation of the instrument demonstrated a favourable internal consistency and test-retest reliability, and good concurrent validity with the measure hypothesised to be related to adolescent drug abuse such as depressive symptoms, greater risk for suicide etc (Martino et al., 2000). In the same study it was also shown to have a high predictive power in differentiating individuals with and without drug-related disorders using the diagnostic system of the DSM-IV.

2.10.3 Drug Use Screening Inventory (DUSI-R)

The Drug Use Screening Inventory ("DUSI-R") (Tarter, Laird, Bukstein, & Kaminer, 1992) estimates the extent and consequences of drug involvement. The questionnaire consists of 159 items and is divided into 10 subscales (substance use, behaviour pattern, health status, psychiatric symptoms, social competence, family system, school adjustment, work adjustment, peer relationships and leisure/recreation) and a lie scale. DUSI-R scores correlated with DSM-III-R criteria for substance use disorders (Tarter et al., 1992). In a later study Kirisci, Mezzich and Tarter (1995) concluded that by assessing multiple domains of functioning, DUSI-R can be used at regular intervals to monitor the person’s progress. The main difficulty with the DUSI-R is the time it takes to complete.

2.10.4 Leeds Dependence Questionnaire (LDQ)

Leeds Dependence Questionnaire ("LDQ") (Raistrick, Bradshaw, Tober, & Weiner, 1994) is a 10-item, self-rated questionnaire designed to measure substance dependence in children and young people. The LDQ has a high test-retest reliability of 0.95 and satisfactory concurrent, discriminant, and convergent validities (Raistrick et al., 1994). Its favourable psychometric qualities and usefulness as a measure of dependence in adult inpatients with mental disorders have been recently confirmed by Ford (2003). Lennings (1999) has also found it to be a useful measure of drug abuse among young delinquent individuals (11-18 years old) correctly predicting increased frequency of a variety of substances abused.
Section 2: Measures examined in this study
Section 3: Purpose of the report

The aim of this report was to gather and systematically report the opinions of clinicians and consumers about measures that are most commonly used and to inquire about the HoNOSCA and the SDQ specifically. A clinician survey was used to identify the main outcome measures used by clinicians as well as to collect feedback about their views of outcome measurement. The measures identified by clinicians and the HoNOSCA and SDQ were taken to focus groups for consumer and family feedback and discussion.

3.1 Project deliverables

The project deliverables included:

- A written questionnaire distributed among CAMHS and Non-Government Organisation (“NGO”) clinicians;
- Telephone interviews with team leaders/service managers;
- Ten focus groups with young consumers of CAMHS and their family/whānau members, including groups with Māori and Pacific peoples as well as latency aged children;
- An analysis of quantitative and qualitative data, and
- A written report with proposed recommendations.

3.2 Project Outline

The work required to meet the aims of this report was undertaken in three phases.

3.2.1 Phase One

A survey of CAMHS and NGO clinicians was conducted. In addition, team leaders and/or service coordinators were identified and invited to participate in brief telephone interviews to obtain more in-depth information.

A list of most commonly used outcome measures was compiled at the end of this phase and consumers were asked to comment on them in the subsequent phases.

3.2.2 Phase Two

Seven focus groups were conducted with child and youth consumers of CAMHS. Two of these groups were with Māori young people. One group included children aged 6-12 years. One group included young adults from a consumer advisory group for the Mental Health Foundation. An individual interview was conducted with a Pacific young person.

The groups were conducted in Auckland, Wellington, New Plymouth and Dunedin.

3.2.3 Phase Three

Three focus groups were conducted with family/whānau members of children and young people who have been consumers of CAMHS. One of these groups was with Māori family/whānau members.

The groups were conducted in Auckland, Dunedin, New Plymouth and Wellington.
3.3 Ethics

Approval from the Auckland Ethics Committee was sought. Two ethics applications were sent: Phase 1 (Clinician Survey) and Phase 2 and 3 (Focus Groups with consumers and their families).

The research team was informed that a formal ethics approval would not be required for Phase 1 as it did not involve access to patients, and therefore the survey phase of the study was considered as an audit. However, management approval from DHBs was required. Letters were sent to Chief Executive Officers of each DHB informing about them of the intended survey of CAMHS clinicians. We were also required to obtain separate approvals from Auckland and Waitemata DHBs.

Approval for Phase 2 and 3 (Focus Groups) was obtained from the Auckland, Wellington, Dunedin and New Plymouth Ethics Committees. We also obtained an approval from the clinical directors of mental health services in the participating DHBs.
Section 4: Clinician Survey and Telephone Interviews

4.1 Method

4.1.1 Clinician Survey

A questionnaire was designed to gather data on the knowledge, views and attitudes towards outcome measurement in CAMHS (see Appendix A). The survey included questions about:

- Clinicians’ knowledge and experience of various outcome measures and psychometric scales (free recall) including advantages and disadvantages of each recalled measure;
- Recommendations about the best outcome measures to be used routinely;
- Opinions about the adequacy of the Information Management and Technology Systems to collect and collate routine outcome measures;
- Attitudes towards routine use of outcome measures and associated concerns and anticipated problems;
- Knowledge and experience of outcome measures in drug and alcohol use, abuse and dependence, and
- A range of questions was asked about the SDQ and the HoNOSCA as these have been recommended for routine use in Australia.

The Participant Information Sheet attached to the survey listed two websites that contain electronic versions of HoNOSCA (www.rcpsych.ac.uk.cru/honosca/supplies.htm) and SDQ (www.doh.gov.uk/pdfs/qpstrengths.pdf) for those participants unfamiliar with these measures who wished to view them. If requested, paper copies of these measures were sent to individual services. We obtained the endorsement of Professor Simon Gowers to review HoNOSCA and Professor Robert Goodman to review the SDQ in this research.

The survey was sent out by email to all CAMHS and NGO clinicians on the distribution list held by the Werry Centre for Child and Adolescent Mental Health. This distribution list has been used previously with success to distribute information about workshops and send out regular newsletters. Prior to the distribution of the survey the email list was updated and the team leaders/clinical managers were contacted to provide updated email addresses of current CAMHS staff.

The Ministry of Health was contacted to obtain a list of Ministry of Health funded CAMHS and NGOs in New Zealand. Each organisation was contacted by telephone and invited to participate in the survey.

In addition, the questionnaires were distributed through the email distribution list of the New Zealand Section of the Child and Adolescent Faculty of the Royal Australian and New Zealand College of Psychiatrists.

Participants were encouraged to return the survey either electronically (as saved attachments) or by ordinary mail using a Freepost number.

Three email reminders were sent out to everybody on the list at approximately one month intervals to facilitate the response rate.

As the results were being collected, a demographic analysis was undertaken to ensure that we were collecting responses from various subgroups in terms of ethnicity, professional background and the type of service in which they were employed. This allowed us to identify
a lack of feedback from Pacific Island clinicians and consult with our Pacific co-investigator on the ways to facilitate the response. Personal visits to Auckland CAMHS increased the return rate from this group of clinicians to a satisfactory rate. Similarly, a low response rate was identified from the participating NGOs and telephone follow-up increased the number of questionnaires returned.

4.1.2 Telephone Interviews with Team Leaders

In order to update the email distribution list, team leaders/service coordinators were asked to identify themselves and provide an updated list of their clinicians’ emails. The team leaders were sent a separate email inviting them to a brief 20-30 minute telephone interview to facilitate the collection of more in-depth information regarding the service-level issues and strategic approaches to implementing routine implementation of outcome assessment in the clinic.

An interview proforma was developed and was used to guide the telephone interviews (Appendix A).

The interview questions were designed to complement the written survey where additional information could be obtained about the “whys and wherefores” of their answers, and other concerns about practical implementation issues they may have wished to highlight.

Issues covered included:

- The experience of the use of outcome measures with various ethnic groups;
- The adequacy of received training in the use of outcome measures;
- Training needs of clinical and/or administrative staff in the use and collection of outcome measures, and
- Management and strategic issues in the implementation of routine outcome measurement.

4.2 Survey analysis

The data generated by the survey of clinicians was entered into SPSS 11.5 for Windows and the responses of the entire sample were described in terms of frequency and range, and the degree of precision of these.

The survey included a number of qualitative comments to several questions. Two researchers read all those comments and generated a list of themes. Subsequently, each response was coded as belonging to one or more of the categories. The reliability of the coding was verified by a third researcher reading greater than 10 percent of the responses and independently coding them using the predefined themes. Categories were collapsed into larger overarching themes. This resulted in inter-rater reliability greater than 85%.

4.3 Telephone interview analysis

Telephone interviews provided complementary information to the survey responses and these data were analysed alongside each other. However, there were a number of unique issues raised during the interview regarding strategic issues such as ability of current systems to cope with routine data collection, levels of staffing, training needs and changes to management structure. These qualitative data have been analysed and presented separately.
4.4 Survey Results

4.4.1 Demographic description of the sample

105 clinicians took part in the survey. 68% were female and 32% were male. The mean age of participants was 41.1 years of age (median = 42; range from 24 to 68 years). Percentages referred to in tables and figures throughout this results section are based on the total sample of 105 respondents, unless otherwise indicated (as in Table 6).

Figure 1: Highest qualification of respondents.
(Note: Some participants selected more than one category – for example those who had PhD and belonged to a professional membership/fellowship.)

![Highest Qualification of Respondents](image-url)
Figure 2: Ethnicity of participants.
(Note: Participants were asked to choose as many categories as applied. Other ethnicities included various European groups, North American, South American, as well as Asian ethnic groups.)

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Percentage of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>NZ European</td>
<td>63.7%</td>
</tr>
<tr>
<td>Māori</td>
<td>13.7%</td>
</tr>
<tr>
<td>Samoan</td>
<td>4.9%</td>
</tr>
<tr>
<td>Cook Island Māori</td>
<td>1.0%</td>
</tr>
<tr>
<td>Tongan</td>
<td>2.0%</td>
</tr>
<tr>
<td>Niuean</td>
<td>1.0%</td>
</tr>
<tr>
<td>Chinese</td>
<td>1.0%</td>
</tr>
<tr>
<td>Other</td>
<td>13.7%</td>
</tr>
</tbody>
</table>

Figure 3: Professional training of participants.
(Note: Participants were allowed to choose as many categories as applied. Other training included general practice, education, tikanga Māori, cultural support and management.)

<table>
<thead>
<tr>
<th>Professional training</th>
<th>Percentage of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychology</td>
<td>37.0%</td>
</tr>
<tr>
<td>Nursing</td>
<td>21.0%</td>
</tr>
<tr>
<td>Counselling</td>
<td>18.1%</td>
</tr>
<tr>
<td>Psychiatry</td>
<td>16.2%</td>
</tr>
<tr>
<td>Social Work</td>
<td>12.4%</td>
</tr>
<tr>
<td>Psychotherapy</td>
<td>8.6%</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>2.0%</td>
</tr>
<tr>
<td>Other</td>
<td>16.2%</td>
</tr>
</tbody>
</table>
Figure 4: Current Place of work – agency where most time is spent.  
(Other agencies included tertiary hospital, university, private practice and Specialist Youth Substance Use Service.)

Figure 5: Region where current workplace is.
Figure 6: Length of time in a post providing mental health service to children and adolescents.

4.4.2 Knowledge and experience of using outcome measures

Participants were asked to list outcome measures or other measures with which they have had direct experience (no prompting was given). The following table presents the measures that were cited most frequently:

<table>
<thead>
<tr>
<th>Measure</th>
<th>Routine use</th>
<th>Occasional use</th>
<th>Know about measure but don’t use currently</th>
<th>No knowledge / no response</th>
</tr>
</thead>
<tbody>
<tr>
<td>HoNOSCA</td>
<td>16.2%</td>
<td>14.3%</td>
<td>8.6%</td>
<td>60.9%</td>
</tr>
<tr>
<td>CBCL</td>
<td>16.2%</td>
<td>12.4%</td>
<td>1.0%</td>
<td>70.4%</td>
</tr>
<tr>
<td>GAF</td>
<td>6.7%</td>
<td>2.9%</td>
<td>1.0%</td>
<td>89.4%</td>
</tr>
<tr>
<td>SDQ</td>
<td>4.8%</td>
<td>10.5%</td>
<td>5.7%</td>
<td>79.0%</td>
</tr>
<tr>
<td>Conner’s</td>
<td>3.8%</td>
<td>20.0%</td>
<td>0.0%</td>
<td>76.2%</td>
</tr>
<tr>
<td>BDI</td>
<td>0.0%</td>
<td>18.1%</td>
<td>0.0%</td>
<td>81.9%</td>
</tr>
<tr>
<td>CDI</td>
<td>0.0%</td>
<td>19.0%</td>
<td>0.0%</td>
<td>81.0%</td>
</tr>
</tbody>
</table>
Participants were asked about their experience with each listed measure:

Table 5: Type of experience with the most commonly listed psychometric measures.

<table>
<thead>
<tr>
<th>Measure</th>
<th>Practical experience</th>
<th>Training received</th>
<th>Research</th>
<th>Limited use / reading</th>
<th>None reported / no response</th>
</tr>
</thead>
<tbody>
<tr>
<td>HoNOSCA</td>
<td>22.9%</td>
<td>17.1%</td>
<td>5.7%</td>
<td>3.8%</td>
<td>50.5%</td>
</tr>
<tr>
<td>CBCL</td>
<td>33.3%</td>
<td>8.6%</td>
<td>2.9%</td>
<td>1.9%</td>
<td>53.5%</td>
</tr>
<tr>
<td>GAF</td>
<td>11.4%</td>
<td>1.9%</td>
<td>0.0%</td>
<td>1.0%</td>
<td>85.7%</td>
</tr>
<tr>
<td>SDQ</td>
<td>14.3%</td>
<td>1.0%</td>
<td>2.9%</td>
<td>9.5%</td>
<td>72.3%</td>
</tr>
<tr>
<td>Conner’s</td>
<td>24.8%</td>
<td>5.7%</td>
<td>1.0%</td>
<td>1.0%</td>
<td>67.5%</td>
</tr>
<tr>
<td>BDI</td>
<td>20.0%</td>
<td>5.7%</td>
<td>2.9%</td>
<td>0.0%</td>
<td>71.4%</td>
</tr>
<tr>
<td>CDI</td>
<td>20.0%</td>
<td>4.8%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>75.2%</td>
</tr>
</tbody>
</table>

4.4.2.1 Advantages and disadvantages of various outcome measures used

Participants were asked to note the advantages and disadvantages of the outcome measures they listed. The qualitative responses were coded post hoc into following categories:

Advantages of measures

1. Ease/simplicity of administration/completion/scoring/interpreting, quick/brief, ability to computer score;
2. Specific characteristics of test: developmentally appropriate, positive, multiple informants, comprehensive;
3. Psychometrics – validity, reliability, empirically based;
4. Assists in diagnosis/screening, identifies needs/problems, supports clinical interview, confirms/denies queries/"suspicions" – including gathering specific information not gained elsewhere;
5. Inexpensive, free to use;
6. Promotes discussion between client and clinician;
7. Widely used;
8. Tracks changes/outcome, and

Disadvantages

1. Specific characteristics of tests: too broad, not collecting enough information;
2. Complicated, incomprehensible;
3. Expensive;
4. Misleading, out of context;
5. Used by untrained people, no training available;
6. Criticisms of psychometrics, cultural bias;
7. Lack of sensitivity to change;
8. Intentional bias (client, clinician), subjectivity;
9. Unavailable, and
10. Non-usable, other.

The results are presented in Table 6 – percentages in this table represent a proportion of people who responded to the question i.e., out of 22 people who listed BDI, 36.4 percent of them believed it to be an easy measure to administer and/or complete.

Table 6: Advantages and disadvantages of the most commonly cited outcome measures.

<table>
<thead>
<tr>
<th></th>
<th>BDI</th>
<th>CBCL</th>
<th>CDI</th>
<th>Conner’s</th>
<th>GAF</th>
<th>HoNOSCA</th>
<th>SDQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of respondents</td>
<td>22</td>
<td>34</td>
<td>17</td>
<td>25</td>
<td>11</td>
<td>35</td>
<td>21</td>
</tr>
</tbody>
</table>

ADVANTAGES – WHY I WOULD PROMOTE ITS USE

<table>
<thead>
<tr>
<th>Feature</th>
<th>BDI</th>
<th>CBCL</th>
<th>CDI</th>
<th>Conner’s</th>
<th>GAF</th>
<th>HoNOSCA</th>
<th>SDQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ease/simplicity of administration/completion</td>
<td>36.4%</td>
<td>24.3%</td>
<td>35.3%</td>
<td>32.0%</td>
<td>27.3%</td>
<td>37.1%</td>
<td>47.6%</td>
</tr>
<tr>
<td>Specific characteristics: developmentally appropriate, positive, multiple informants, comprehensive</td>
<td>13.6%</td>
<td>81.1%</td>
<td>29.4%</td>
<td>52.0%</td>
<td>9.1%</td>
<td>37.1%</td>
<td>61.9%</td>
</tr>
<tr>
<td>Psychometrics – validity, reliability</td>
<td>18.2%</td>
<td>29.7%</td>
<td>17.6%</td>
<td>20.0%</td>
<td>-</td>
<td>17.1%</td>
<td>19.0%</td>
</tr>
<tr>
<td>Assists in diagnosis – screening, identifies needs, supports clinical interview</td>
<td>22.7%</td>
<td>32.4%</td>
<td>52.9%</td>
<td>84.0%</td>
<td>27.3%</td>
<td>17.1%</td>
<td>4.8%</td>
</tr>
<tr>
<td>Inexpensive, free to use</td>
<td>-</td>
<td>2.7%</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>2.9%</td>
<td>-</td>
</tr>
<tr>
<td>Promotes discussion between client and clinician</td>
<td>13.6%</td>
<td>2.7%</td>
<td>11.8%</td>
<td>-</td>
<td>-</td>
<td>2.9%</td>
<td>-</td>
</tr>
<tr>
<td>Widely used</td>
<td>4.5%</td>
<td>10.8%</td>
<td>-</td>
<td>20.0%</td>
<td>9.1%</td>
<td>5.7%</td>
<td>-</td>
</tr>
<tr>
<td>Tracks changes/outcome</td>
<td>59.1%</td>
<td>29.7%</td>
<td>47.1%</td>
<td>20.0%</td>
<td>54.5%</td>
<td>31.4%</td>
<td>-</td>
</tr>
</tbody>
</table>

DISADVANTAGES – WHY I WOULD NOT WISH TO SEE ITS USED

<table>
<thead>
<tr>
<th>Feature</th>
<th>BDI</th>
<th>CBCL</th>
<th>CDI</th>
<th>Conner’s</th>
<th>GAF</th>
<th>HoNOSCA</th>
<th>SDQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specific characteristics of tests: too broad, too narrow</td>
<td>22.7%</td>
<td>5.4%</td>
<td>17.6%</td>
<td>12.0%</td>
<td>54.5%</td>
<td>-</td>
<td>33.3%</td>
</tr>
<tr>
<td>Complicated, incomprehensible</td>
<td>13.6%</td>
<td>48.6%</td>
<td>23.5%</td>
<td>24.0%</td>
<td>-</td>
<td>25.7%</td>
<td>4.8%</td>
</tr>
<tr>
<td>Expensive to use</td>
<td>13.6%</td>
<td>24.3%</td>
<td>17.6%</td>
<td>16.0%</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Misleading, out of context</td>
<td>4.5%</td>
<td>13.5%</td>
<td>-</td>
<td>32.0%</td>
<td>-</td>
<td>2.9%</td>
<td>4.8%</td>
</tr>
<tr>
<td>Used by untrained people, no training available</td>
<td>9.1%</td>
<td>8.1%</td>
<td>23.5%</td>
<td>16.0%</td>
<td>-</td>
<td>14.3%</td>
<td>4.8%</td>
</tr>
<tr>
<td>Criticisms of psychometrics, cultural bias</td>
<td>4.5%</td>
<td>10.8%</td>
<td>5.9%</td>
<td>-</td>
<td>18.2%</td>
<td>20.0%</td>
<td>4.8%</td>
</tr>
<tr>
<td>Lack of sensitivity to change</td>
<td>-</td>
<td>5.4%</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>4.8%</td>
</tr>
<tr>
<td>Intentional bias (client, clinician), subjectivity</td>
<td>9.1%</td>
<td>8.1%</td>
<td>17.6%</td>
<td>12.0%</td>
<td>36.4%</td>
<td>20%</td>
<td>-</td>
</tr>
<tr>
<td>Unavailable</td>
<td>-</td>
<td>5.4%</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
4.4.3 Recommended measures

Participants were asked to recommend measures for routine use to be completed by clinicians, family, children and young people, teachers and other relevant people.

**Figure 7: Recommended clinician-rated measures for routine use.**

*(Note: CBCL and SDQ are not clinician-rated measures; however, they were listed as recommendations by the respondents.)*

Other clinician-rated measures included a range of 11 instruments; however, none of those has been listed by more than three respondents.

