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Contents

EXECUTIVE SUMMARY	1
1 INTRODUCTION	3
1.1 Context	3
1.2 The Consumer Outcome Measures	4
1.3 Consumer Consultation Project	7
2 FINDINGS FROM PREVIOUS WORK	9
2.1 Outcomes for consumers are about more than relief from symptoms	11
2.2 Consumers want the link between health outcome and service quality to be recognised in self-assessment measures	14
2.3 Consumers rate their outcomes differently from clinicians	15
2.4 No single measure is universally accepted as the best measure	15
2.5 The process of measurement is as important as the outcome measure	17
2.6 Comprehensiveness needs to be balanced by brevity	18
3 METHODOLOGY	19
3.1 Sample	19
3.2 Information workshops	20
3.3 Focus groups	21
4 FINDINGS FROM FOCUS GROUPS	23
4.1 Consumers' views about the domains to be captured in a self-rating instrument	24
4.2 Consumers' views on the suitability of the BASIS-32	30
4.3 Consumer views on the process of consumer self-assessment	33
5 DISCUSSION AND RECOMMENDATIONS	38
5.1 The content domains for consumer self-assessment	38
5.2 The inclusion of consumers' perceptions of service quality in outcome assessment	41
5.3 The suitability of the BASIS-32	43
5.4 Consumer ownership	44
5.5 Steps towards development of a new instrument	44
5.6 Victorian or national instrument?	46
5.7 Promoting 'good practice' in routine outcome assessment	47
5.8 Recommendations	47

APPENDIX 1 - BASIS-32	50
APPENDIX 2 – LETTER OF INVITATION TO CONSUMERS TO ATTEND FOCUS GROUPS	52
APPENDIX 3 - LETTER OF INVITATION TO CONSUMERS TO ATTEND INFORMATION WORKSHOPS	54
APPENDIX 4 - FOCUS GROUPS QUESTIONS	57
APPENDIX 5 - OHIO MENTAL HEALTH CONSUMER OUTCOMES SYSTEM ADULT CONSUMER FORM A	59

EXECUTIVE SUMMARY

This report presents the results and recommendations of consultations with mental health consumers about the introduction of measures designed to regularly assess their health outcomes. Consultations focused on gathering information from consumers about their opinions on the range of areas that should be covered in a self-rating instrument and the process of outcome measurement more generally. Consumers were also asked to evaluate the suitability of the BASIS-32, the interim consumer self-rating instrument being introduced for routine use in Victoria.

Several conclusions are outlined in the report that flow directly from our consultations.

First, consumers support the introduction of routine outcome assessments and see the process as having potential to contribute to the treatment they receive. Reservations expressed by consumers concern the suitability of the current measure (BASIS-32) to meet their needs and the capacity of mental health services to engage in 'good process'.

Second, consumers articulate a broad range of content areas that they believe are essential to an understanding of their personal outcomes. These include 'Quality of Life'; Functioning; Physical Health and Health Risks; Relationships; Illness Symptoms; Coping and Recovering from Illness; and Satisfaction with Service Quality. Consumers gave the BASIS-32 a mixed report when evaluated against these areas. On the positive side, the instrument is seen to be relevant in its content and brief to complete. Its failings were identified as lack of coverage of key content areas, its exclusive focus on difficulties, the inclusion of several items regarded as invasive or insensitive, the ambiguity of several items and inadequate instructions about the purpose of the instrument. From the consumers' perspective, it is not a suitable instrument to retain in an unmodified form for the long-term.

Third, consumers are concerned about many aspects of the process of outcome measurement that are not addressed simply through choosing the 'right' instrument. Key process issues from the consumers' perspective include how the consumer is approached for information, how outcome measurement is used to strengthen therapeutic dialogue and the use of consumer ratings in treatment planning.

Finally, consumers are seeking a different approach to implementation of consumer self-ratings than has been the case to date. In particular, they want to see strong consumer involvement at all stages,

commencing with the design of a new instrument that reflects their views.

The report makes five recommendations for future action.

1. That Victoria initiate the development of a new consumer self-rating instrument