**Figure 8: Recommended family-rated measures for routine use.**

Other family-rated measures included a range of 9 instruments; however, none of those has been listed by more than three respondents.
Figure 9: Recommended routine measure for completion by children or young people.


Other measures rated by children and young people included a range of 11 instruments; however, none of those has been listed by more than three respondents.

![Figure 9: Recommended routine measure for completion by children or young people.](chart1.png)

Figure 10: Recommended teacher-completed measures for routine use.

![Figure 10: Recommended teacher-completed measures for routine use.](chart2.png)

4.4.4 Optimal number of measures and completion time

Participants were asked about what they would view as the optimal number of measure that could be practically used in their service and the maximum practical time needed to complete a routine outcome measure by a child or young person and family).
Figure 11: Optimal number of routine measures as recommended by participants.
(Note: 25 (23.8%) of respondents did not answer this question.)

Figure 12: Maximum practical time needed to complete a routine outcome measure per case/child/young person/family as viewed by respondents.
(Note: 25 (23.8%) of respondents did not answer this question.)

4.4.5 Opinions about Information Management and Technology (IM&T)
Participants were asked a range of questions about their experiences of Information Management and Technology (IM&T) in the place where they work. Participants were asked to provide their level of agreement on a 7-point Likert scale (a ‘don’t know/unsure’ option was available) to the specific statements that are quoted in the annotations to figures 13-17.
Figure 13: “Our current IM&T systems would be able to manage the routine collection of outcome data”.

![Graph showing percentage of respondents' level of agreement with the statement about IM&T systems' capability to manage outcome data.]

Figure 14: “We could probably use the current IM&T system with modification”.

![Graph showing percentage of respondents' level of agreement with the statement about using the current IM&T system with modification.]

32 Section 4: Clinical Survey and Telephone Interviews
Figure 15: “We would need completely new data management systems”.

Out of those who provided comments to these questions (N=43):
- 39.5% were concerned about the inadequacy and problems with the existing IT/computer network system and lack of IT support at the place of work;
- 30.2% suggested that the data collection should be computerised (e.g. computer scored measures, appropriate databases developed, etc.);
- 23.3% were concerned about the lack of computer and data entry-related resources needed for implementation of routine outcome data collection;
- 18.6% reported needs to have more IT training;
- 7% were concerned about privacy and confidentiality of data stored electronically, and
- 9.3% were satisfied with current IT systems.
4.4.6 Opinions about current staffing levels

Clinicians were asked whether the current levels of clinical and administrative staffing would be sufficient to cope with routine outcome data collection.

Figure 17: “Current levels of administrative staffing would be sufficient”.

Figure 18: “Current levels of clinical staffing would be sufficient”.

Percentage of respondents
4.4.7 Opinions about collection of ethnicity data

We asked a number of questions about the ways ethnicity data were collected at the services that participants worked in.

Figure 19: “Meaningful ethnicity data is routinely collected”.

Figure 20: “The collection of ethnicity data could be improved”.
Figure 21: “Who decides on the ethnicity of the child or young person that is recorded?”

![Bar Chart](chart1.png)

Figure 22: “Who records the ethnicity of the child or young person?”

![Bar Chart](chart2.png)
4.4.8 Clinicians’ opinions about the use of outcome measures

Respondents were asked a number of questions about the importance, practicality and overall support for the introduction of the routine use of outcome measures. They were also asked whether they anticipated any problems with the introduction and implementation of outcome measurement and whether they had any concerns about the potential for misuse of the data.

In addition to asking clinicians to indicate their opinions on a range of statements, participants were also given a chance to state the reasons behind their views and/or comment accordingly. These qualitative responses were coded into several categories that represented the majority of the answers.

Figure 23: “How important is the use of outcome measures in CAMHS?”

Out of those who provided comments to this question,
- 67.9% believed that outcome measures are important in CAMHS because they support service delivery (provision and development of quality services, accountability of clinician/clinic/service, resource allocation, recruitment, data used in research, evidence based work, evaluating the effectiveness of types of therapy/interventions);
- 45.7% also thought that they support clinical work (evaluation of own work, measuring of progress of individual clients, feedback to clinician/child/youth systems, partnership between clinician-client);
- 2.5% of respondents also commented that the introduction of routine outcome measurement may intrude on client-clinician relationship;
- 6.2% were concerned about the inadequacy of the instruments (including the need to pilot measures), and
- 1.2% expressed their concerns about the potential for the misuse of data by management.
Figure 24: “Do you support routine use of outcome measures in CAMHS?”

Out of those who provided comments to this question,
- 53% believed that outcome measurement would support service delivery;
- 22.7% believed that it would support clinical work;
- 18.2% were concerned about the quality/inadequacy of tools;
- 10.6% were concerned that outcome measures would intrude on client-clinician relationship, and
- 9.1% were concerned about the misuse of data by management.

Figure 25: “As a clinician, how practical would you find routine use of outcome measures?”
Out of those who provided comments to this question,

- 40.8% believed that problems with staff’s willingness to take on extra work were the major issues (inability to cope with extra work/no time to do it, ethos/philosophy of workplace, resistance/non-compliance of staff, lack of consistency across teams/services, poor quality of data/reports, incomplete/falsified data, concerns about the mechanisms of data collection, training issues);
- 21.1% anticipated problems such as lack of resources including lack of computers/IT issue, lack of administrative staffing/support, increased costs of running clinic;
- 9.2% were concerned about problems with inadequate measures, and
- 15.8% did not foresee any problems and commented on their current practice of outcome measures with positive consequences.

**Figure 26: “Are you concerned about the potential for misuse of outcome measures?”**

Out of those who provided comments to this question,

- 49.4% were concerned about the way measures would be used by clinical staff (how and who uses them (over-reliance, used by staff with intentional bias, used against client, data not utilised/integrated));
- 36% were concerned about the use of data by management (used against clinicians, tied to funding, dictating direction of services, concerns about DHB and/or Ministry of Health use of data);
- 23.4% were concerned about the inadequacy/quality of the instruments (validity and reliability, not comprehensive enough, quantitative vs. qualitative measures, accuracy/sensitivity of tools, consistency, cultural bias of measures);
- 10.4% had philosophical objections (general worth of measures, quality of outcome definition, philosophy of measurement of people), and
- 14.3% said that they could not see any reasons for concern (have not considered it or had only positive experiences with measures).
Figure 27: “Do you anticipate problems with the introduction and implementation of routine use of outcome measures?”

Out of those who provided comments to this question,

- 84.3% believed that staff willingness or ability to take on extra work (being overworked, not having any more time, poor morale, compliance issues) were the major complications;
- 32.5% felt that the problems with administering measures such as lack of time, administrative support, resources or IT issues were the major causes of anticipated problems;
- 16.0% were concerned about the quality of tools and whether meaningful results would be gained;
- 14.5% were concerned about the misuse of data by the management in terms of changes to funding and direction of services, and
- 9.6% believed that resistance from clients should be considered.
4.4.9 Opinions about SDQ and HoNOSCA

We asked a range of questions specifically about SDQ and HoNOSCA. Participants were first asked if they have ever heard of, used or received training in SDQ and HoNOSCA.

Figure 28: Participants’ knowledge, experience and training in SDQ and HoNOSCA.

Respondents’ opinions were then sought on a number of statements related to acceptability, meaningfulness and cultural relevance of the two measures.

Figure 29: The SDQ and HONOSCA are measures of outcome that are practical to use.
Figure 30: SDQ and HoNOSCA are measures of outcome that are meaningful.

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Figure 31: The SDQ and HoNOSCA are measures of outcome that are possible to use across most cultures.
Figure 32: SDQ and HoNOSCA are measures of outcome that are meaningful for use with Māori and Pacific Island children and young people and families.

Figure 33: SDQ and HoNOSCA are measures of outcome that are acceptable to me as a clinician.
Figure 34: SDQ and HoNOSCA are measures of outcome that are acceptable to my colleagues.

Figure 35: SDQ and HoNOSCA are measures of outcome that are acceptable to children, young people and their families/whānau.
4.5 Telephone Interviews results

Fifteen telephone interviews were carried out with team leaders/clinical managers. The responses, which clarified the answers to the questionnaire, were treated as part of the survey and analysed in conjunction with it. However, a number of unique issues were identified and are presented here.

Team leaders were asked to comment on the IM&T systems and their ability to cope with an introduction of routine outcome measures. Of the 15 respondents:

- Seven were concerned about an insufficient number of PC’s;
- Six believed that the data collection should be done electronically (e.g. by computer scoring) to aid the process;
- Three believed that instead of building new computer systems, new programmes/software are needed;
- Two were concerned about the extra workload the routine outcome data-entry would create;
- Two complained that the existing databases were difficult to use and/or could not be used to retrieve relevant information, and
- Three suggested that outcome data should be entered by the administrative staff while two believed that clinicians would be able to do it if they had easy computer access.

Team leaders were asked to comment on the way staffing levels would be affected by the introduction of routine outcome data collection. Of the 15 respondents:

- Ten believed that extra staff would need to be employed (e.g. statistician, data entry person, researcher to oversee data collection);
- Five were concerned about the extra work that would be generated and how it would be handled;
- Five talked about staff recruitment and retention problems in CAMHS;
- Five would like to see a computer system in place to handle data collection and storage, and
- Three believed that routine data collection would cut down on clinical time.

Questions were also asked about staff training needs. Of the 15 respondents:

- Thirteen believed that all staff needed training, while two thought that only key people required training and that those key people could later support others on the team;
- Seven would like a comprehensive training package introduced (the use of outcome measure, the meaning of results etc), while three believed that ongoing, continuing education was necessary;
- Two believed that training needed to be interactive and that staff needed to feel part of it;
- Two would like a trainer sent to the area to cut down on the travel cost and time;
- Staff motivation and reluctance towards extra workload were seen as the major barriers to successful training;
- Four believed that the lack of resources was an impediment to training, and
- Five were concerned about the time constraints.
Team leaders were also questioned about any changes that may need to take place within their service management structure at organisation level to facilitate the collection and collation of data. Of the 15 respondents:

- Eight believed that the introduction and implementation of routine outcome measurement needed to be driven by a trained coordinator/research assistant/statistician;
- Ten believed that no major changes were needed but that a training campaign should be in place to educate clinicians about the importance of outcome measures;
- Seven believed that simplicity was the key issue (e.g. computer systems, brief measures, efficient system of data collection and reporting) in facilitating compliance in the use of outcome measures, and
- Five believed that adequate resources needed to follow otherwise the data collection would be flawed and inconsistent.

During the telephone interviews we also asked the team leaders/service coordinators about their experiences of using the measures they have listed with various ethnic groups. Twelve of them commented on this question.

Many commented that the services they worked in were largely mono-cultural and thus there were limited opportunities to develop a view of the use of measures with other ethnicities. A few services had a more diverse range of clients from Māori, Pacific and Asian communities, as well as refugees of various ethnicities.

While some team leaders were unable to comment about the cross-cultural use of measures, others said the measures used in the services have been applied to all clients (when required or routinely if such system was in place). Some have commented that Māori clients, if required, are referred to Māori mental health services. No difficulties or differences have been reported about the use of standardised questionnaires with different ethnic groups. The clients’ acceptance of the measures has mostly been based on the lack of negative feedback or refusal to complete. Limited discussion or consultation with clients and their families has actually taken place.

Commonly used measures such as CBCL, HoNOSCA, Conner’s, and GAF were considered to be relevant to clients of all ethnicities as they provide baseline information, and assist in the assessment process and progress to be monitored.

Very few comments were made about the cultural inappropriateness of measures. Concerns included lack of family/whānau dimension and Western or Anglocentric culture bias. Other general concerns included lack of New Zealand standardisation and norms.

Possible difficulties were noted around clients for whom English is not a first language. This may apply to Pacific and Asian people, as well as refugees. This is often more of problem with parent-rated measures. Clinicians have been required to explain the measures to their clients verbally to ease the language difficulty. One team leader commented about the rise of Māori children whose first language is Te Reo Māori and who may have difficulty completing a measure in English.

### 4.6 Conclusions from clinician responses

Responses were received from 105 clinicians representing a response rate of approximately 30% (the actual number of people working in the CAMHS in DHBs and NGOs is unknown but is roughly estimated at around 350).
The sample that responded included people from all disciplines, from Māori and Pacific groups, from all areas in New Zealand and included experienced and inexperienced clinicians. It therefore includes a reasonable representation of clinicians working in the sector.

It is striking how few clinicians reported knowledge of and experience with outcome measures. Only around one-fifth used measures routinely or occasionally, and 60-80% either did not know about outcome measures or did not respond to the question.

HoNOSCA was the clinician rated outcome measure most frequently recommended for use and the CBCL was the consumer and teacher measure favoured by clinicians, although the Conner’s Teacher Rating Scale was also a popular choice.

Of those clinicians who responded, the majority thought that the number of measures should be limited to two and the time taken to complete the measures limited to 30 minutes or less.

Opinion was divided about whether current IT systems could cope with routine outcome data collection, but most thought that current systems would be adequate with some modification.

Access to computers was adequate for 41% of clinicians and significantly limited for 19%.

Two-thirds of clinicians thought they did not have adequate clerical staff to cope with routine data collection on outcome and well over one-half thought the clinical staffing levels were also inadequate for this task.

Although most services collected data on ethnicity, most clinicians thought that the way this was done could be improved. The child or young person or their family mostly decided ethnicity which was mostly recorded by clinicians or administrative staff.

There was strong support from clinicians for outcome measurement with over 80% considering it “important” or “very important” and 67% supporting its introduction.

There were high levels of concern over the possible misuse of outcome data, with over 70% of clinicians expressing some concern. The main concerns were that the results may be used inappropriately and out of context by clinicians, used in a negative way by managers against clinicians or to limit access to services, or were about the limitations inherent in the measures.

Most clinicians anticipated problems with the introduction of outcome measures, mostly because of the work involved and the lack of IT capability.

While three-quarters of clinicians had heard of HoNOSCA less than one-half had had any experience with it, while less than one-half of the clinicians had heard of the SDQ and only a one-fifth had ever used it.

Of those who did know about the measures, most thought they were practical and meaningful measures. Most did not know whether they were meaningful across cultures.

From the telephone interviews with team leaders it was ascertained that just under one-half of them were concerned about staff access to computers and two thirds thought extra staff would be needed to oversee the data collection. Most (more than 80%) thought training of clinicians was important. Many (almost two thirds) believed that no major changes were needed but that a training campaign should be in place to educate clinicians about the importance of outcome measures. Little was known about cross-cultural use of measures.
**Section 5: Focus Groups**

Focus groups with children and young people and their family/whānau members who have been consumers of CAMHS were conducted in order to gather their feedback on the acceptability, use and meaningfulness of outcome measures that might be used routinely in clinical practice.

In order to ensure consistency Ms Karolina Stasiak (research coordinator) was present at all the focus groups.

A gift/koha was provided to all participants. Children and young people were given a single movie pass while parents/whānau members were offered a $20 grocery voucher.

5.1 Method

5.1.1 Focus Groups with youth

Seven focus groups with young consumers of CAMHS were held in Auckland, Dunedin, New Plymouth and Wellington, and included Māori groups and a group of children (8-12 years of age). Despite several attempts to recruit a group of Pacific young people, only one person agreed to be interviewed.

The focus groups followed an in-depth semi-structured format. The discussion facilitator began with open-ended questions before focusing on more specific closed questions ensuring discussion covered specific areas.

We asked about participants’ experiences of outcome measures and other standardised psychometric forms in the services they might have accessed. They were asked to comment about their encounters and satisfaction with completing written measures. They were asked whether their family/whānau members, teachers and/or clinicians ever completed such measures and what they thought about the process.

After the initial discussion, the participants were shown a range of measures identified in the clinician survey as most commonly used in CAMHS services as well as the HoNOSCA and SDQ. Participants were asked to inspect and even try completing a part of each measure to have a first-hand experience of the types of questions asked and the ease/difficulty of answering them. They were then asked for feedback on acceptability, ease of use, relevance and overall appeal of the specific measures.

5.1.2 Focus Groups with family/whānau

Two focus groups for family members who had accessed mainstream CAMHS were organised in New Plymouth and Dunedin. Groups included parents, one parent only, and/or members of the extended family.

The groups followed a similar format to the one used with children and young people. However, additional questions were asked about the participants experience of data collection, what barriers might exist to its routine collection, and any concerns they may have about outcome measurement causing distress or offence (and how this may be overcome). Additional issues that were discussed included the need to measure other dimensions such as consumer satisfaction and global measurement vs. evaluation of individual treatment plans.
5.1.3 Focus Group with Māori

Two hui were held with taitamariki and their whānau. Clinicians working within the service approached and recruited taitamariki and their whānau. The first hui occurred at a Māori Child and Youth Mental Health Clinic. Four clinicians were present at the first hui to support the participants and actively took part in the discussion.

The second hui involved taitamariki accessing mainstream services. Both groups were facilitated by Māori.

5.1.4 Focus Groups with Pacific children and young people and their families

We planned to organise two groups of children and young people and parents/family of Pacific CAMHS consumers in Auckland through clinicians or the clinic’s database. This proved impossible. Reasons for this are outlined in the section on Pacific participation. In the end we were only able to interview one Pacific young person.

5.2 Data analysis

All focus groups were audio-taped and transcribed for analysis using qualitative methods. Thematic analysis was used to search for and identify common threads or themes and interrelationships between themes that extended throughout the interviews. This was accomplished by the researchers reading and re-reading the transcripts. NVIVO Software was used to manage and support the process of identifying and coding of these themes. Two people coded each transcript and themes were refined in discussion with the research group. Māori transcripts were coded by a Māori research assistant as well as by one of investigators. The results were then reviewed by Dr Sue Crengle. The analysis of the interview with the Pacific young person was overseen by Ms Ettie Pasene-Mizziebo to ensure that themes pertinent to Pacific people were included and that the interpretation of the data was appropriate from a Pacific peoples’ perspective.

5.3 Findings from the focus groups

Ten focus groups were conducted with 55 participants.

<table>
<thead>
<tr>
<th>Participants</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children / Tamariki 12 years and under</td>
<td>7</td>
</tr>
<tr>
<td>Young people / Taitamariki aged 13 to 19 years</td>
<td>27 (including 5 Māori and 1 Pacific youth)</td>
</tr>
<tr>
<td>Parents / whānau</td>
<td>21 (including 6 Māori whānau members)</td>
</tr>
</tbody>
</table>

A thematic analysis was undertaken based on the discussions. The groups for children and young people and for the family/whānau members followed essentially the same format (see Method section) and therefore the analysis was carried out concurrently on all the transcripts. However, some issues were raised during the parent groups that were not discussed with the groups of children and young people and vice versa. The analysis of the Māori and Pacific transcripts was completed alongside the analysis of the other transcripts and the common themes are presented in this section. However, issues of cultural significance and relevance will be presented in the Māori and/or Pacific chapters.
In the section that follows we have organised the themes around five main categories. Cultural issues (specific to Māori and Pacific peoples) are discussed in Sections 6 and 7 respectively.

**Table 7: Summary of themes emerging from consumer focus groups.**

<table>
<thead>
<tr>
<th>Implications of outcome measurement</th>
<th>Process of outcome measurement</th>
<th>Content, informants and information received</th>
<th>Cultural issues (See Sections 6 and 7)</th>
<th>Feedback about specific measures (positive and negative)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive reasons for measurement</td>
<td>Being informed, in control and having a choice</td>
<td>The domains assessed</td>
<td>Māori Issues Assessment of more than just the individual</td>
<td>BDI</td>
</tr>
<tr>
<td>Objections to use of measurement</td>
<td>Rapport and trust</td>
<td>The validity and importance of people’s perspectives</td>
<td>Cultural identity</td>
<td>CDI</td>
</tr>
<tr>
<td>Impact of measurement on in treatment</td>
<td>Privacy, confidentiality and access to results.</td>
<td>Need for cultural sensitivity</td>
<td></td>
<td>CBCL</td>
</tr>
<tr>
<td>Impact of measurement on access to services</td>
<td>Procedure and format</td>
<td>The need for tino rangatiratanga</td>
<td></td>
<td>Conner’s</td>
</tr>
<tr>
<td>Feedback and communication</td>
<td></td>
<td>Hua Oranga</td>
<td>GAF</td>
<td>HoNOSCA</td>
</tr>
<tr>
<td>Pacific Issues: Need for cultural appropriateness</td>
<td></td>
<td></td>
<td></td>
<td>SDQ</td>
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<tr>
<td>Difficulty in talking about mental health</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Relevant informants for Pacific young people</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Language and translation</td>
<td></td>
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</tbody>
</table>

We have attempted to represent consumers’ views as accurately as possible. However, we present only a sample of the quotes to serve as illustrations and to provide context for the summaries we made on behalf of the participants’ discussions and issues raised.
5.3.1 Implications of outcome measures

5.3.1.1 Positive reasons for measurement

There was a great deal of support for the use of outcome measures, especially if the instruments were to be used to help consumers receive adequate help and aid in their recovery. What is of most interest are the reasons put forward in favour of systematic measurement.

By filling in a form parents felt that they were being listened to and accessing the support they needed.

> But yeah, I mean, I'd fill out any forms that I could if I, yeah if I thought it would help, I wouldn't hesitate. I'd sit out and fill out forms (Parent).

The process of completing a measure validated parents’ concerns about their child or young person’s problems and needs.

> Regardless of what form you were filling out it felt good because you finally had someone listening to you and trying to help you through what we were going through (Parent).

Participants believed that knowing the results of the measures could be valuable and provide a greater insight into the child or young person’s problems:

> But yeah, it was valuable having, just even being able to see the results for myself because it showed where my son was feeling secure, where he was feeling insecure, it highlighted some strengths and it pointed out some weaknesses needing attention, so it was valuable (Parent).

Similarly, children and young people commented that being able to complete measures and see their individual results might help them clarify issues and problems they may have. Ultimately, they were supportive of the process if it was there to help them.

> I imagine it would be quite reassuring for some people just sorting it out (Young person).

> Because if you, if I was looking at this and then I think about it and then I think, oh yeah I really do have a problem because I see other people are happy and doing lots of all these kinds of things (Young person, Māori).

> If it’s going to help us it would be okay (Child).

Many young people preferred to write things down than discuss them, especially in the early stages of therapy. Completing a written measure felt easier and more comfortable than talking to a clinician when entering the services. It also removed some embarrassment from talking about difficult issues.

> It would probably make it easier, it’s not so intimidating. You don’t have to answer questions directly so if there’s something you don’t want to talk about to that person you can just tick a box or whatever and then they get an idea from that rather than you having to express it verbally (Young person).
If you fill it out on a sheet of paper you’re not looking in their face, you’re not..., you get actually some room to think and I reckon it’s a good idea, questionnaires and stuff (Young person).

Another reason in favour of measurement was the positive experience of tracking their own progress.

I probably think it would be a good idea just to start off with so that everyone knows where you are and then there's obviously going to be some difference down the track and if it's two months down the track and two months later if it's bad or worse - you can be better if it started off with that (Young person).

However, some young people only wanted to know the results if they indicated an improvement. Seeing progress was reported as an empowering experience, but being told a lack of improvement was considered detrimental to their well-being. Young people felt that seeing a negative outcome when they were already vulnerable would only make them feel worse.

I don’t know, if it was kind of like in the upper half then I kind of wouldn’t mind seeing it but if it was like real low I don’t think it would be very good, just be depressing. But it would be good kind of seeing if you’re like progressing to higher up that would be kind of good (Young person).

Well I wouldn’t personally like to look at it if I was really depressed. I definitely wouldn’t because then I’ll just get more depressed because that’s what they’re thinking of me, yeah (Young person, Māori).

5.3.1.2 Objections to use of measurement

Some of the objections and/or reservations about outcome measurement were broad concerns about validity and the ability of questionnaire to reflect the complexity of mental health or well-being accurately:

One person can be quite a lot of things, like one person could be like just about everything (Young person).

A related concern was that mental health fluctuates and it is difficult to measure at any one time point. As measures are limited to an assessment at a specific time there was concern that they might not be a true reflection of progress:

Like I can be really unwell and like get better and then I can get better and then I can get really unwell and then I can get better - so what's the point in having these forms, filling them out - maybe I'm well at the time and then next day I get unwell, so? (Young person)

Some participants believed that questionnaires were invalid because they consisted of standardised questions with restricted options for a given response. They were concerned that standard questions could not produce a true reflection of their views and some felt they were being coerced to provide information that was not true.

Well you're answering somebody else's questions - like somebody else is putting words in your mouth when you're filling out that form. They're saying, do you think this is a good thing or a bad thing and you might think it's just medium. That's one of the faults with any form (Young person).
Yeah, a bit too much because they can sort of coerce the children into putting what they think is the correct answer (Young person).

Others were concerned about the inability to provide context when answering questions on a standardised form. Some parents said that they would like to be allowed to explain things more precisely than the forms allow. They wanted the outcome assessment to be integrated with other information to ensure an accurate reflection of their child or young person’s situation and problems.

Some of them weren’t relevant but they were like on a one number scale so you just had to circle a number what you thought and you didn’t really get to explain anything (Parent).

And as I say, to just take those alone without integrating it with the rest of the child’s notes and reports and the other assessments, you’re going to get a slightly unbalanced view of that particular child (Parent).

Some young people believed that it was necessary to talk to a clinician about their problems so as to explain things more clearly.

If you speak to someone about it you can get more depth on what it is. It’s kind of like, I mean, like “Do you steal things?” and that’s a question they used because that’s the only one I can remember, but I remember that because it was rather amusing watching the psychologist say, “I steal things” when she was reading it out to me and I had to say, “One to five”, “Yes/no” thing. And I’m sitting there and she goes, “I steal things” (Young person).

A family context is missing from most standardised measures. Most assess only the individual child or young person and are unable to capture family issues and problems that should be addressed in treatment:

I think there’s duality though, because I think sometimes the family are half the problem and so you’d have to be really careful about how you dealt with that. You know, if you would be a clinician (Parent).

Another concern was the ability and willingness of a child or young person to complete a written questionnaire.

My son would get so frustrated that he would just give up and he wouldn’t fill it in if you gave him one. He would probably prefer to hear it spoken to him I guess (Parent).

The questions, yeah I’m just thinking when I was child yeah I probably wouldn’t be too, I’d be like, “Oh mum can you answer these for me because I don’t really want to.” (Young person)

Finally, a concern was expressed that questionnaires given to children or young people when they enter the services or when they are unwell might have a negative impact on their well-being.

Yeah I suppose too if you were overweight and you had a problem and you read that in there, it would just make you worse to see something like that. You know,
that, you know, could be part of your problem and then to read it would just make you feel worse (Young person, Māori).

Yeah, actually I think if I was feeling really sick it would actually be too much because just even reading that much would be too much (Young person).

5.3.1.3 Impact of measurement on treatment planning and case management

Parents wanted to ensure that the results of the measures would be used to good effect and that the exercise of filling in the forms would not go to waste.

*Well I guess as a parent, I mean, if I was presented with one of these forms when she, before she goes into hospital or on her exit, I'd still be wanting to know what difference it's going to make. You know, is it going to change how you treat her, is it going to make things better, are you actually going to hear what we're saying? I want to know as a parent what benefits there are* (Parent).

*Does it become another piece of paper that it means they have to fill out that they'll just stick in the child’s clinical notes and not pay any attention to* (Parent).

A concern expressed by parents and young people was that the results of measures may result in labelling of problems. For some, the potential impact was negative.

*I think these are really good but if I was to pull this up and it had, “I like animals” and I didn’t like animals and I put down “Not true” they might think you’re a bit psycho, sort of thing. Yeah* (Young person, Māori).

Parents were worried that the measures might be used in a simplistic way as a diagnostic tool to label their child or young person.

*But I mean, in an ideal world they would have all the people you suggested previously, but I have heard of a lot of people who have gone through the system and that's basically all that's been used and that's a worry that you've then got children labelled as ADD or ADHD on a very simple questionnaire* (Parent).

However, the opinion on labelling was divided. Some people believed that a measure might be able to identify their child or young person’s problems clearly, which would enable them to seek the help they needed:

*Labelling is a big problem anyway. I spent five years trying to get my autistic child diagnosed and the closest I came was one doctor said, “I suspect there’s an autistic spectrum just bordering but I'm reluctant to label because labels stick”. Therefore, I had another year I couldn’t get help until I finally got a doctor who was willingly to label him. Labels can be very useful* (Parent).

*I love labels, label my child and then I can go and get some help for him* (Parent).

5.3.1.4 Impact of measures on access to services

A major concern expressed by many parents was that the results of outcome measures may be used to limit access to services.
But to be influenced by these, depending on where your kid scores on this, this is going to say whether or not your kid’s going to get access to services or whether your child’s not (Parent).

I mean, the score your child gets on one of these could decree whether or not they’re going to get service or whether they’re not at some point in the future and that as a parent concerns me (Parent).

Parents were concerned about the motivation of managers and funding bodies of the mental health sector that lay behind the introduction of the outcome measurement system. They were worried that the results were going to be used to limit the services and lead to the discharge of those who did not meet certain criteria on a standardised tool. Others wanted to know whether adequate resources would follow the introduction of routine assessment to enable those in the need to access appropriate interventions.

That may be the medical profession’s aim but what about the politicians on the side? They’re stakeholders and they have access no doubt to all of this statistical information which should tell them that, oh golly gosh there’s 20% of our kids have now turned 16 so they should be out the door and we’ve just got this little nice test that we’ve just proved that they’ve made x amount of progress; that’s it, end of service (Parent).

- And if it identifies it and interventions are needed, are those resources going to be available?
- Just because they can see you need it doesn’t mean to say they're going to be there (Parents).

Others were more optimistic and believed that outcome measurement could be used to standardise the delivery of mental health care across the country to balance regional inequalities:

Well I think it will standardise service provision across the country a little bit better so that you know if your child has been in services here in New Plymouth and you go to Auckland then and you’re going to get similar sort of service based on similar sorts of information; and what you understand by ADHD is pretty much the same as what the doctor I take my son to in Auckland is going to understand as ADHD and how it presents in terms of where on these scales, where they are. So that would be helpful because I think there’s huge regional differences in how services are delivered (Parent).

5.4.1 Process of outcome measurement

We asked participants about the process of outcome measurement. It was clear that the way the measures were introduced, how results were presented and the extent of client’s ability to maintain control over the process were important factors that would impact on the measurement process. This was seen by many as more important than what was measured. It could be said that “how is more important than what”. If the process of measurement is carried out in an acceptable way, the content of measures and the information collected will be seen as more meaningful.

Participants talked about a number of factors that could make the procedure of outcome assessment more acceptable. These included the environment in which instruments are completed, the number of measures that are introduced, the amount of time it would take to
complete measures and the format of the measure. The way feedback is given was also seen as important.

5.4.1.1 Being informed, in control and having a choice

Because many clinical situations are different, young people thought that each case should be dealt with individually. They wanted to be better informed, consulted and more in control over the assessment process. They thought young consumers should be given options about how and when the measures were introduced and results presented.

This applied to choice of informants, for example, some felt that a teacher report would not be relevant to their case:

Well you have to think about it individually - you can't just get anyone to do it. You need, as a human go, “Oh this person has nothing to do with their teachers, they're secretive” so obviously it would be stupid to get their teacher’s comment (Young person).

Young people believed that the clinician should seek their permission before measures were sent out to other informants:

Well I think it would be wrong doing it without the person's permission (Young person).

Similarly, the ability to choose when and where the forms are introduced instead of being forced to complete them at a certain time or location was seen as important. Being more informed and in control of the assessment process made them feel more comfortable about it.

You should really ask them what their preference is (Young person).

Give them the choice, I think, at that time (Young person).

Young people wanted to have a degree of choice over whether they were required to answer all the questions on a questionnaire and believed that they should not have to answer irrelevant questions.

I think it's important to not have to answer them, very important to have “Don't know” as an option (Young person).

The theme of autonomy and being allowed to decide for oneself reoccurred. For example, young people wanted to be able to choose whether the results were fed back to them. The participants believed that each person should have their own preference taken into account. They believed that the mental health services should be required to provide them with individual options.

I reckon, this is just my opinion, but if it’s open whether you want to see them or not, you know, because some of the things that the teacher might write, you know, or say you mightn’t look at that teacher the same way, you know (Young person, Māori)

- Yeah, whether they want to look or if they did or not because I don’t know because some people mightn’t want to know and some people might like to know, you know.
- Choice is good.
- In the service it’s supposed to be that you have as much choice as you want (Young people, Māori).

5.4.1.2 Rapport and trust

The need for a trusting relationship with the clinician or person administering the measure is seen as crucial. The measures should be given by somebody whom the child or young person knows and trusts:

Yeah I just wouldn’t want to talk to a stranger (Young person, Māori).

I found it easier filling it in if someone I knew had given it to me. Like you go to the hospital and somebody you don’t know gives you this form and says fill it out (Young person).

Children and young people felt that it was important to have established rapport with their key worker before the measures were introduced. They wanted to be able to have a face-to-face interaction with the clinician first and get to know them. Having the measures given out by someone they knew and trusted made them more acceptable:

Mm, I think you’d have to have a trust thing built up first to actually share something with that person. Even to tell each other their hobbies or something like that, just start off real basic, not just an adult person to me, “You’ve got problem, I’m helping you”. That would freak someone out (Young person, Māori).

The clinician should explain the questionnaire and the process to the child or young person and make them feel comfortable about answering the questions:

- I reckon your clinician or whoever is the first person you come to see should go through it with you so like you get to know them so like they can go through the questionnaire with you.
- So you’d like them to, for example, sit down with you and -
- Yeah, go through it with you maybe (Young person).

Participants highlighted the need to trust their clinician if they were to share personal information. This was particularly important for more personal questions.

Well I wouldn’t want to, I do think this one but I wouldn’t want to say “I look ugly” that would be a bit hard for me to say, “I look ugly”. Be a bit tricky because that’s the personal too (Child).

5.4.1.3 Privacy, confidentiality and access

Related to the theme of trust, was the need for privacy and confidentiality when completing measures. Many young people found some of the questions on the measures very personal and thus difficult to answer. They were concerned about whether the information was going to be treated with discretion.
Many participants wanted to complete the measures in a private setting. The fear of having their answers seen created a higher likelihood of giving dishonest responses:

Actually I’ve done another one before and I had to do it at school and the principal was sitting next to me and no one knew at that time that there was anything wrong with me so I was busy trying to hide what I was writing and then I was like, no maybe I’ll just make everything up. So that was, yeah, that was not a good situation to be in to do it. So it’s got to be someone you trust to be with you (Young person).

Privacy was especially important if the questions related to the client’s satisfaction with their clinician and the help received.

Yeah, especially if you’ve got something nasty to say about your clinician, you don’t want her to see it (Young person).

- But if you’ve been asked to do a form maybe two months into your treatment and there maybe questions about whether you like the service, you know, whether you like your clinician or the service you’ve been receiving.
- Well I think with certain questions you could ask for privacy (Young people).

All participants believed that the information received should be treated as highly confidential. Children and young people wanted the information to remain confidential between them and their clinician. They were concerned about other people such as their teachers finding out information they had assumed to be private.

- Yeah so that’s kind of keeping things confidential between one person and another, is it? (Child)
- Yes. My teacher told me that she found out something and I was, oh no she wasn’t supposed to know that! (Child)

But the only thing sometimes I wish she [clinician] hadn’t told my teacher some things that she has (Child).

When we introduced and explained the idea of outcome measurement many participants questioned us about who might have access to the information. Recognising its confidentiality, they did not want it divulged outside the immediate circle of their therapist and/or authorised family members.

I wouldn’t want too many people knowing about this. I would just want one, or like two or three people knowing about this, I wouldn’t want the whole hospital knowing about it (Child).

I don’t want many people to know, the people who are meant to know about this, like my care worker and my doctor and stuff like that (Child).

Another substantial sub-theme that emerged during the focus groups related to access to results. Children and young people generally preferred to have access to their own results as well as clinician- teacher- and parent-rated measures. However, many did not want their parents to have similar rights.
I’d be more worried about my parents were going to see my answers. I’d prefer it definitely they weren’t, they have no right to see my answers, they are private and personal (Young person).

Some children and young people recognised that there may be circumstances when their parents should be able to have access to their results, particularly when there were safety issues.

If you were suicidal I think that your parents should look at it because they could keep a check of you. But like there are some people out there that don’t want their parents to know what they’re thinking and stuff. But like if it’s really bad then their parents should know because they can keep an eye out on them, suicidal kids they’ve always got to have their parents to be there (Young person, Māori).

Some children and young people would like to be consulted regarding the extent to which other people might have access to their results. Others expressed a wish at least to be informed about what information others would be able to access.

I think that one should be up to the individual, you know, but is it like if you were 16 or under would your parents have the right to look at it? (Young person, Māori)

Well I think that the teachers should be involved and that, but we should know what the teachers are going to be told before they are told (Child).

Many children and young people wanted to have access to the forms their parents had completed.

Well if I had a mum who filled in a form I would like to see it, see what’s been written down (Child).

It would be interesting to see like from their point of view what things were, just to see what it’s like for them (Young person).

Similarly, some wanted to know what their teachers wrote about them:

I don’t know whether she has but if she, well if she did I would like to know what she would say because what she’s my teacher and I don’t know what the form’s about and I would want to know but and my Robin, my key worker, does talk to my teacher sometimes, well quite a lot and tells me what we’ve been about and stuff (Child).

Not all children and young people wanted to see the results of the teacher or parent measures, particularly when they knew that the questions were of personal nature; they did not want to be embarrassed by seeing them.

And if you did the youth one and you knew your parents were doing one, you kind of know they were getting asked questions like, “Does your child play with themselves in public?”, and you’d want to see it, but you wouldn’t (Young person).

Some young people felt that seeing what other people say about them on the measures might change how they perceive those people. Some were afraid of being hurt by seeing how they are perceived. Others believed that seeing an unfavourable teacher report might be damaging to the relationship they had with them at school and would prefer not to know about it.
I would, yeah I’d like to see them but I wouldn’t ... because then the person’s judged, they’d judge people but I can see it from the other side, sort of, they’ll judge them and they won’t respect them, you know, teachers (Young person, Māori)

You know, my nana could tell the truth in this and it might be heartbreaking (Young person, Pacific).

Parents had a different perspective. While many children and young people wanted their results to remain confidential, parents thought they should be able to have the information about their child or young person’s progress. Some parents felt that there was not sufficient communication between them and the clinician. In some instances the age of the child or young person meant that the clinician felt unable to disclose information.

And as a parent, it’s whether or not I’m gonna know about it because as a parent I want to know this is my child and I am ultimately responsible, this is the information I want. If you’ve got it, it’s actually mine because it’s my kid (Parent).

Similarly, parents wanted to have access to the teacher report and to be able to see how the teacher rated their child or young person.

- Yeah because I mean if it was my child I’d go to the teacher filling it out or whatever eh?
- Exactly because yeah, because if you’d want to know how your kid is at school, you know, and if you get a look at what they’ve written and you don’t like it.
- Your feelings would change (Parents, Māori).

For some, being assured privacy was essential especially if they were asked to provide feedback about their satisfaction with the clinician. Others did not want their family members to see their responses.

- Well I don’t really mind being shut in a room but I wouldn’t really especially want to take it home I don’t think.
- You wouldn’t?
- No.
- Why not?
- Just ’cause people and family’s around and you don’t want them to see the answers and stuff (Young person).

But it’s still, it’s not, you feel like somebody’s watching over your shoulder or you have to and they might see it or something you want it to be a private thing (Young person).

5.4.1.4 Procedure and format of measures

Some participants preferred to have the measures completed at home while others wished to have to have the clinician present at the time in order to support them and give them any needed clarification:

I found that easier, physically easier doing it at home where I could just spread everything out and I could just, you know, circle stuff (Young person).

But at home, I mean, if you have a question about the question like you said, you can’t really ask anyone about it so it’s probably better done here than at home
because then if you need to talk then you’ve got someone to talk to as well as someone to ask you questions (Young person).

- I’d rather do it there. I’m likely to forget it if I took it home.
- Get it over it done with it while it’s in front of you (Young people).

It was important that the children and young people felt safe in the place where they were completing the questionnaire. Being left alone to fill out a form in an unknown place felt uncomfortable and worried the children and young people:

I think the ones in hospital are really scary because I got put in a small room and they gave me the things to fill out and then they shut the door and walked off and I was thinking they’re watching me and they’re going to get into my mind and stuff (Young person).

In addition, participants were concerned about the frequency of administering measures. Some experienced having to fill out several measures on several occasions and found it burdensome:

- It’s really annoying having to every time I went into hospital I had to fill out another one.
- I just wish they could like fax them round everywhere so you don’t do the same thing every time.
- So there’s too many of them you had to fill out?
- Yeah, you fill out the same thing and different ones and stuff (Young people).

But I do remember there were a hell of a lot of them (Parent).

We asked the participants how long a measure should be and almost all said they instruments should be brief. Many said the number of questions determined the amount of attention they were prepared to devote to it and that the longer the measure the more likely they were to lose interest and answer the questions inaccurately. In addition, a long measure might be especially difficult to complete when a person is unwell or in crisis.

- It's just the level of how well you're going to pay attention to it because if it's too long you're just going to make answers.
- That's true.
- So maybe like five, ten minutes at the most.
- Five or ten minutes - do you agree with that?
- Yeah (Young people).

It was about 50 questions, it was quite a lengthy thing so we took it in sort of like three bites with a child whose attention span is five seconds (Parent).

5.4.1.5 Feedback and communication

Many people reported a lack of communication between them and the clinician about outcome measures. Some parents were not told what their children or young people were asked to complete and similarly, children and young people were often given forms without having any explanation about them.

- I didn’t know whether my daughter filled anything or if there were any results or anything, there was no communication there.
- Would you have wanted that?
- Yeah, definitely. There was nothing, I couldn’t get any information at all (Parent).

They just say, kept saying, here’s another form - fill it out (Young person).

Parents wanted any information provided to them to be straightforward, comprehensible and presented in a simple language. They thought that the results should be accompanied by appropriate education so that they would better understand the implications of the results. However, they wanted to be treated with respect without being talked down to.

And in a form we can understand, common language, don’t try and confuse us with science. And a lot of parents, as parents we often get treated like we’re dumb which really frustrates me. I had a doctor look over my shoulder at the nurse behind me and say “Tell the mother”. OK? Like, hello (Parent).

I think though that there’s an awful lot of information that they get, that they actually couldn’t give parents without having some sort of education around what that means, and I think that’s probably unrealistic given funding and things like that. (Parent).

Many parents preferred to be given written feedback on their children or young people’s results allowing them the time to study it. If they were presented the results during a clinical session, they often found it the information overwhelming and difficult to grasp. Presenting results orally was not sufficient and many found it difficult to understand or remember after the session. Parents wanted to be able to take the feedback away and have the time to assess it carefully. That way they could also return to the clinician and discuss things should they disagree about any of the conclusions.

That’s the other thing, if they’re going to collate these figures and assess our child then they need to come to us with preferably something written because when somebody sits there and tells you something about your child it goes in there and out there, you know, you don’t hear anything past the first sentence quite often. So something written and you can take away and look at and think, okay, this is what they think of my child and then you can go back to them and say “I think you’re wrong on this point”. Whereas if they’re just assessing and not telling you where they’re assessing and then they can tell you why they’ve come to that conclusion and you can debate it. But if you’ve just got your child in a service and they’re not telling you anything it’s a little bit scary (Parent).

Some children and young people also believed that being able to see their results would give them an opportunity to reflect on the results and compare them with their own perception of themselves:

Maybe explain why they fill it out because if I saw that and went back and matched it up with what it’s supposed to mean I think I will, ... I don’t remember that, a thing like that, but maybe it appeared like that. (Young person)

5.5.1 Content of measures, informants and information received

5.5.1.1 The domains to be assessed

Some participants wanted to ensure that the measures were holistic and assessed their global functioning in domains other than mental health.
You know, if you’re going to access one area of the child you need to get it a broad view, you need to be looking at their physical development and all of those types of things as well (Parent).

Others were concerned about the validity of broad outcome measures in capturing and assessing their children and young people’s particular needs and problems. They were anxious that a general measure was not adequate and resulted in meaningless results about the overall effectiveness of services.

Because the more generic it becomes, the less validity the information has, so if we’re not going to target and I’m very much aware that it’s hard to target because it’s hard to diagnose. But it’s almost like doing something because we have to but are we delivering anything or are we just, you know, is it a lip service exercise by the time you water it down for all the possibilities? (Parent).

Parents wanted to know about the suitability of outcome measures for particular disorders. Many were concerned that the measures were not specific or relevant to the individual needs and problems of their children or young people. Instead of establishing a general measure to assess all children and young people in the services they believed that disorder-specific instruments were needed.

That’s quite, I suppose, what the focus here is the fact that we were concerned that maybe you cannot generalise one standard form to evaluate a range of mental health issues and then try and put them together and get valid data about good valid answers (Parent).

They might need to look at grouping them under diagnostic, say like these are ones where you suspect mood disorder, these are the ones where you suspect behavioural problems, risk, etc. that they can actually say, here’s one for each of those disorders (Parent).

On the other hand, some parents wanted a more general instrument to capture a wider range of their children and young people’s needs and symptoms. They believed that only such broad instruments would allow measuring the outcomes and monitoring the performance and effectiveness of services country-wide.

I’m not sure that I see any of them as being sufficiently general or covering a really wide range of needs or points that children who have these symptoms have to form a sort of one form that’s all tick the boxes, here, in Kaitaia to Invercargill, Health Ministry approved global assessment of services and outcomes. I’m really not sure that any of those provide that answer, if that’s what the Ministry’s looking for (Parent).

Furthermore, some parents wanted to see an outcome measure assessing their satisfaction with the service received:

Yes, I was wondering whether to do it now or after having a look because these measures, like you said, are sort of quite behavioural they tend specifically into depression and that sort of thing but also a question of interest is whether you would like to see other things measured such as for example your satisfaction of the service that you’re using or treatment plans and goals and that sort of thing (Parent).
The usefulness and validity of using foreign measures in New Zealand was also debated. Participants frequently wanted to know the country of origin of the questionnaire and often identified and commented about the overseas measures (e.g. by spotting a US spelling or an unusual word). Adult participants wanted to know whether any research was conducted on the validity of the measures using New Zealand population and whether they were standardised in New Zealand.

Some children and young people believed that it was difficult to relate to some of the descriptions and words used on the overseas measures.

> Yeah, New Zealanders should do the ones for people in New Zealand so we can, I don’t know, relate, I just feel like, I don’t know, they just talk in a different way and put things in different ways (Young person).

> - Oh, so what I would like to stop people being confused to have forms that were done in New Zealand and I could understand and not have words like “Mom”.
> - Yeah, “Mom” instead of “Mum” (Child).

There was confusion about some of the words used in the questionnaires and we needed to clarify expressions such as “acts smart” (CTRS). To avoid misunderstandings, some participants suggested that unfamiliar terms be accompanied by appropriate definitions.

> - Some of that is because it’s an American form and for them “smart” means “cheeky”.
> - Oh (Child).

> I think it would be good if it had definitions for some things because you don’t always know what all the words mean like “impudent”. What does that mean? I don’t know what that means (Young person).

### 5.1.1.2 Informants – the validity and importance of people’s perspectives

Another issue participants discussed at length concerned the informants and the value of their perspectives. Who completes the questionnaire was seen as crucial. We discussed with the participants the need for self-, family-, teacher- and clinician-rated assessment and received various feedback about each.

Some parents believed that clinician measures may not be an accurate assessment because a child or young person may behave differently in a clinical setting.

> Most of the kids if they know someone's there watching them they're totally different. It's like you take your child into a clinical environment to be assessed and they're quite different to what they would be at home (Parent).

The value of self-report was discussed. Some parents were concerned about the reliability and validity of the child- and youth-rated assessment. They believed that children and young people were capable of manipulating their responses.

> Yeah because my son knows what people expect of him because he's smart enough for that thing so he reacts accordingly. I said that to someone and he said, “Well what do you want me to say so I can get out of here?” (Parent).
Some young people pointed out that self-report questionnaires may be prone to various biases such as social desirability so that young people may respond in a way that is expected of them. Others argued that it was easy to be dishonest on a self-report especially when asked about personal things by individuals they did not trust.

I think with some of these I sort of think there’s a correct answer for this. Like, I try to be nice to other people and I’m like well you’re supposed to do that so that’s I could put that “Yes, I do do that”. But that’s probably not very good (Young person).

- The CAT team came to my house like at night and everything and they gave me it and I kind of lied on it to make it sound more interesting as if I was crazy, so yeah, I think that was the wrong way to do it.
- Because it was easy to lie on it? Is what that you think?
- Yes, because if they were people I knew better I wouldn’t care about kind of talking about myself, like because they were strangers (Young person).

On the other hand, a self-report was often seen as the most appropriate measure to use in assessing outcome and gaining relevant information about the individual as many young people and children pointed out.

So I like this one, you know, I would like to write it down myself and answer those questions, you know (Young person, Māori).

Of special significance is the feedback we received during the focus group for children. In discussing the SDQ, we explained to the participants that the form was designed for children aged 11 and up. However, the children told us that they would like to be able to complete their own self-report:

- For some people who get things filled in, [they] get parents to fill them in for kids who are less than 10 and the kids don’t get to fill in a form. What do you think about that?
- I don’t think that’s right. Because I think people like 10 and below should have their say in things, not get someone else to say it for them. I think with younger kids should have their say in what they think, not someone else just, “Well I think I know what’s best for them”.

- Because it if it was about me, I would want to fill it out, not have someone else, another person. I don’t want that to happen (Children).

The same participants told us that self-report forms for younger children should be easy to understand.

There were other concerns about the differences in perspectives in different informants. Young people believed that it was essential that the measures were completed by those who were closest to them. They did not want it assumed that the parents were the most appropriate informants.

It would be sensible but not necessarily for a parent to fill it out - maybe a person that you spend quite a lot of time with. Like I don’t spend any time with my parents - they have no idea (Young person).
Some of the young respondents questioned the value of the parent report. Under some circumstances they believed that it was inappropriate for the parents to complete an outcome measure. They talked about being dishonest with their families and hiding their emotions. They did not believe that their parents always knew them well enough to answer questionnaires accurately. They thought that parental views might be subjective, inaccurate or conflict with their own perceptions.

- Let's think about would you like your parents or the people in your life who are close to you filling out a form?
- No.
- No. Why not?
- Because they could write stuff on you that's not true.
- They don't know you?
- Because it's not like they've got your brain so they don't know exactly what's going on (Young person).

Well I think the ... I know that I did this and I know that other people have done it but you spend so much time hiding everything that's going on that what they were writing could be completely different and I don’t know whether that would be a good thing or a bad thing (Young person).

Some young people also acknowledged that their parents might be biased in their favour:

And to choose who’s going to fill it out because if it’s a parent they could be quite biased towards you because they’ll think, “Oh this is my darling child, there’s nothing ever wrong with them.” (Young person).

Some young people were concerned that the measures may identify issues their parents were unaware of. They were attempting to protect their parents from knowing some negative aspects about them and did not want their parents to feel inadequate about their lack of knowledge.

Yeah, and you don't want them to feel that they should know these things when sometimes it's perfectly reasonable just not having a clue (Young person).

On the other hand, some of the young participants acknowledged the value of the parents’ perspective. Some of them saw their parents as close allies and they were interested in knowing their views. Young people realised that they might not be able to judge their own behaviours accurately. They believed that the parent report could offer them insight and a different perspective. Also they understood that a parent measure might provide additional information for their clinician and might be useful in helping them.

If it's the way they see you acting or reacting to something, then it would be helpful (Young person).

Okay, I think that would be a good idea because like coming - I talk to my mum about most things and coming from home it would sort of give, I don't know, a different perspective on the way that I think and the way that she sees how I think because it could be different, so I think it's a good idea (Young person).

While the above concerns about the validity of parents’ reports were largely expressed by the young people, the parents and the young respondents both discussed the issue of teachers’ reports. There was much debate about the acceptability, relevance and objectivity of the teacher report and opinions were divided.
Some young people were supportive of a teacher report and believed that it might be useful to seek out information about their school and classroom behaviours and problems. School was seen as an important environment in which children and young people spend considerable time interacting with others and thus a teacher report might be valuable.

Yeah even that like to show like your personal feeling like positive of what you are or that kind of thing. Like that's the environment and like that's the people kind of thing (Young person, Māori).

I think it would be good to have these two because maybe you’re not as depressed at school or with your mates than you are with your family kind of thing (Young person, Māori).

On the other hand, some children and young people and their parents did not see the appropriateness of reports from teachers. They felt that their teachers did not know them sufficiently to have insight into their problems and needs.

Because they really don’t know the person inside so, “cries often and easily”, that could be not just like an emotional kind of thing, you could have just hurt yourself, you know, you could be grazed (Young person, Pacific).

But I think the one that went to the school, although it was detailed, for the length of time that they know the child from, I don’t think it was long enough to really make a good assessment (Parent).

If you gave a teacher in the first term something to fill in about the child, their view of the child in the first term is quite often quite different from the end of the year, you know. How long has this teacher actually known this child in making an assumption or do they actually know the child? (Parent).

Children and young people also raised the issue of feeling shame, and would not want their teacher to know that they were experiencing problems with their mental health. Young people talked about the stigma attached to mental health issues and were concerned that a form sent out to the teacher would identify them as accessing the services.

No, well that's just going to, well not really ones.... but I'm just saying some teachers you might like to pretend that they have no idea about you. I mean, you might get along with them well and maybe you're ashamed of being whatever, whatever you call it and so it would just be stupid putting you in a position where you're going to feel embarrassed admitting something to a teacher (Young person).

Because then the person’s judged, they’d judge people but I can see it from the other side, sort of, they’ll judge them and they won’t respect them, you know, teachers shouldn’t treat a child in this kind of way (Young person, Māori).

Young people did not want to be perceived or treated differently by their teachers after an assessment was completed:

Like me personally, my school doesn't know that I come here and I wouldn't want them to because I know at my school it's just not done and I don't want to be treated differently than what I am now. I don’t want to be felt sorry for; I just want to go on (Young person).
Not only were the participants concerned about the objectivity of the teachers completing outcome assessment but also they wanted to ensure that the clinicians and other people working with their children and young people were trained and knowledgeable in the administration of the measures.

And also, these professional people that are administering them, what about people at schools, will they know how to fill them in? (Parent)

Moreover, parents wanted to be assured that the clinicians assessing and working with their children and young people were objective about the measure they were completing or interpreting. They believed that the quality of the information may be compromised if the clinician had a preconceived assumption about their client or was too involved in the treatment and management of their case. Some proposed that an independent person was involved in the process to ensure its impartiality.

Yeah, yeah, because especially, kind of, information that’s maybe had four or five sessions of interviewing, questioning and assessing, not just the child, the family dynamics and you know, I mean I don’t know that their judgment is always 100% impartial either. They’ve already begun to formulate an idea of what they think is wrong with your child (Parent).

5.6.1 Feedback about specific outcome measures

In the second part of the focus groups we presented the participants with a number of outcome measures identified by the clinicians in the clinician survey as the most widely used. We explained each measure individually, providing background information about its purpose and intended use. Following that we asked the participants to read through the questions and consider whether or not they thought it was meaningful, useful and acceptable to them. We also asked about the overall appeal of each form and its ease of completion.

5.6.1.1 Beck Depression Inventory II (BDI-II)

Although the Beck Depression Inventory II ("BDI-II") is not a comprehensive outcome measure, it is used frequently so we sought feedback from the participants during the first two focus groups with young people and parents.

There was a positive reaction to the measure from some of the people who believed that the instrument had thorough and clear symptom coverage.

I think these are great. I think they’re really clear. I think they give you room for degrees of that feeling which you don’t always get and I think they’re very clear what they’re asking. I think it’s a really honest thing and I think also it probably helps the person think about what’s going on with them (Parent).

There were positive comments about its clear layout and brevity making it easy to complete.

I quite like this too because it gives the definitions here, the titles and if you just ask somebody that’s hard to sort it out into categories but that gives certain definitions here, certain areas you know, that I like and it’s very clear you know. Yeah I think that would be a good one for any age (Parent).
When we had the discussion we thought that was the better of the lot. I know that I'm saying it but just the layout and the headings made it more straightforward (Young person).

On the other hand, others believed that its format and the way the statements were grouped and labelled could predispose the person to complete in the form in a certain way.

I feel that the time one, the way that they’ve collected these in their groups and given them a specific title tends to more flavour and colour the response that you're going to get from the child filling that out (Parent).

Some people argued that it only focused on the difficulties and negative feelings while it lacked positive statements and strengths. Young people and their parents believed that the BDI-II could make them feel depressed just by reading the questions. They suggested including statements that were positively framed to balance the overall content of the measure.

- It seems more negative of anything, well not completely negative, but like it says, “I do not feel sad”, it could say “I feel great” or “I feel happy”.
- Yeah I agree with that. It doesn’t have anything really to do with anything that you’ve achieved (Young person).

I think they should have started at 21 and worked back. I think the ones they’ve got on the front page; by the time they got over the page they would be suicidal. It's kind of bringing them down on the first question. But do you know what I mean, like whoever did this should have started a little bit lighter instead of going straight into they’ve got suicidal guilt and stuff on the first page (Parent).

Other people questioned the usefulness of depression scales by pointing out that the difficulty in decision making as being one of the signs of depression:

I sort of think decision making is one of the elements of depression; how good would they be at making decisions in which one they fit? (Parent)

5.6.1.2 Child Depression Inventory (CDI)

We sought the feedback on Child Depression Inventory (“CDI”) from the children, as this is a measure designed for use with the young age group. We chose the short version of the measure to make it easier for the children to familiarise themselves and comment on it in a short amount of time.

The children found the questions relatively easy to understand:

- So is it easy for everybody to understand? Is it easy to understand the questions?
- Yeah little bit easy (Child).

There were some items that the children did not find acceptable. They were concerned that some of the options were too narrow and felt uneasy being forced to choose when neither of the statements reflected them accurately.

- I do understand the question like it says item 9a meeting friends – “I wish I had more”. I have like some friends but I don’t wish I had more.
- So maybe you’ve got enough friends.
- Yeah I’ve got enough.
- So the actual question, “I have plenty of friends” doesn’t really describe things exactly for you and it might be better to have it “I have enough friends”, would that be right?
- Yes.
- Because some people don’t need to have many friends? Just someone?
- Yeah (Child).

As previously mentioned, a general concern was raised about the difficulty in answering what the young people considered questions about personal or private feelings. This concern was again raised with regards to CDI by the children interviewed, and who felt uneasy or embarrassed about answering them. This particularly related to item 7, which focuses on the child’s perception of their looks where one the options is “I look ugly”.

[Name of child] said that some of the questions are a bit personal, they ask about personal things and he would like to be asked about them only if they were, what did you say [name of child]?
- If they were ones that would help and because that particular is not very nice.
- I agree, some of these things are I don’t know, are a bit personal. Like item 7, that’s personal (Children).

5.6.1.3 Child Behaviour Checklist (CBCL) and Youth Self Report (YSR)

We presented the CBCL and the YSR to the participants and explained that they were very similar measures designed by the same author for different informants.

Several people believed that CBCL was very comprehensive and covered several important domains including general health presenting a broad picture of a child.

Yeah I’m just going through that, that’s a bit more giving you a broader outlook on what the kids are like. It poses similar questions to the Conner’s but this is just a bit more explicit and yeah a bit more explanatory in what they’re asking you and what you can tell them (Parent).

I like this because it just talks about your general health, you know, the questions are like that question there “Rashes or other skin problems”, you know (Young person).

Many participants liked the questions because they focused on various symptoms of mental illness. They thought that the measure inquired about relevant and meaningful issues that could better inform their clinician and influence treatment planning. The questions were seen as succinct and valid.

But I think this is really good because they’re specific to like, all of these are specific like symptoms of mental illness so I think that’s really important (Young person).

Yeah, it ... I think that the questions in the Youth Self Report, that would have been the best part in it or the best out of all of them. I don’t think the style was particularly good but the questions were to the point (Young person).

There were several negative comments about CBCL and YSR. Many participants commented that it was a long questionnaire and would take a long time to complete.
Well, I look at this and it’s like “Arghhh!” (Young person)

It’s got too many words in it (Young person, Pacific)

I found it really, yeah it took me ages and I couldn’t fill it out (Parent).

Participants pointed out that that they were likely to lose interest and ability to focus with such a long measure. In addition, they believed that with a long measure they were less likely to respond honestly.

I think it’s probably a bit long, most teenagers would get half way through and then just circle to make little pictures rather than what they really think (Parent).

I’d just fill each, I’d just circle anything because I’d want to finish it (Young person).

Some people suggested splitting the completion of CBCL into more than one session to make it easier and less tiring.

But if you have one page and then two weeks later another page, instead of all of it together (Parent).

Some people thought the questions were negative and it might be distressing for the parents to answer those in relation to their child or young person:

The little questions and stuff, parents would worry anyway and if they get all these little things that are sounding bad, they’re going to worry even more (Young person).

Some people were surprised about some of the particular items and questioned their relevance:

Oh my God, they ask if they pick their nose! (Young person)
The things like “I bite my fingernails” you really wonder why they want to know that? (Young person)

Many young people believed that the age range of the CBCL was too wide. Since most of them were in the middle or late adolescence they did not see the relevance of some of the items to their age group.

I think they need to have like because “Drinks alcohol without parent’s approval” -
I think they need to have a more specific age group form (Young person).

I reckon some of it’s too babyish (Young person).

Following the above point, some young people assumed that it would be difficult for their parents to know some of the details asked about in the CBCL. They believed people of their age did many things without their parents’ knowledge and that it was inappropriate to ask parents to comment on those things.

But once you get to about 12 or 13, I don't know, you're just kind of changing, you don't want your parents [to know] what you do every single day (Young people).
Some questions were seen as difficult to understand and needed clarification:

> Because, you know, it’s too cramped up and you have to be like concentrating to read it and there’s some words in there like we can’t explain like, you know, it says “I am nausea”, oh “Nausea do you feel like that”, or something like that. But yeah, some of us don’t know the spellings of some words so it would be like no, no, sort of thing (Young person, Pacific).

There were also negative comments about the layout. The font was seen as too small and the room for comments was inadequate.

Many comments were raised about the difficulty of completing the first section of CBCL and/or YSR which asks about the child or young person’s hobbies, sports and chores and the informant needs to compare themselves (or their child or young person) with the average person in that age group. This was seen as difficult and time consuming to complete, requiring a lot of insight.

> But these ones, you know, the average ones they’ll take me ages because okay yeah. Oh “What do you do?”, “What’s your sport?”, okay “How many times there do you go?” Okay, so you’re an average, so I’m less than average, okay thank you okay, and I’ll ring another friend kind of thing so you’ll be average. Oh these questions, they’d probably take me an hour to figure out (Young person, Pacific).

Moreover, the act of comparing and rating oneself against the average peer was seen as unacceptable. Many young people questioned the meaning of the word “average”. Being compared to another person of the same age was seen as subjective and difficult because of the differences in people’s chronological and mental age.

> So what’s average? It seems kind of silly to me because it says, “List the sports you like”, for instance, I like mountain biking but like it says it’s got “Less then average”, “Average” and “More than average” but if you’re at all interested it’s going to be more than average isn’t it, because the average person isn’t interested in sports (Young people).

Young people did not think their parents were capable of comparing them against their peers because they might not know other young people outside their family.

> Well, these questions say, compared to others of the same age, well they might not know others of the same age (Young person).

It has been suggested that teachers may be better informed to compare the young person against their peers as they spend more time dealing with them:

> I was thinking, in a way the questions that compare you to average or not average, teachers would probably know that better than the parents know and they’re around more with different aged kids (Young person).

**5.6.1.4 Conner’s Teacher Rating Scale (CTRS)**

We presented the participants with the short version of the Conner’s Teacher Rating Scale (CTRS) and sought their feedback.

Many people believed that it was a useful measure for the teacher to complete because it focused on behavioural issues that were easily identifiable. They also believed that it could
provide useful information about the child or young person’s classroom behaviour. It may also open communication channels between the clinician and the relevant people in the child or young person’s environment.

I think they’re mostly ones that your teacher could easily decide. It would be quite easy for an outsider to perceive (Young person).

Yeah, I reckon it would be a good thing for the teacher to fill out so the counsellor will know like if you do fidget and stuff and if you are doing good at school and if the teacher thinks you’ve got fears and stuff, especially what’s going on at school. Because they’d put down their recommendations and stuff (Young person, Māori).

CTRS was seen as a comprehensive measure. It could be used to assess children and young people with various disorders.

This is actually quite good, you could use this questionnaire on both of my children that have totally different disorders and it covers a wide range and it’s short and to the point (Parent).

Another positive feature of CTRS was its brevity and ease of completion, especially for a busy schoolteacher.

Yeah, I quite like that one, it’s quick, to the point (Parent).

The questions were seen by some as acceptable and to the point.

It doesn’t really say that about ..., it doesn’t say like, he’s real bad, it’s like he fidgets a lot. You can’t really be insulted by that (Young person).

There were also various negative comments made about the CTRS. Some people simply did not think it was an acceptable scale and did not feel at ease with it, while others complained that it did not allow for any context to the child or young person’s behaviours:

I also don’t like Conner’s scale. No I don’t think it’s ... no it just reading through it I just didn’t like it, didn’t feel comfortable with it (Parent).

It doesn’t give you a lot of room to explain (Parent).

Many comments were made about the way the scale inquired about either extreme or negative behaviours without allowing the informant to identify any of the child or young person’s strengths or positive characteristics:

It’s interesting that there’s quite, yeah there’s polars like submissive or defiant. Well it’s like well “What one’s right, eh?: What’s the right answer? What’s normal in there? (Young person).

I could not, I wouldn’t be able to sit there and do this to a child. I’d have to have something positive in there. “Smiles when he comes to see me”. (Young person).

It’s almost leading them to look negatively at the person, you know (Young person).
Some people questioned the relevance of the questions and did not think they were meaningful in mental health outcome assessment:

- I used to do that a lot. I used to day dream a lot, look out the window and day dream.
- I mean it could be their teaching that’s making them day dream (Young person).

There were also negative comments about the format of the CTRS – about its font and layout:

I really don’t like the font on that, it looks like a school report (Young person, Pacific).

I think it should be swapped over, like if you read the question first, then you do the rank, you know, from left to right because that’s how we read, yeah not from right to left (Young person).

Some participants believed that the CTRS was more appropriate for use with younger children because of its classroom behaviour focus. To make it more appropriate for use with older adolescents, they suggested including questions about the young person’s academic work.

That’s for a young person I reckon, you know, somebody like still at primary school (Young person, Pacific).

5.6.1.5 Global Assessment of Functioning Scale (GAF)

When we presented the Global Assessment of Functioning Scale (“GAF”) scales to the participants there were many initial comments and questions about it. Some wanted to know whether it was used as a standard in all services, others concluded that it seemed like a summary of all the other forms. Others were concerned about its use in allocating clients to appropriate services. There were comments about the difficulty of the language and definitions, making it only usable for a trained clinician (which of course is its intended user group).

Yeah it’s a clinician one because I would need a dictionary to read it (Parent).

The GAF was seen as a useful tool for the clinician to assess their client and discuss with them their needs and progress if used routinely.

I reckon it’s a useful because you’ve got these, it’s something simple for use because some of these I don’t understand, but you do understand it so it would be easy for you and you could break it down when you discuss it with your patient (Young person, Pacific).

Clinicians are great because like I said, a clinician’s job is to be there when you’re unwell, not when you’re well so some of these questions for the person’s safety, may need to be asked (Young person).

The GAF was also considered acceptable because it removed some of the focus away from self-perceptions of mental health and instead focused on the functioning of the person as seen by the clinician.

I like this one because especially with younger juvenile kids. Those ones that are like in homes, you know, because some of them they feel bad or yucky or don’t like themselves and these kind of questions would really, oh the rankings would be easy.
and the questions as well but, you know, asking them, “Oh what’s your mum’s name?” and all that, they’d be like, “Umm, my real mum or my real dad?” or that kind of thing (Young person, Pacific).

There were some negative comments about the GAF around its subjectivity and minimalism:

- It looks incredibly subjective for something that's in DSM four or five (Parent).
- It doesn’t seem to be much of an assessment. You know, if they can just put a circle around a number (Parent).
- So it must be a bit basic, I can’t kind of work out how it works (Parent).

Some participants doubted whether the ratings were useful and possible to allocate. Others commented that since mental health can fluctuate greatly, the ratings on the GAF scale may not be an accurate reflection of the person’s well-being. There were additional comments that it may be difficult for the clinician to precisely discriminate between the ratings.

- Sort of 71 today and yesterday was 80 and tomorrow who knows? (Parent)
- I think the scale’s probably too big - from a zero to 100 there is a lot of numbers. What’s the difference between a 63 and a 64? (Young person)

Not everybody agreed that a scale used in mental health assessment should focus largely on functioning in life:

- I mean, come on, and more seriously it folds together two arguably different things – [it] acts as a measurement of mental illness and success in life but they’re different things. I mean, stick them both in the same scale. Way to go guys, not impressed (Young person).
- I don’t like the, yeah I don’t like the sort of mental illness and the behavioural issues mixed (Young person).

Finally, as previously discussed in the previous section on the issue of negative impact of the results on mental health, a concern was also raised with regard to the GAF scale. Participants were concerned about the negative impact on individuals who found out their GAF score was low.

- I shouldn’t think it would be really nice to be shown it after it was filled in and find your score to be really low (Young person).
- Yeah, say if the doctor gave it to you and you got 11 or something. Probably be quite depressing (Young person).

5.6.1.6 Health of the Nation Outcome Scales For Children and Adolescents (HoNOSCA)

When we presented the HoNOSCA to the participants we were asked a number of questions about its use. Some people believed that the information used to score a child or young person should be a part of a standard initial assessment. On the other hand, some believed that the information required was very detailed and it may be unrealistic to expect the clinician to have such extensive knowledge about a child or young person in the early stages of treatment.
Because it’s essentially sort of a clinical tool, would the psychiatrist really have that comprehensive information there anyway? (Parent)

And it requires an awful lot of information to actually start it (Parent).

Some were concerned about the difficulty and possible subjectivity in allocating the ratings on the scale. Some also pointed out the necessity of the clinician having a strong therapeutic alliance with the client in order to elicit some of the sensitive information.

Item 3 - like it says things like to get number three is a small overdose, then number four a serious overdose, how are you supposed to know what that is? (Parent)

I think depends on their relationship with the child doesn’t it? I mean, the alcohol substance solvent use bit, misuse, I mean it depends on, I don’t know, yeah how honest are the kids with their clinician? (Parent)

There was much positive feedback about HoNOSCA because of its comprehensiveness, the depth of information it covered, and its potential clinical usefulness.

I like this, I think this is really good - it goes into a lot of detail (Parent).

It probably raises some quite good questions (Young person).

As I say, I can see it as a good tool as compiling that information together into a concise form (Parent).

Some people believed that having completed the HoNOSCA, the parents could be assured of the thoroughness of the clinician’s assessment. Many people appreciated the fact that HoNOSCA gathered a broad range of information about the child or young person, including environmental factors, to give a wider picture of the client. This was seen as clinically important and meaningful.

Would that be useful in terms of, if you have surveys of school, from the family, from health care professionals, from whoever else has been involved with this child, it would be a very useful tool for the clinician to pool that information together and give themselves a generalised overview to relate all that data. I think I can see it’s useful (Young person).

Oh I think it’s because it’s a wide range, like it’s not just yourself, it’s your family and your environment and relationships, school and it’s not you filling it out and seeing what you’ve got inside, information where they kind of like see a theme and if you’ve got a problem (Young person, Māori).

That’s another thing is ... that’s reassuring .... that if they’ve completed something like this they obviously have tapped into all those domains and they’re not simply basing their diagnosis and therefore their treatment of my child on 20 years clinical experience which is all very nice and I would certainly put value on that but this tells me that this person’s been thorough so I like it (Parent).
The HoNOSCA was also seen as a useful tool to gauge the effectiveness of services if used routinely to measure individual outcomes using the baseline-follow up model:

I can see this being also useful in terms of evaluating how successful the service is for a particular user over a long period of time (Parent).

If this had been administered say six months after into his assessments and treatments and what not and then again just before we leave, then you’d have a reasonably good assessment of how well the service had performed (Parent).

Some parents also pointed out that HoNOSCA may be useful for children and young people in ongoing or long-term treatment making it possible for various services to gauge the child or young person’s prior difficulties and needs.

It would also be quite useful if your child was moved onto a different psychologist or psychiatrist for a specific reason, if they had this to follow them so the new person dealing with a new problem would see what the previous problems were and where that leads in from (Parent).

Furthermore, the way the scale divided the ratings into several separate areas was considered valuable from the consumer’s perspective. This allowed differentiation between problems in different areas and may be more useful than an overall score, allowing for better progress review.

- Oh I like these kind of numbers because it changes for every one.
- Yeah.
- Yeah I like that so if I was to see my total score then I’d think, “Oh I must be pretty bad” but then I’ll read back on all those numbers that you’ve put down and then I’d feel much better because I’d know what each number meant and not just “True”, “False” (Young person, Māori).

Several young people wished to be engaged and have an input into the process of a clinician-completed measurement. They believed that they had the right to discuss the assignment of ratings and, jointly with the clinician, contribute to the final results. They thought that a solely clinician-rated instrument may not be fully accurate and wanted to be able to disagree if they considered it erroneous. Furthermore, knowing the results of the clinician-measure had the potential to help them realise how the therapist perceived their health and that in itself may be beneficial.

Yeah, to see what they've come up with and maybe, if you don't agree on something, then to change it because I know like we don't get to read our notes and like it's only their perception of what they see. So if these forms, if we could have an input into the forms would be really good, yeah (Young person).

Some participants compared the HoNOSCA to GAF and believed it to be a more acceptable and less subjective scale because of the way it divides the assessment into separate components.

Yeah, the questioning with the “zero”, “one”, “two”, “three”, that’s a good deal more specific than being asked to make value judgments so to speak (Parent).

There were some negative comments about HoNOSCA. Some young people were concerned that the scale grouped together a diverse range of unrelated problems. They believed that by
doing so, the overall picture of the child or young person assessed might be inaccurate and biased.

> It does sort of shove things together a bit like for number 11 “property and self care and independence” - that's got like e.g. “problems with basic activities and also complex skills” (Young person).

> It just seems a bit stupid putting things like “wash yourself” alongside things like “money managing” because money managing, heaps of people have problems with whereas most people can toilet themselves and dress themselves (Young person).

Several young people questioned the meaningfulness of the HoNOSCA and the way it defined the extent of the problems. Some young participants believed that definitions such as “mild” or “moderate” were imprecise, ambiguous and subjective.

> - I think words like “mild to moderate” and “severe”, I find those vague. It doesn’t really mean anything.
> - I don’t know whether that would mean something to a doctor more but I would think that that would be a little bit hard to go, okay where are they on that scale, and you know.
> - Yeah, it says “mildly excessive” and stuff like that.
> - And “moderately severe”.
> - Yeah.
> - And you wouldn’t know if that’s severe (Young people).

Finally, some people believed that the HoNOSCA was a lengthy and time-consuming instrument, difficult to implement in a busy clinical practice.

> I think it might take a lot of time that clinicians don’t actually have (Parent).

**5.6.1.7 Strength and Difficulties Questionnaire (SDQ)**

We showed participants the double-sided SDQ self- and parent-reports with impact supplement and the follow-up questions.

There were many positive comments and wide acceptance of the SDQ. Many people believed that it was a valid and meaningful measure collecting clinically relevant information. Some compared it favourably to the CBCL and believed that it was more suitable for young people.

> I think this one’s generally pretty good (Young person)

> It still asks some pertinent questions (Parent).

> Yeah, the questions are more grown up (Parent).

SDQ was seen as a quick and simple measure. The measure was judged to be brief but covering a broad range of important issues. The fact that it was a brief measure without collecting a great amount of detail was deemed acceptable.

> Yeah, it’s just nice and clear and I think you could tell a lot from it, be reasonably easy to fill out, I think (Young person).
I personally think that it is quite good looking at the questions, the way they ask. It’s fairly easy (Parent).

Yeah. Because this one would take you probably about ten minutes to do (Young person).

The 3-point response scale was considered unambiguous and easy to answer.

As a parent I thought that was easy to fill out and reasonably clear and it wasn’t asking you to think of huge degrees, you know, if things start getting up to rate it one to five I start thinking, “Oh are they are three or are they really four?”. And I gather a lot of this you don’t want that detail for, you just want a quick response because it’s likely to be more, so I like that because it doesn’t ask me to think too hard about it (Parent).

It’s easier with three because you can like pick the end ones or the middle or in-between, like with this one you kind of want there to be something in-between those two (Young person).

Several young people preferred to have their parents/caregivers complete the SDQ instead of other measures because it was a more general assessment and did not ask many specific or personal questions.

Actually I think it would be better to have my parent, I’d feel better about my parents doing something that was less specific, because if they were doing something that’s got all these little gritty details I think that my parents were going to start thinking that yes, I did do those things just because it’s on the form so it must be common or something, you know (Young person).

Parents of younger children believed that it was a developmentally appropriate questionnaire with easy to understand questions.

Yeah, quite different and I like it how it’s very simple for the youth one is in really simple language (Parent).

Some young people liked the SDQ because it asked questions that were seen as less invasive or private.

I think they’re a bit better because they’re not as personal (Child).

- What do you like about them?
- Because they’re not that personal, not interfering in your life (Child)

And the answers aren’t that personal (Young person, Māori)

As previously discussed, our youngest participants expressed their wish to be able to complete their own self-assessment and could see the applicability of SDQ.

But it’s fine, but this one actually is 11 to 17 but it’s fine, it’s fine with me. It would be ... I wouldn’t mind filling it in myself; it would be fine with me. The only problem is, don’t know if I had one for my age group, I don’t know if it would be good, but I think this one’s quite good (Child).
To make it easier for the younger children, the children in our focus group suggested that some of the words be made easier for them to understand and that the font be made bigger:

Yeah, it’s easy to understand for me but other people it might not be so. Some words like ‘somewhat’. Young people might not understand. They should alter the words for people who are younger (Child).

Well there’s one thing is the print is a bit small and I would like if it was a bit bigger and I think about the same way as the other one, like not many people being able to see that one (Child).

SDQ was also received well for its positively framed questions allowing those completing it to record information about the child or young person’s strengths.

- No just everything, you know, the questions are really good and it’s more spread out, you know, it doesn’t look so scary. No, but it’s good.
- It’s good for it not to look scary?
- Yeah, we don’t want to do that, do we?
- And it’s like they’re saying it in different ways, like if they do look like the person who was going to fill this out, if they do care about people, like “I fight a lot”, “I am helpful if someone was hurt”. So they’re actually asking it in different words.
- Yeah I think I know what you’re saying, looking at it from more of the positive side.
- Yeah (Young person, Māori).

There were relatively few specific negative comments about the SDQ. Some believed that it was a simplistic measure, which did not collect enough information and would have to be accompanied by additional assessment.

It’s a bit simplistic really (Parent).

Possibly couldn't be used, you know, but would have to be used in conjunction with something else, yeah but (Parent).

There were also some comments about particular questions and concerns that they covered too many unrelated symptoms potentially leading to an imprecise assessment of outcome.

- Number 26 is a bit bizarre – “Do you have any difficulties in the following areas, emotions, concentration, behaviour or being able to get along with other people?”
- Okay. Too many things in one question?
- Yeah, it's a bit of mixed up.
- Yeah, because you might have difficulties in concentration but not with emotions (Young people)

There was also some uncertainty about the restrictiveness of the 3-point scale:

With only three choices for the categories, it’s a wee bit [more] restrictive than the one we previously had, at least, I agree when you’re getting up to five or six or seven, the variations between if it was a three or four “is not true”, “is true”, “is somewhat true” - does that really cover the sort of variations? (Parent)
5.4 Conclusions from focus groups

Overall, all groups appeared in favour of CAMHS using outcome measures, to assist in the assessment and measure progress. The broad reasons for support of measurement included the way it can:

- Validate parental concerns and clarify issues for the child or young person;
- Provide insight into child or young person’s problems and needs;
- Make it easier for the child or young person to disclose problems, and
- Allow for tracking of progress and outcome.

Most of those in support of the use of measurement also expressed some specific reservations and a few individuals were opposed to use at all. Objections or reservations expressed included:

- The limited ability of standardised measures to capture the complexity of mental health;
- The restrictive nature of standardised assessments;
- The ability and willingness of some children or young people to complete written measures, and
- The potential negative impact of introducing written measurement at the initial stages of entering a service.

There was concern about the impact of outcome measurement on treatment planning and case management and about the consumer’s ability to access or continue services. Specific issues related to:

- The need for measures and their results to be incorporated into a treatment plan;
- The potential for measures to be used as simplistic diagnostic tools;
- The way results could be used to limit access to services, and
- The potential of collected outcome data to standardise the services.

The actual process of measurement was seen as more important than the content of specific outcome measures. Participants highlighted the following factors that make the process more acceptable:

- Young people and children want to be informed and consulted about the measurement process;
- A trusting clinical relationship needs to be developed prior to the introduction of the outcome assessment;
- Privacy and confidentiality of results must be respected;
- Access to results should be discussed and negotiated with the child or young person and their family;
- Factors such as environment, number of measures, format and length of time to complete a measure all contribute to the acceptability of the process, and
- Feedback and communication of results should be done routinely.

The content of measures and the value of multiple perspectives gained were discussed. Participants would like the measures to:

- Be comprehensive and holistic to assess the child or young person’s global functioning;
- Be flexible and suitable to assess specific disorders;
• Address client’s satisfaction with the received services, and
• Be standardised and adapted to New Zealand.

Who completes the measurement was seen as crucial. Particular issues discussed related to:
• The value of self-report (including self-report for children under 12 years of age);
• The need for a relevant informant to complete a measure, and
• The need for objectivity of teacher-rated assessment.

Specific feedback was sought about several standardised measures.
• Beck Depression Inventory II (BDI-II) was accepted for its brevity and ease of completion, however, its negativity was viewed with concern.
• Child Depression Inventory (CDI) was also deemed easy to complete by the young children. However, several items were of concern because of their personal nature.
• The Child Behaviour Checklist (CBCL) and Youth Self Report (YSR) were judged to be comprehensive measures covering important symptoms and domains of mental health and well-being. However, they were criticised for their length and the irrelevance of some of the items to older adolescents. Furthermore, young people particularly disliked and objected to the first section of the form requiring the informant to compare the consumer to the average young person of the same age.
• The Conner’s Teacher Rating Scale (CTRS) was seen as a brief useful teacher-rated assessment with pertinent questions. However, it was criticised for its lack of positive, strength-based questions. CTRS was seen as a more meaningful assessment of younger children.
• The Global Assessment of Functioning Scale (GAF) was considered a useful clinician measure which focused on the person’s functioning. However, the allocation of GAF ratings was seen as imprecise and subjective.
• The Health of the Nation Outcome Scale for Children and Adolescents (HoNOSCA) was regarded as a detailed instrument which ensured a thorough clinician’s assessment. However, it was believed that the validity of assessment was dependent on the quality of the therapeutic relationship. To reduce the subjectivity of clinician assessment, young people wished to have an input into the assignment of ratings. HoNOSCA was seen as more acceptable measure than GAF because of its broader focus and coverage of multiple domains.
• The Strengths and Difficulties Questionnaire (SDQ) received much positive feedback and was seen as a simple yet meaningful measure collecting relevant information. When compared with other measures it was preferred because it asked more general and less invasive questions. Children expressed their wish to be able to complete their own self-rated SDQ. Negative comments about SDQ concerned its simplicity, particular questions covering too many unrelated symptoms and the restrictiveness of the 3-point scale.
Section 6: Māori perspectives

It is imperative that the views of Māori clinicians, tamariki, taitamariki and whānau were included in this work. This section describes Māori participation, provides information on specific Māori concerns, and documents feedback about Hua Oranga.

6.1 Māori participation

6.1.1 Consultation

Consultations with Māori were undertaken during the development of the grant application. Discussions were held with a number of Māori working within the mental health field who were supportive of the project and who agreed to act as advisors and kaumātua support.

6.1.2 Māori participation in the project: research team

Dr Sue Crengle has been a member of the research team during all phases of the project. She has had experience working in the mental health sector and has Māori health research expertise. In addition, Melissa Taitimu, a Māori trainee clinical psychologist facilitated one of the Māori youth focus groups and participated in the qualitative analysis of the transcript of that hui.

6.1.3 Māori participation in the project: research participants

Māori participants included eighteen clinicians (four present at the hui), five tamariki, taitamariki, six whānau members, and staff working at a Māori community child and youth mental health service. Tamariki, taitamariki and whānau were involved with both kaupapa Māori and ‘mainstream’ services.

Several hui were held prior to the conduct of the hui at the kaupapa Māori service. Prior to the beginning of the project, the principal investigator (Sally Merry) met with the team leader of the kaupapa Māori service and invited the team to participate in the study. The invitation was accepted and a series of meetings was arranged. Sally Merry, Sue Crengle, Rawiri Wharemate and Karolina Stasiak (project co-ordinator) met with the staff of the service and discussed the most acceptable way of carrying out the research process. A subsequent meeting was held with clinicians and interested participants to explain the study further and to finalise the date for the hui with tamariki, taitamariki and whānau.

6.1.4 Dissemination

We held two hui in Auckland and Wellington to present and discuss the findings before finalisation of this report. It is planned that a summary of the results in lay language will be made available to all participants and copies of the finalised report will be sent to any participants who request this. Results were also presented at the CAMHS conference in September 2003 and at the CAMHS Sector Meeting in November 2003. A report from this project will be published by the Health Research Council, will be distributed to relevant stakeholders and will be available as a downloadable file online. Papers will be prepared for publication in scientific journals.
6.2 Consultation over Hua Oranga

Dr Te Kani Kingi provided background information about Hua Oranga. Although a great deal of work has gone into the development of Hua Oranga, work on validation of its use with tamariki and taitamariki is at an early stage and Dr Kingi’s advice was that Hua Oranga could not be included as a measure for tamariki and taitamariki at this time. It was agreed that feedback from tamariki, taitamariki and whānau on the concept of the measure would be valuable so that although we knew that the measure could not be recommended for inclusion currently, we would nevertheless retain it for discussion in the Māori focus groups. It was also agreed that we would ensure that staff from a kaupapa Māori service that had been involved in the evaluation of Hua Oranga for use with adult consumers provide us with feedback about the potential future use of this measure with a younger population. This was done.

Dr Kingi also kindly reviewed the all sections on Hua Oranga (please refer to section 2.8) for this report; his feedback is included.

6.3 Survey – results from Māori clinicians

Fourteen (13.3% of the overall sample) clinicians who identified themselves as Māori responded to the survey. Ten were trained as social workers and nurses, three identified as counsellors, two were psychologists, one was a psychiatrist and two worked in tikanga Māori management and education (participants were able to choose as many categories as applied). Six clinicians worked in CAMHS outpatient units, four in NGOs, one in an inpatient unit and the remaining three in other types of agencies including a Māori mental health community service. Four respondents came from the Northern region, three from the Midland region, four from Central region and three from the Southern region. Five Māori clinicians had over 10 years of experience, two had worked between 5 and 10 years, four between 2 and 5 years and the remaining three had worked less than 2 years in the CAMH Services. Three held certificates and/or diplomas, six had postgraduate certificates and/or diplomas, four had a bachelor degree, three were qualified with Masters degrees, and one had a professional Membership/Fellowship.

The number of Māori clinicians in the sample was too small to undertake a separate analysis of responses from Māori clinicians and therefore only the major findings are presented here:

- All Māori clinicians who responded to the survey believed that outcome measurement was important;
- Most (12) would also find it practical, one was neutral and one would find it impractical;
- The majority (13) supported routine use of outcome measurement in CAMHS (one was neutral);
- Eleven Māori clinicians have heard of HoNOSCA and 6 were familiar with SDQ, and
- Only two have used either of the measures before.

6.4 Results from Māori focus groups (hui)

Four Māori clinicians were present at the hui held at the kaupapa Māori service to support the participants. They also took an active role in the discussion and their comments have been included in the theme analysis. The group’s facilitator and the research team believe that the clinicians’ attendance was beneficial and that they did not appear to influence or affect the voices of tamariki, taitamariki and whānau.
The information obtained about outcome measurement and the specific measures was very similar across Māori and non-Māori groups. The same range of themes and issues were identified. Furthermore, there were no apparent differences in the perspectives of the participants relating to these themes and issues. A summary of these themes and issues is presented in this section. The reader is referred to Section 5 for a more comprehensive description of these findings.

In addition, a number of themes specific to Māori were identified during the hui. This section reports these findings fully. Feedback regarding Hua Oranga is also presented in this section.

6.4.1 Summary of themes and issues highlighted during Māori hui

6.4.1.1 Knowledge and acceptance of outcome measures

A relatively limited knowledge of outcome measurement was apparent among the Māori participants. Many did not recall being asked to complete any measures in the services they had accessed. However, the initiative to introduce routine outcome measurement was welcomed as important and beneficial to the clinical process. The importance of outcome measurement was seen in its ability to track progress and monitor the effectiveness of the intervention.

A few reservations were voiced about the time at which an outcome measure may be completed; some believed that it may not be appropriate to ask tamariki, taitamariki and their whānau to complete a measure when he/she/they were in crisis and urgent need of an intervention. It was also felt that it was important that the need for a completed measure did not supersede the need to work with the tamariki, taitamariki and their whānau.

Confidentiality and a well developed trusting relationship with the clinician were seen as crucial elements in facilitating accurate outcome assessment.

6.4.1.2 Format of measures

Brevity and ease of completion were seen as essential components of an acceptable measure. A preferred measure should also be comprehensive and the associated feedback should be presented back to the client in a simple manner. Measures such as CBCL were seen as time-consuming, requiring more than one session to be completed. However, some people were supportive of it because of the specific and pertinent issues covered that might otherwise be missed.

6.4.1.3 Impact of measures on the resource allocation to mental health services

The clinicians present at the hui discussed the way outcome measurement data on a national level may impact on the regional services. They were concerned that resource allocation may be tied to the results and were concerned that funding may be changed as a consequence of results rather than based on regional service development and population needs.
6.4.2 Māori specific themes

6.4.2.1 Assessment of more than just the individual

Concerns were raised about measures that only assessed the individual and did not address other domains of the person’s life or did not ask the whānau about their perspective. It was believed that a measure that was acceptable and meaningful for Māori clients should have a broad focus.

Oh I think it’s because, it’s a wide range, like it’s not just yourself, it’s your family and your environment and relationships, school and it’s not you filling it out and seeing what you’ve got inside (Young person, Māori).

6.4.2.2 Cultural identity

An issue discussed by participants at the Māori Mental Health Service concerned the need for the measures to capture the client’s stage of cultural development (such as iwi, hapū, te reo, tikanga Māori). As well as asking for a child or young person’s name, some would like to be asked about their Māori identity by asking to specify their iwi. Some suggested that such information could be used to match clients to clinicians. However, there were also concerns that collection of such data could be misused and Māori could be misrepresented in statistical analyses. For example, high rates of utilisation of services by people from one hapū or iwi could be (mis)used to label the hapū or iwi as having high rates of mental health problems when in fact the rates could reflect good access to services in that area (compared with other areas).

6.4.2.3 Need for cultural sensitivity in mental health measurement

Māori participants also talked about the need for cultural sensitivity and the importance of culture in mental health assessment. Participants wanted the outcome measurement to be culturally appropriate and sensitive. Culture was seen as an important influencing factor on the well-being and behaviour of an individual. Mental health workers should be aware that what may be an unusual behaviour in one culture may be acceptable and normal in another.

- Can I say a question, just looking at this, do you see any dimensions that stood out and you are able to identify who you were in terms of your Māori identity?, Do you see it important to cover culture in terms of what you’re doing here?
  - Definitely.
  - And why would that be?
  - Because cultures have different traditions and different ways of life. Yeah, so you know maybe, if a person who is seeing you might think a different way of you, whereas for the culture that’s just normal, that’s just the way you are, yeah.
  - Can you give us an example or you don’t know?
  - Like even like those Muslims who starve themselves. It’s their culture.
  - Yeah, Ramadan.
  - Whereas, well I’m a Māori and I love eating! And I don’t see the point in starving myself. (Māori young people).

6.4.2.4 The need for tino rangatiratanga (self-determination)

The theme of being able to exert choice and be in control over the measurement process emerged during the Māori hui and was highlighted by the kāumatua present at one of the hui. Although tino rangatiratanga can be applied at individual, whānau, hapū and iwi levels, it was clear from the transcript of the hui that the participants were referring to the ability of the
tamariki, taitamariki and whānau to be self-determining in relation to the outcome measurement process and the information obtained during the assessment process.

You’re talking about the Treaty and you’re talking about Kaupapa Māori, you’re talking about rangatiratanga when you say, “Here, fill this out”, there’s no tiratanga, you don’t have the self-determination about what is happening with your opinion. I think that’s an important issue (comment from Kāumātua).

Yeah that’s what I was saying, in Kaupapa Māori it’s yours so you can trust it because it’s your mana, your honour. If I can’t see it I don’t like it (comment from Kāumātua).

6.4.2.5 Feedback about Hua Oranga

Overall, Hua Oranga was received positively by the Māori participants. Favourable comments were made about its brevity, ease of completion and comprehensibility:

Yeah it looks like a lot but if I was to look at each question I consider it’s to the point, it doesn’t like beat around the bush (Young person, Māori).

It was believed that Hua Oranga was more whānau based and more appropriate for use with Māori clients. Hua Oranga was seen as a holistic measure which attempts to assess the person’s mental health on several domains, gauging behavioural outcomes but also addressing other domains such as spirituality:

- They are not that personal.
- Yeah it’s not just the outside.
- But your inside too (Young people, Māori).

Moreover, other positive comments were made about the way Hua Oranga asks specific questions about community involvement and peer relationships – issues that are important to Māori and their understanding of well-being.

There were also some concerns about the wording used in the measure. Some people were surprised that English words were used instead of Māori. Some participants preferred to see more Māori words used throughout the measure. There was also some confusion among taitamariki about the meaning and ambiguity of some of the words and terms used:

If you knew that when they say “mental well-being” that’s not “mental psycho” kind of thing, it’s yeah, because if I was reading I wouldn’t know anything about that. But other than that, these are pretty good questions (Young person, Māori).

- Is it just the wording there that makes you unsure?
- “Healthier from spiritual point of view”. If I didn’t know what that means I’d probably think – “Ghosts!? What’s that got to do with it?”
- So define exactly what they’re asking a little bit more?
- Mm (Young person, Māori).

Participants also pointed out that some questions were potentially open to individual interpretation such as “As a result of the intervention are more able to communicate with the whānau”. This was seen as an ambiguous question, not easily answered, especially by taitamariki.
There were also comments raised about use of Hua Oranga with clients who identify themselves with more than one ethnic group. There were concerns that some tamariki and taitamariki with two (or more) ethnic groups may feel disloyal to their other ethnic group when asked to complete a Māori measure. Furthermore, this may be more pronounced in tamariki and taitamariki whose identity changes with their development. It was noted that tamariki and taitamariki should be able identify their cultural identity by themselves without being forced by their whānau or clinician.
Section 7: Pacific issues

7.1 Pacific participation

7.1.1 Consultation

Prior to starting the project we discussed the ways in which Pacific issues would be addressed in the project. The DHB from which we attempted to recruit participants was selected as having a high number of Pacific people in the population, one of the investigators worked in the local CAMHS and we had support from the team at the service. We discussed the project with the local Pacific mental health service. Workers there were supportive but the service had adult consumers so they were unable to recruit young people for us. They offered their premises to hold the focus groups.

7.1.2 Pacific participation in the project: research team

To ensure that we worked appropriately cross-culturally we had a Pacific co-investigator, Ettie Pasene-Mizziebo, as one of the core group of investigators. She has participated in all phases of the study. Monique Faleafa, a Pacific Clinical Psychologist Intern, was employed to contact and facilitate discussion groups with Pacific children and young people and their families.

7.1.3 Pacific participation in the project: research participants

We planned to organise two focus groups for Pacific young people and their families. We first attempted to recruit Pacific people through their clinicians at the CAMHS service. This was not successful so we used the Patient Information Management System to generate approximately 40 names of potential participants, and the Pacific Clinical Psychologist Intern from the service was asked to assist in contacting the individuals. Despite numerous attempts to contact the people on the list, many had moved out of the area, phone numbers had been changed or disconnected and the remainder declined the invitation to participate because of ongoing mental illness or for other reasons.

Two participants who had previously agreed to be interviewed cancelled at the last moment and only one participant remained (a young person) so a single interview was carried out.

7.1.4 Possible reasons for the limited Pacific participation in the study

We consulted extensively with our Pacific co-investigator about ways to increase and promote Pacific participation in the study (in all phases). Despite her involvement in the project, we have not been able to meet our intended goal of recruiting young Pacific CAMHS consumers and their families for two focus groups. Similarly, our attempts to facilitate Survey responses from Pacific clinicians have met with initial difficulties, although these were finally resolved (see next section).

It has been suggested by our Pacific researcher that the reason for the difficulties in recruitment and low participation rate is the unfamiliarity with the concept of outcome measurement among Pacific peoples. The idea of routine outcome assessment is fairly new in the Child and Adolescent Mental Health Services and it may be that many Pacific clinicians, young consumers and their families have limited experience of the process. Many Pacific consumers might have not been asked to complete a written measure before and those who had may not have been given adequate information about it resulting in further confusion. Consumers may have been
unwilling to participate in the study due to their suspicions about the purpose of the study and feeling unable to enter an informed discussion about it. This was a factor with the Pacific clinicians (see below) but we were able to overcome the difficulties and achieve a reasonable feedback from this group.

7.2 Survey – results from Pacific clinicians

A preliminary demographic analysis of the survey identified a lack of responses from Pacific Islands CAMHS clinicians. Consultation took place with Ettie Pasene-Mizziebo to investigate ways in which feedback from Pacific clinicians could be facilitated. Personal visits to Auckland CAMHS services have facilitated an increase in the survey response rate by Pacific mental health workers. Of the 105 clinicians who took part in the survey, eight (7.6% of the overall sample) identified themselves as belonging to one Pacific Ethnic group.

Three of the Pacific clinicians were trained as psychologists, two were counsellors, two worked in cultural support role, one was a nurse, and one was involved in art/music therapy (participants were able to choose as many categories as applied). All were from CAMHS outpatient units in the Northern region. Two Pacific clinicians had over 5 years of experience, two have worked between 2 and 5 years and three had worked less than 2 years, and one had CAMH Services. Three held certificates/diplomas, three had bachelor degrees, two held postgraduate diplomas, and one held a Masters degrees.

The numbers of Pacific clinicians in the sample was too small to undertake a separate analysis of responses from Pacific clinicians and therefore only the major findings are presented here:

- The majority (6) believed that routine outcome measurement was important, one believed it was unimportant and one was unsure;
- Four believed that outcome assessment would be practical, three were neutral, and one was unsure;
- The majority (7) supported the introduction of routine outcome measurement to CAMHS (one was unsure);
- All had heard of HoNOSCA before, two were familiar with SDQ, and
- Six had used HoNOSCA before, two have had used SDQ.

7.3 Results from Pacific interview

Please note: as previously noted on page 91 despite many attempts by the research team to recruit Pacific Island consumers for the study, we were only successful in recruiting one young person. Consequently, to protect the anonymity and confidentiality of the young person who participated in the interview, we report the themes only and have removed the verbatim quotes.

The analysis below pertains to one young person only. As such, it should not be viewed as representing the views of other Pacific Island young people in the service. Further consultation with other young Pacific Island consumers are required to establish, whether in fact, the themes below are representative of other Pacific young people who use the Child and Adolescent Mental Health Services.

7.3.1 Need for cultural appropriateness in outcome measurement

A need for cultural appropriateness in outcome measurement was highlighted as an important issue. Forms and the process in which they are completed need to take into the client’s cultural identity. Clinicians working with young people of Pacific ethnicity should have a cultural
awareness and be sensitive to the needs. Culturally relevant questions may need to be incorporated into outcome assessment.

### 7.3.2 Difficultly in talking about mental health

One of the themes that emerged during the focus groups with young people attending mainstream CAMHS services concerned some people’s preference to write things down instead of discussing verbally their mental health and care with the clinician. This issue came up during the interview with the young Pacific person who told us that it may be easier for some Pacific young people to answer written questionnaires than talk. This may be particularly true if the young person does not fully trust their clinician or when there may be a cultural mismatch or clash of values.

Stigma around mental illness may stop young Pacific people from discussing their mental health problems or needs because of the stigma associated. For some Pacific young people talking about mental health issues may bring about feelings of embarrassment or apprehension. Young people may fear being judged or misunderstood when talking about their mental health or wellbeing. Communicating difficult issues through a written measure may be more acceptable to some.

Another related issue concerned modesty among Pacific peoples. Some of the questions on the CBCL were seen as particularly difficult to answer because they inquired about personal attributes, which may be difficult to acknowledge for some.

On the other hand, it is possible that some young Pacific people may exaggerate instead of addressing more private and personal issues that are more difficult to acknowledge or talk about. Clinicians administering measures to young Pacific people should be aware of such cultural differences.

### 7.3.3 Relevant informants for Pacific young people

As previously discussed, young people wanted a relevant informant to complete the measure. This may be particularly true for the Pacific people as in many Pacific cultures children and young people are parented by their extended family. Therefore, a measure may need to be completed by another family member, instead of the parent.

### 7.3.4 Language and translation

The issue of limited English language ability for some Pacific people was raised. There may be a need to have the forms translated to Pacific languages for some families and furthermore, some older people may not be able to read and would require an interpreter.

### 7.4 Recommendation for a way forward

After discussions with our Pacific co-investigator who has reviewed the Pacific clinicians’ results and the feedback from the consumer, we recommend that outcome measurement is introduced for routine use with Pacific children and young people. However, future consultation should take place with Pacific people regarding the acceptability of outcome measurement. Ideally this should be driven by a Pacific organisation of mental health workers and researchers. It is more likely to be successful if the initiative is steered by Pacific people who would educate, communicate with and disseminate the findings to Pacific people.
The feedback from the consumers and clinicians suggests that routine collection of outcome measurement is an acceptable process to Pacific mental health consumers and workers. Useful information can be gained to benefit the clients’ well-being and the effectiveness of services for Pacific young people can be better monitored. English as a second language has been identified as an issue, which may prohibit use of outcome tools among some family members. There is anecdotal evidence that some families rely on the young person’s interpretation and explanation of what is being completed. Translation of the measures into Pacific languages may be required.

It is proposed that the issue of acceptability and meaningfulness of individual measures is revisited in approximately two years time when there is a better understanding and knowledge of the measurement system among the Pacific community. More valuable feedback can be gained then and the process can be evaluated fully and adjusted if necessary.

Training needs of Pacific clinicians should also be addressed to ensure that measures are correctly completed, scored and interpreted for the client and his/her family.
Section 8: Drug and Alcohol Measures

8.1 Consultation over drug and alcohol measures

We consulted with Dr Gail Robinson, Principal Investigator of the MHRDS study on outcome measurement in alcohol and drug abuse services. Due to a lengthy ethics process their study is in its early stages so that we have been unable to compare our findings with theirs. We have ensured that we have considered all measures they have identified as possible outcome measures. We have also consulted with Dr Grant Christie, senior trainee in child and adolescent psychiatry who has a special interest in this area and who has just completed a research project using one of the outcome tools we have considered for implementation. We asked respondents in the clinician survey if they knew about and/or used any outcome measures used in young people with problem substance use, including drug and alcohol. Following that, we asked them to comment about their advantages and disadvantages when used to assess outcomes in young people.

8.2 Survey – results regarding drug and alcohol measures

Fifteen clinicians (14.3%) responded to the questions asking about use of drug and alcohol measures. Please see section 3.1 for a description of the measures referred to here.

Figure 36: Knowledge and use of drug and alcohol measures.
(Note: Eight other measures were cited, however, none was cited more than once. HoNOSCA was cited as a drug and alcohol measure by 3 participants.)

Because of the small numbers of respondents to this section of the report, it was not possible to provide a detailed analysis of the responses to questions pertaining to the advantages and disadvantages of each measure.
Overall, AUDIT and DAST were seen as quick and simple measures, which may be useful in identifying and quantifying drug and alcohol use problems. It was, however, criticised for being unsuitable for use with young people and only covering alcohol dependency. DUSI was deemed useful in quantifying and tracking drug and alcohol-related outcomes and having sound psychometrics. However, it was criticised for being too long.
Section 9: Summary and recommendations

9.1 Summary

Routine outcome measurement will be established in order to measure the effectiveness of child and youth mental health services in a coordinated way across the country. This study was conducted to collect information on the use and acceptability of outcome measures to mental health professionals and to young consumers and their families.

The study had three phases: (1) a clinician survey and telephone interviews of team leaders; (2) focus groups with children and adolescents who had been consumers of mental health services; (3) focus groups with family members. Participants for all phases of the study were collected from across the country and we tried to ensure good representation from Māori and Pacific people, from all clinical disciplines, from NGOs as well as from CAMHS and from young consumers from different developmental stages. We included outcome measures that addressed mental health, alcohol and drug use and abuse and the specific Māori mental health measure Hua Oranga. The aim was to produce recommendations for a practical way forward in the implementation of routine assessment in day-to-day clinical practice in Child and Adolescent Mental Health Services in New Zealand.

Overall there was good support for the use of outcome measures from all the groups we surveyed, including clinicians, young consumers and their parents. There were some caveats. None of the measures was seen as ideal. It is difficult to achieve a balance between measures that capture the overall experience of consumers and yet are short enough for routine use in busy clinical services so that some compromise is inevitable. This was recognised by the people in this study.

The SDQ does not have a self-rated version for children under the age of eleven. The children we spoke to were indignant about this and felt that they should be able to report on their own well-being with a different perspective from their parents. While we agree, when we approached Professor Robert Goodman to discuss the possibility of developing such a measure he reported that this had been attempted in England. While the measure developed was well accepted by the children, unfortunately it was not possible to show that it measured mental health of the children with any degree of accuracy. Therefore it will be necessary to depend on parent reports of mental health for children at this stage.

It is clear that consumers regard the information collated in outcome measurement as sensitive and personal. If collection of accurate information is to be achieved then care is needed over the way in which information is collected, stored and disseminated. Concerns that children and young people may not fill in questionnaires accurately were borne out by young people in our focus groups who reported that they did not fill in questionnaires accurately if they were in a situation where their responses may be seen by someone they did not trust, when they were unsure what was going to happen to the information or where the questionnaire was too long and they became bored, in which case they started to make answers up.

Clinicians were supportive but concerned about the ability to include outcome measurement in services struggling with inadequate clinical and clerical staff and with inadequate IT resources. They were also concerned that measures may be used to monitor individual performance in a punitive way. The recommendations below are made with these concerns in mind.
9.2 Recommendations

9.2.1 Based on the feedback we have had, we recommend the introduction of the HoNOSCA and the parent and adolescent versions of the SDQ as routine outcome measures in Child and Adolescent Mental Health Services. Although they have limitations we believe they are the best of the instruments available and have the endorsement of all the groups we interviewed. These may be supplemented by measures that are specific to particular situations such as the Conner’s rating scales for children and adolescents with attention deficit hyperactivity disorder.

9.2.2 As neither the HoNOSCA nor the SDQ has been validated for use in the New Zealand population consideration should be given to carrying out this work and in particular ensuring that both retain their psychometric properties with all groups in New Zealand including Māori (tangata whenua) and ethnic minority groups.

9.2.3 We did not find a short valid outcome measure suitable for assessment of drug and alcohol use with young people. Short measures have been established for adults, and the validated scales for young people are too long for routine use. We recommend that this issue be revisited once the review of measures for use in the adult services is complete. Consideration should then be given to adapting and validating the adult measure, or developing a measure “from scratch”.

9.2.4 A detailed explanation of the measures, their uses and information about access to results should be given to young consumers and their families prior to their administration. Information should also be available in writing.

9.2.5 The SDQ should be administered within the context of a therapeutic relationship. It should not be handed to the young consumers and their families before they have seen a clinician.

9.2.6 The setting provided for the completion of questionnaires should be chosen with care to ensure privacy and support for young consumers and families. Because of the sensitive nature of the information, we recommend that questionnaires be administered within the clinical service and not sent to the young consumer’s home.

9.2.7 The results of outcome measures, completed both by young consumers and their families, and by clinicians, should be discussed with the children and young people accessing services and their families. Particular care should be taken with results that show that the child or young person is facing a great deal of difficulty, as these results are likely to be demoralising. Putting results in context, indicating that other children or young people may have comparable levels of difficulty and still improve, and providing hope for change and recovery may help to reduce the negative impact of scores indicating high levels of distress or difficulty.

9.2.8 Although it is reasonable for parents to have access to the overall results of tests, individual questions are considered very personal by children and young people and individual responses to questions should not be available to parents without the child’s or young person’s permission. Parental access to information should be clarified for young consumers.

9.2.9 Likewise, young consumers should have access to the overall results of clinician and parent ratings, again without access to detail that may be distressing or unduly personal.
9.2.10 Questionnaires should not be onerous. Based on the feedback from this project we recommend that clinician ratings be as brief as possible, those for children be limited to 5-10 minutes, those for adolescents be limited to 10-15 minutes and those for adults be limited to 30 minutes. The HoNOSCA and SDQ would fall into these time limits.

9.2.11 While Māori and Pacific people, both clinicians and consumers, did not raise any objections to the introduction of HoNOSCA or SDQ the feedback we had from these communities was not as extensive as we would have liked. In particular, we had a great deal of difficulty recruiting Pacific consumers. Therefore, although we recommend the introduction of the outcome measures in these communities, we also recommend that the situation be reviewed after two years, when clinicians and consumers have had more experience with the measures. In particular attention should be paid to the issues of cultural awareness in the administration and interpretation of measures and the cultural sensitivity of measures used. At this stage the status of Hua Oranga for tamariki and taitamariki should also be reviewed to see if it should be incorporated for Māori services. Following feedback we also recommend consideration be given to recommendations for oral presentation and feedback of outcome measurement with Māori consumers (tamariki, taitamariki and whānau).

9.2.12 The collection of ethnicity data should be improved.

9.2.13 We recommend that IT systems be upgraded where necessary in order to provide a user friendly interface to facilitate data entry and provide immediate feedback of results for clinicians in a form that will be useful for clinical work. It is likely that most services will need a substantial upgrade in the number of computers available and staff needed to support the technology.

9.2.14 The clerical and clinical capacity of services should be reviewed to ensure that they are adequate to cope with the increase in workload that routine outcome measurement will entail.

9.2.15 Clinicians should be trained in the use of HoNOSCA and in the characteristics and uses of the SDQ. The training should include recommendations on the best way to administer the self-rated questionnaires and present results to young consumers and their families.

9.2.16 The scope, purpose and processes around the use of outcome measures should be explicit and transparent. These should be set out in documentation prior to their introduction. As part of that process, clinicians should be reassured that outcome measures will not be used to monitor individual performance but will rather be used in assessing and monitoring effectiveness of services overall.
Section 9: Summary and recommendations
Section 10: References


Section 11: Glossary of Māori words

<table>
<thead>
<tr>
<th>Hapū</th>
<th>Subtribe</th>
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<tbody>
<tr>
<td>Hui</td>
<td>Meeting, seminar</td>
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<tr>
<td>Iwi</td>
<td>Tribe</td>
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<tr>
<td>Kāumatua</td>
<td>Elder</td>
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<tr>
<td>Kaupapa</td>
<td>Method, purpose, strategy</td>
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<tr>
<td>Mana</td>
<td>Respect, authority, prestige</td>
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<tr>
<td>Rangatāhi</td>
<td>Māori young people</td>
</tr>
<tr>
<td>Rangatiratanga</td>
<td><strong>Rangatiratanga</strong> is sovereignty, chieftainship or realm; see Tino rangatiratanga</td>
</tr>
<tr>
<td>Te reo</td>
<td>Language; in this context refers to Māori language. ‘Te’ is a singular from of ‘the’</td>
</tr>
<tr>
<td>Taitamariki</td>
<td>Māori young people</td>
</tr>
<tr>
<td>Tamariki</td>
<td>Māori children</td>
</tr>
<tr>
<td>Tangata whenua</td>
<td>‘The people of the land’ – the indigenous people of an area or country</td>
</tr>
<tr>
<td>Tikanga</td>
<td>Customs, customary practices</td>
</tr>
<tr>
<td>Tino rangatiratanga</td>
<td><strong>Tino</strong> is absolute. <strong>Rangatiratanga</strong> is sovereignty, chieftainship or realm; <strong>Tino rangatiratanga</strong> is Māori sovereignty / self-determination / control specifically with reference to the obligations in Article II of te Tiriti o Waitangi (the Treaty of Waitangi)</td>
</tr>
<tr>
<td>Tiratanga</td>
<td>In the example used, it refers to tino rangitanga (see page 88)</td>
</tr>
<tr>
<td>Whānau</td>
<td>Family, including extended family</td>
</tr>
</tbody>
</table>

Note: Māori words may have different meanings and nuances in different contexts. This Glossary has been created specifically for this report, using the M. Ngata English – Māori Dictionary, which is accessible via the website [http://www.learningmedia.co.nz/]. The M. Ngata English – Maori Dictionary uses a system of headwords in English and Maori with sentences to illustrate usage; it uses Ngati Porou dialect in the spelling of words.

The macron – the line over vowels - as in ‘Māori’ - indicates that the vowel is long.
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Appendix A

Clinician Questionnaire and Clinician Information Sheet
Child and Youth Outcome Measures: examining current use and acceptability of measures in mental health services, and recommending future directions.

Participant Information Sheet (Clinician)

We would like to ask you to assist us in a study that aims to address the use and acceptability of child and youth mental health outcome measures in New Zealand. This project is funded by a Health Research Council contract.

WHO IS INVITED TO THE STUDY?

We are inviting approximately 300 clinicians from all parts of the child, youth and family mental health sector to assist us in this study.

WHO IS RUNNING IT?

This study is being carried out by the Centre for Child and Adolescent Mental Health, specifically by the following individuals: Dr Sally Merry, Dr Andrew Parkin and Dr Ian Lambie from the Centre; Assoc. Prof. Fred Seymour from the Department of Psychology; Dr Sue Crengle who is the Head of Discipline, Division of Māori and Pacific Health and Mrs Ettie Pasene-Mizziebo who is a Team Leader and a family therapist at Campbell Lodge. Ms Karolina Stasiak is a Project Co-ordinator supporting this study.

BACKGROUND TO THE STUDY

This study was initiated by the New Zealand Mental Health Research and Development Strategy (MHRDS), which is funded by the Ministry of Health, administered by the Health Research Council and supported by the Mental Health Commission.

Measures of outcome are needed in order to gauge the effectiveness of treatment in the mental health sector. An outcome measure is a measure that could be applied at a point of entry to a service, periodic review, and at discharge from service. Therefore, it should measure change in the areas assessed.

Currently little is known about the outcome of treatment but District Health Boards are expected to start to establish routine outcome measurement in services. The Ministry of Health wishes to establish the optimal measures of outcome by consultation with clinicians and consumers. This study is part of that process.

In Australia a national review of measures (Bickman et al., 1999) and subsequent national meetings has recommended the use of specific measures for all States, that information should be collected from consumers, clinicians and carers, and that other measures may be added for specific groups. These measures will be supported by national protocols for application, and training of staff. The measures selected for routine use are the clinician-rated Health of the Nation Outcomes Scales for Children and Adolescents (HoNOSCA) and the Strengths and Difficulties Questionnaire, which can be parent-, teacher-, and self-rated. The views of New Zealand clinicians and consumers about these measures are therefore being sought.
The aim of this project is to gain information on what measures (if any) are currently used in New Zealand centres; what measures are acceptable to consumers, families and clinicians; what measures are used to assess substance abuse (if any) and what the issues are for Māori and Pacific peoples. The study will have three phases: (1) questionnaire asking clinicians for their views on the issue; (2) face-to-face consultations with child and youth consumers; (3) face-to-face consultations with family members.

WHAT WOULD BE INVOLVED?

Your help is being sought in Phase 1 of the project in which we aim to gather and systematically report the opinions of clinicians in the Child and Adolescent Mental Health Sector and Non Government Organisation on the acceptability, use and meaningfulness of existing outcome measures that might be used routinely in clinical practice. We intend to survey over 300 clinicians from all parts of the child and youth mental health sector. Additionally, clinical coordinators will be invited to participate in a telephone interview. The project aims to produce recommendations for a practical way forward to the implementation of routine assessment using standardised measures in day-to-day clinical practice in New Zealand. You are invited to contribute to this – your thoughts and experience in this area are valued. Please could you assist with this study by spending approximately 15-20 minutes completing this questionnaire.

When completing this questionnaire you can either

a) complete this questionnaire in an electronic form and return it to k.stasiak@auckland.ac.nz. When navigating between the boxes in the survey, it is advised that you use the arrow keys or a mouse; or,

b) complete this questionnaire on your computer, print it out and return it Freepost 175365 to Karolina Stasiak, Division of Psychiatry, Faculty of Medical and Health Sciences, The University of Auckland, Private Bag 92019, Auckland.

Please note that as you type your responses, the provided boxes will expand in size to accommodate the length of your answers.

If you choose the first option, your email address will be separated from your response as soon as we receive it. However, if you want to ensure complete anonymity you may want to choose the second option.

If you are unfamiliar with and wish to look at HoNOSCA and SDQ (you don’t need to if you prefer not to), then your team coordinator should have been sent a copy by us, if not please call us on the number below or you may view then on these websites:

http://www.rcpsych.ac.uk/cru/honoscales/honosca/supplies.htm (pdf file of glossary, score sheet and self-rating assessment)

HOW WILL THE INFORMATION BE USED?

The information you give us will be used to help us produce recommendations on the implementation of routine assessment using standardised measures in day-to-day clinical practice in New Zealand. A finalised report will be sent to the Mental Health Research Development Strategy Steering Committee for publication as MHRDS Report.
YOU DO NOT HAVE TO TAKE PART

This is an invitation to take part but it is completely voluntary. No material, which could personally identify you, will be used in any reports on this study.

ANY QUESTIONS?

We would be delighted to answer any questions or discuss this study with you further. You can talk to any of us:

- Sally – (09) 373 7599 ext 86981
- Ian – (09) 373 7599 ext 85012
- Fred – (09) 373 7599 ext 88414
- Andrew – (09) 373 7599 ext 84619
- Sue – (09) 373 7599 ext 87866
- Ettie – (09) 276 0200

You can also call us toll-free on **0800 OUTCOMES** i.e. **0800 688266**.

If you have any queries or concerns about your rights as a participant in this study, you may wish to contact the Health Advocates Trust:

- Northland to Franklin 0800 555 050
- Mid and lower North Island 0800 423 638 (4 ADNET)
- South Island 0800 377 766

**We invite you to have your say.**

**Thank you for your help!**
### WHAT OUTCOME MEASURES DO YOU OR YOUR AGENCY USE IN CLINICAL PRACTICE?

Please list here outcome measures or other measures such as goal attainment scales, questionnaires etc. that you have had direct experience of, making comments on their strengths and weaknesses as outcome measures (i.e. self- or clinician-rated scales/questionnaires used before and after intervention). Please complete for as many measures as you feel familiar with and wish to comment on. If you wish to comment on more than four, then make copies of this page. Please give your answers in the boxes provided (they will expand to accommodate the length of your answers).

1. **Name of measure:**

<table>
<thead>
<tr>
<th>What experience I have with it (e.g. training, clinical practice):</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>How often I use it and why:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Advantages and strengths – why I would promote its use:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Disadvantages and weaknesses – why I would not wish to see it used:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

2. **Name of measure:**

<table>
<thead>
<tr>
<th>What experience I have with it (e.g. training, clinical practice):</th>
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</thead>
<tbody>
<tr>
<td></td>
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<table>
<thead>
<tr>
<th>How often I use it and why:</th>
</tr>
</thead>
<tbody>
<tr>
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</table>

<table>
<thead>
<tr>
<th>Advantages and strengths – why I would promote its use:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Disadvantages and weaknesses – why I would not wish to see it used:</th>
</tr>
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<tr>
<td></td>
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<tr>
<td>3. Name of measure:</td>
</tr>
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</tbody>
</table>

What experience I have with it (e.g. training, clinical practice):

How often I use it and why:

Advantages and strengths – why I would promote its use:

Disadvantages and weaknesses – why I would not wish to see it used:

<table>
<thead>
<tr>
<th>4. Name of measure:</th>
</tr>
</thead>
<tbody>
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</tbody>
</table>

What experience I have with it (e.g. training, clinical practice):

How often I use it and why:

Advantages and strengths – why I would promote its use:

Disadvantages and weaknesses – why I would not wish to see it used:
OPTIMAL NUMBER OF MEASURES AND COMPLETION TIME

What would you view as the optimal number of outcome measures that could be practically used in your service?

What would you view as the maximum practical time needed to complete a routine outcome measure per case/young person/family?

YOUR RECOMMENDATIONS

Of the outcome measures you know, which (if any) would you recommend for routine use:

a) to be completed by clinicians:

b) to be completed by family:

c) to be completed by child/young person:

d) to be completed by teacher:

e) to be completed by other person, please specify who ____________________:
## YOUR OPINIONS ABOUT INFORMATION MANAGEMENT & TECHNOLOGY

Please think about your experiences of Information Management & Technology (IM&T) where you work and put an X underneath your selected response to indicate your opinion on the following statements:

### Our current IM&T systems would be able to manage the routine collection of outcome data

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Somewhat agree</th>
<th>Neutral</th>
<th>Somewhat disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Don’t know/Unsure</th>
</tr>
</thead>
<tbody>
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</tbody>
</table>

### We could probably use the current systems with modification

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Somewhat agree</th>
<th>Neutral</th>
<th>Somewhat disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Don’t know/Unsure</th>
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</table>

### We would need completely new data management systems

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Somewhat agree</th>
<th>Neutral</th>
<th>Somewhat disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Don’t know/Unsure</th>
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</tbody>
</table>

### Meaningful ethnicity data is routinely collected

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Somewhat agree</th>
<th>Neutral</th>
<th>Somewhat disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Don’t know/Unsure</th>
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</table>

### The collection of ethnicity data could be improved

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Somewhat agree</th>
<th>Neutral</th>
<th>Somewhat disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Don’t know/Unsure</th>
</tr>
</thead>
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</tbody>
</table>

### Current levels of administrative staffing would be sufficient

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Somewhat agree</th>
<th>Neutral</th>
<th>Somewhat disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Don’t know/Unsure</th>
</tr>
</thead>
<tbody>
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</tr>
</tbody>
</table>
## Current levels of clinical staffing would be sufficient

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Somewhat agree</th>
<th>Neutral</th>
<th>Somewhat disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Don’t know/Unsure</th>
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</table>

In the place where you work:

### Who decides on the ethnicity of the young person that is recorded?

<table>
<thead>
<tr>
<th>The young person</th>
<th>Parents</th>
<th>Other members of the whānau</th>
<th>Clinicians</th>
<th>Administrative staff</th>
<th>Any of these</th>
<th>No agreement</th>
<th>Don’t know/Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

### Who records the ethnicity of the young person?

<table>
<thead>
<tr>
<th>The young person</th>
<th>Parents</th>
<th>Other members of the whānau</th>
<th>Clinicians</th>
<th>Administrative staff</th>
<th>Any of these</th>
<th>No agreement</th>
<th>Don’t know/Unsure</th>
</tr>
</thead>
<tbody>
<tr>
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</tr>
</tbody>
</table>

### Do you have dependable access to a PC?

<table>
<thead>
<tr>
<th>Whenever I need it</th>
<th>Somewhat limited</th>
<th>Significantly limited</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>

### Have you any further comments on IM&T?

<p>| |</p>
<table>
<thead>
<tr>
<th></th>
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<tr>
<td></td>
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</tbody>
</table>

Appendix A: Clinician Questionnaire and Clinician Information Sheet 115
**YOUR OPINIONS ABOUT THE USE OF OUTCOME MEASURES**

Please put an X underneath your selected response to indicate your opinion on the following statements:

**How important is the use of outcome measures in Child and Adolescent Mental Health Services?**

<table>
<thead>
<tr>
<th>Very important</th>
<th>Important</th>
<th>Somewhat important</th>
<th>Neutral</th>
<th>Somewhat unimportant</th>
<th>Unimportant</th>
<th>Completely unimportant</th>
<th>Don’t know/Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Please state your reason for this:

**Are you concerned about the potential for misuse of outcome measures?**

<table>
<thead>
<tr>
<th>Very concerned</th>
<th>Concerned</th>
<th>Somewhat concerned</th>
<th>Neutral</th>
<th>Somewhat unconcerned</th>
<th>Unconcerned</th>
<th>Completely unconcerned</th>
<th>Don’t know/Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

Please state your reason for this:

**As a clinician, how practical would you find routine use of outcome measures?**

<table>
<thead>
<tr>
<th>Very practical</th>
<th>Practical</th>
<th>Somewhat practical</th>
<th>Neutral</th>
<th>Somewhat impractical</th>
<th>Impractical</th>
<th>Completely impractical</th>
<th>Don’t know/Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Please state your reason for this:

**Do you anticipate problems with the introduction and implementation of routine use of outcome measures?**

<table>
<thead>
<tr>
<th>Yes – major problems</th>
<th>Yes – some problems</th>
<th>Yes – minor problems</th>
<th>No, I don’t expect any problems</th>
<th>Don’t know/Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>

What problems do you anticipate and why?
Do you support routine use of outcome measures?

<table>
<thead>
<tr>
<th>Fully support it</th>
<th>Support it</th>
<th>Somewhat support it</th>
<th>Neutral</th>
<th>Somewhat oppose it</th>
<th>Oppose it</th>
<th>Completely oppose it</th>
<th>Don’t know/Unsure</th>
</tr>
</thead>
</table>

Please state your reason for this:

FURTHER COMMENTS

If you have any further comments, please make them here:

OUTCOME MEASURES OF DRUG AND ALCOHOL USE

Do you know of any outcome measures that are used in young people with problem substance use, including drug and alcohol? If so, please list them here (unless you have commented on them above):

Have you used any outcome measures that are used in young people with problem substance use? If so, please list them here:

What experience I have with it (e.g. training, clinical practice):

How often I use it and why:

Advantages and strengths – why I would promote its use:

Disadvantages and weaknesses – why I would not wish to see it used:
ABOUT YOU

Please put an X in the box under your selection

This section is again voluntary and is only intended to give us better information about the people who work in CAMHS and NGOs.

Please indicate your professional training (please put an X underneath the responses you select and choose as many as apply):

<table>
<thead>
<tr>
<th>Art / drama / music therapy</th>
<th>Counselling</th>
<th>Nursing</th>
<th>Occupational therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Psychiatry</th>
<th>Psychology</th>
<th>Psychotherapy</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Please specify:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Please specify:</td>
<td></td>
</tr>
</tbody>
</table>

What is your current place of work – agency where you work most of the time:

<table>
<thead>
<tr>
<th>CAMHS Outpatient / Community</th>
<th>Child or adolescent day / Inpatient</th>
<th>NGO</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>

What region is your current workplace in? Chose the main one if you work in more than one.

<table>
<thead>
<tr>
<th>Northern Region</th>
<th>Midland Region</th>
<th>Central Region</th>
<th>Southern Region</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

What is your length of experience in child, adolescent and family mental health?

<table>
<thead>
<tr>
<th>Less than 6 months</th>
<th>6 months to 1 year</th>
<th>1 to 2 years</th>
<th>2 to 5 years</th>
<th>5 to 10 years</th>
<th>More than 10 years</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

How do you describe your ethnicity? (Choose as many as apply)

<table>
<thead>
<tr>
<th>New Zealand European</th>
<th>Māori</th>
<th>Samoan</th>
<th>Cook Island Māori</th>
<th>Tongan</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Niuean</th>
<th>Chinese</th>
<th>Indian</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Please specify:</th>
</tr>
</thead>
</table>
Please indicate your age:  

Your gender:  
<table>
<thead>
<tr>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
</table>

Please indicate your highest qualification:  

<table>
<thead>
<tr>
<th>Undergraduate</th>
<th>Postgraduate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Certificate</td>
<td>Postgraduate Certificate/Diploma</td>
</tr>
<tr>
<td>Diploma</td>
<td>Masters</td>
</tr>
<tr>
<td>Bachelor degree</td>
<td>Professional Membership / Fellowship</td>
</tr>
<tr>
<td></td>
<td>PhD</td>
</tr>
</tbody>
</table>
The remaining section of this questionnaire is asking for your opinion and experience with the Health of the Nation Outcome Scale for Children and Adolescents (HoNOSCA) and Strengths and Difficulties Questionnaire (SDQ). If time permits, please complete it if you have heard or used those outcome measures in the past.

**About your use of outcome measures in clinical practice**

Have you heard of any of these measures before? (Please put X for yes or no to each)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>HoNOSCA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SDQ</td>
<td></td>
<td></td>
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</tbody>
</table>

Have you used any of these measures? (Please put X for yes or no to each)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>HoNOSCA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SDQ</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Have you had training in the use of these measures? (Please put X for yes or no to each)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>HoNOSCA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SDQ</td>
<td></td>
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</tbody>
</table>

Please write any comments on the training issues:

---

**SPECIFIC ISSUES**

There are specific issues relating to the HoNOSCA and SDQ that we would like to know more about. We would like to know the strength of your opinion about the following statements.

Please put an X for each of your responses:

*The HoNOSCA is a measure of outcome that is practical to use.*

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Somewhat agree</th>
<th>Neutral</th>
<th>Somewhat disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Unsure/don’t know</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

Comment if you wish:
The HoNOSCA is a measure of outcome that is meaningful.

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Somewhat agree</th>
<th>Neutral</th>
<th>Somewhat disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Unsure/don’t know</th>
</tr>
</thead>
</table>

Comment if you wish:

The HoNOSCA is a measure of outcome that is possible to use across most cultures.

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Somewhat agree</th>
<th>Neutral</th>
<th>Somewhat disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Unsure/don’t know</th>
</tr>
</thead>
</table>

Comment if you wish:

The HoNOSCA is a measure of outcome that is meaningful for use in Māori and Pacific Island young people and families.

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Somewhat agree</th>
<th>Neutral</th>
<th>Somewhat disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Unsure/don’t know</th>
</tr>
</thead>
</table>

Comment if you wish:

The HoNOSCA is a measure of outcome that is acceptable for use in Māori and Pacific Island young people and families.

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Somewhat agree</th>
<th>Neutral</th>
<th>Somewhat disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Unsure/don’t know</th>
</tr>
</thead>
</table>

Comment if you wish:

The HoNOSCA is a measure of outcome that is acceptable to me as a clinician.

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Somewhat agree</th>
<th>Neutral</th>
<th>Somewhat disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Unsure/don’t know</th>
</tr>
</thead>
</table>

Comment if you wish:
**The HoNOSCA is a measure of outcome that is acceptable to my colleagues.**

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Somewhat agree</th>
<th>Neutral</th>
<th>Somewhat disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Unsure/don’t know</th>
</tr>
</thead>
</table>

Comment if you wish:

**The HoNOSCA is a measure of outcome that is acceptable to young people and their family/whānau.**

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Somewhat agree</th>
<th>Neutral</th>
<th>Somewhat disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Unsure/don’t know</th>
</tr>
</thead>
</table>

Comment if you wish:

**SDQ**

**The SDQ is a measure of outcome that is practical to use.**

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Somewhat agree</th>
<th>Neutral</th>
<th>Somewhat disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Unsure/don’t know</th>
</tr>
</thead>
</table>

Comment if you wish:

**The SDQ is a measure of outcome that is meaningful.**

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Somewhat agree</th>
<th>Neutral</th>
<th>Somewhat disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Unsure/don’t know</th>
</tr>
</thead>
</table>

Comment if you wish:

**The SDQ is a measure of outcome that is possible to use across most cultures.**

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Somewhat agree</th>
<th>Neutral</th>
<th>Somewhat disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Unsure/don’t know</th>
</tr>
</thead>
</table>

Comment if you wish:
The SDQ is a measure of outcome that is meaningful for use in Māori and Pacific Island young people and families.

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Somewhat agree</th>
<th>Neutral</th>
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Comment if you wish:

The SDQ is a measure of outcome that is acceptable for use in Māori and Pacific Island young people and families.

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<th>Strongly disagree</th>
<th>Unsure/ don’t know</th>
</tr>
</thead>
</table>

Comment if you wish:

The SDQ is a measure of outcome that is acceptable to me as a clinician.

<table>
<thead>
<tr>
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</table>

Comment if you wish:

The SDQ is a measure of outcome that is acceptable to my colleagues.

<table>
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Comment if you wish:

The SDQ is a measure of outcome that is acceptable to young people and their family/whānau.

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</table>

Comment if you wish:
THE USEFULNESS OF THESE OUTCOME MEASURES

Strengths and weaknesses of these measures

Please consider how useful you believe these measures to be in clinical practice and use the following questions to report your thoughts on this. (For instance, please consider issues such as culture, clinical assessment of global functioning, and assessment of specific problem areas).

Only complete this if you did not comment about this in the previous section.

**HoNOSCA:**

What experience I have with it (e.g. training, clinical practice):

How often I use it and why:

Advantages and strengths - why I would promote its use:

Disadvantages and weaknesses - why I would not wish to see it used:

**SDQ:**

What experience I have with it (e.g. training, clinical practice):

How often I use it and why:

Advantages and strengths – why I would promote its use:

Disadvantages and weaknesses – why I would not wish to see it used:
ADDITIONAL COMMENTS ON HoNOSCA AND SDQ:

Please return this questionnaire by either:
1. emailing it to k.stasiak@auckland.ac.nz
2. or, printing it out and returning it Freepost 175365 to Karolina Stasiak, Division of Psychiatry, Faculty of Medical and Health Sciences, The University of Auckland, Private Bag 92019, Auckland.

THANK YOU FOR TAKING THE TIME TO HELP!
Telephone Interview Proforma
Name of TL:
If other role: specify:
Location:
Survey number:
Time of interview:
Duration:

With reference to responses about outcome measures.
IF NO MEASURES ARE USED/RECOMMENDED:
Are you aware of any measures being used in your service/team? If so which ones?

How often?

MEASURES USED: For each one clarify any comments about experience:
In clinical practice
In research
Age range of young people used it with
Nature of setting in which used:
  CAMHS, inpatient, etc
  Particular disorders or general use
Nature of training received:
  From whom, when?
  Was the training received sufficient to then use / score up / interpret the measure?
Direct experience of the measure:
  Over what time period have they used it?
  Frequency of use during this time
Experience of use with different ethnic groups:
  With which ethnic groups have you used this measure?
  How much experience have you had in using this measure with each of the different groups you listed?
    (e.g. none / once or twice / a few times / frequently)
  Was it an appropriate instrument to use?
    Why / why not?
  What value did it have in measuring outcome in each of the ethnic groups with which you have used it?

Clarify reasons for advantages or promoting its use / disadvantages would not want to see it used
Can you explain further?
What did you mean by …?
How did you arrive at the final list of recommended outcome measures?
[If this isn’t already obvious from previous responses]

With reference to the optimum number and time needed
How did you arrive at:
  a) the optimum number of outcome measures, and
  b) Maximum practical time needed to complete?
With reference to your opinions about information management and technology

*To further clarify responses, ask:*
Can you explain further?
What did you mean by …?

**Current systems able to manage:**

**Modification needed:**

**New data management system needed:**

**Ethnicity data is collected:**

**The collection of ethnicity data could be improved:**

**Current levels of admin staff would be sufficient:**

**Current levels of clinical staff would be sufficient:**

**ANY FURTHER COMMENTS ON IM&T:**

With reference to specific questions on use of outcome measures:

*Clarify reason for response to each as listed in questionnaire, i.e.:*

  **Importance of outcome measures:**

  **Concern about use of outcome measures:**

  **How practical:**

  **Anticipate problems – why and what kind:**

  **Your support of use of routine measures:**

With respect to the HoNOSCA and SDQ questions

*To further clarify responses, ask:*

Can you explain further?
What did you mean by …?

Specifically ask about experience of use with different ethnic groups:

  **With which ethnic groups have you used this measure?**

  How much experience have you had in using this measure with each of the different
groups you listed?
  (e.g. none / once or twice / a few times / frequently)

  **Was it an appropriate instrument to use?**

  **Why / why not?**

  **What value did it have in measuring outcome in each of the ethnic groups with which
you have used it?**
* With respect to the HoNOSCA & SDQ forced-response questions

To further clarify responses, ask:
Can you explain further?
What did you mean by …?

Questions on staff training
What training will staff in your service need to administer these outcome measures?
   Administrative staff
   Clinical staff

What proportion of staff is trained in use of these measures?

Are there any barriers to staff training?

If so, please specify.

Questions on management / strategic issues
Are there any changes that will need to take place within your service’s management structure or the wider structure of your organisation to facilitate the collection and collation of data?

If so, please could you specify?
Participant Information Sheets
Information Sheet (Child)

We would like to invite you to take part in a study.

WHO IS INVITED TO TAKE PART IN THE STUDY?

We are asking about 10 children who have been to (name of service) to help us with this study.

WHAT IS THE STUDY?

Sometimes kids or their parents are asked to fill in forms about themselves. We want to know what you think about those forms.

WHAT WOULD BE INVOLVED?

We want to talk to you and a few other children to find out what you think about forms. Then we will show you some of those forms and ask you to have a go at filling them in (we won’t look at the results). We want to know if they are easy and helpful.

We want to tape what you say so that we can really understand what you think. It will take about 45 minutes.

HOW WILL THE INFORMATION BE USED?

What you tell us will help us decide which forms might be used in New Zealand services like (name of child’s service).

All the information you give us is confidential (secret) and we will not tell people what you have told us.

YOU DO NOT HAVE TO TAKE PART!

It is your decision whether you take part. Your doctor or therapist will not mind if you decide not to. You will get care whether or not you take part. You can also stop being in the
study at any time you want. If you do not want to answer any of
the questions during the discussion that is also fine.

This study has been approved by the Auckland Ethics Committee.

**WHO IS RUNNING THE STUDY?**

- Sally – (09) 373 7599 ext 86981
- Ian – (09) 373 7599 ext 85012
- Fred – (09) 373 7599 ext 88414
- Andrew – (09) 373 77999 ext 84619
- Sue – (09) 373 7599 ext 87866
- Ettie – (09) 276 0200
- Karolina – (09) 373 7599 ext 83890

**ANY QUESTIONS?**

We would be happy to answer any questions or discuss this study
with you further. We have an 0800 number, which you can call for
free: 0800 OUTCOMES

If you have any worries or questions about your rights you can
contact a helper (the Health and Disability Advocate):

- Northland to Franklin 0800 555 050
- Mid and lower North Island 0800 423 638 (4 ADNET)
- South Island 0800 377 766

Thank you for thinking about taking part in this study. One of us
will contact you in the next few days to see if you would like to take
part and tell you when and where we will meet.
Information Sheet (Adolescent)

We would like to invite you to take part in a study.

WHO IS INVITED TO TAKE PART IN THE STUDY?

We are asking about 6-12 young people who have been to (name of service) to help us with this study.

WHAT IS THE STUDY?

Sometimes young people or their parents are asked to fill in questionnaires about themselves. We want to get your point of view about questionnaires that are used in New Zealand.

WHAT WOULD BE INVOLVED?

We want to talk to you and a few other young people to find what you think about questionnaires. Then we will show you some of those forms and ask you to have a go at filling them in (we won’t look at the results). We want to know if they are easy, helpful and whether you like them or not.

We want to tape what you say so that we can study your answers. We will also summarise things for you so that you can what we have discovered.

The meeting will take up to one hour.

HOW WILL THE INFORMATION BE USED?

What you tell us will help us decide which questionnaire might be used in New Zealand services like (name of service).

All the information you give us is confidential (secret) and we will not tell people what you have told us.

YOU DO NOT HAVE TO TAKE PART!

It is your decision whether you take part. Your doctor or therapist will not mind if you decide not to. You will get care whether or not you take part. You can also stop being in the study at any time you want. If you do not want to answer any of the questions during the discussion that is also fine.

This study has been approved by the Auckland Ethics Committee.
WHO IS RUNNING IT?

Sally – (09) 373 7599 ext 86981
Ian – (09) 373 7599 ext 85012
Fred – (09) 373 7599 ext 88414
Andrew – (09) 373 7599 ext 84619
Sue – (09) 373 7599 ext 87866
Ettie – (09) 276 0200
Karolina – (09) 373 7599 ext 83890

ANY QUESTIONS?

We would be happy to answer any questions or discuss this study with you further. You can talk to any of us. We have an 0800 number, which you can call for free if you wish: 0800 OUTCOMES i.e. 0800 688266.

If you have any worries or questions about your rights you can contact a helper (the Health and Disability Advocate) on 0800 555 050.

Thank you for thinking about taking part in this study. One of us will contact you in the next few days to see if you would like to take part and tell you when and where we will meet.
Child and Youth Outcome Measures: examining current use and acceptability of measures in mental health services, and recommending future directions.

Parent Information Sheet

We would like to invite you to take part in a study.

WHO IS INVITED TO TAKE PART IN THE STUDY?

We are inviting approximately 30 family/whanau members whose children have previous experience of child and youth mental health services to help us with this study.

WHAT IS THE STUDY?

Clinicians need to use standardised questionnaires, called outcome measures to assess the effectiveness of child and youth mental health services across New Zealand. We are seeking your opinions on what you think are acceptable and meaningful outcome measures in mental health services.

WHO IS RUNNING IT?

There are several people involved in the running of the study. Dr Sally Merry and Dr Andrew Parkin are child and adolescent psychiatrists, Dr Fred Seymour and Dr Ian Lambie are psychologists; Dr Sue Crengle is a doctor at the Department of Māori and Pacific Health and Mrs. Ettie Pasene-Mizziebo is a therapist from South Auckland. Ms Karolina Stasiak is a project manager who is helping us in the project.

WHAT WOULD BE INVOLVED?

We would like to invite you to a focus group discussion to find out what you think about outcome measures in child and youth mental health services. The interview will follow a semi-structured format to ensure that we cover particular areas. During the discussion we would like to ask you to tell us about your experience, knowledge and satisfaction with outcome measures used in the services that you have accessed. We will also present you with several questionnaires reviewed for this project and ask you for your feedback on their meaningfulness, practical use, and acceptability. Finally, we would like to find out whether you have any concerns about the use of questionnaires in child and youth mental health services and how this could be overcome.

The discussion will be run by two trained interviewers and it will be audio-taped so that we can later type it up and analyse it.

We expect that the session will last approximately one hour.
HOW WILL THE INFORMATION BE USED?

The information you give us will be used to help decide which outcome measures might be used throughout New Zealand to assess the effectiveness of child and youth mental health services.

The discussion will be typed and we will study your answers. We will make recommendations on your behalf to the providers of health care about the findings so that they can choose the best outcome measures for use.

We will also summarise the key findings for you. When writing up studies like this, quotes from the interview are often used. This is done with great care so that individuals cannot be identified.

As with all the studies, all the information you give us is confidential and only the research team will have access to it. Consent forms and tapes will be stored in locked cabinets. We will not put your names on the tapes but will use identification numbers instead. We will refer to people who took part in the study only in very general terms such as age, gender.

YOU DO NOT HAVE TO TAKE PART!

This is an invitation to take part in the study but it is completely voluntary (your choice). Your doctors and key worker will not mind if you decide not to take part. You will receive further care whether or not you take part. You can also withdraw from the study at any time you want. If you do not want to answer any of the questions during the discussion that is also fine.

This study has been approved by the Auckland Ethics Committee.

ANY QUESTIONS?

We would be delighted to answer any questions or discuss this study with you further. You can talk to any of us:

Sally – (09) 373 7599 ext 86981
Ian – (09) 373 7599 ext 85012
Fred – (09) 373 7599 ext 88414
Andrew – (09) 373 7599 ext 84619
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You can also call us on a free 0800 number: 0800 OUTCOMES.
If you have any queries or concerns about your rights as a participant in this study, you may wish to contact a Health and Disability Advocate:

- Northland to Franklin     0800 555 050
- Mid and lower North Island 0800 423 638 (4 ADNET)
- South Island             0800 377 766

Thank you for thinking about taking part in this study, one of us will contact you in the next few days to see if you are interested in participating and to give you details about when the meeting would take place.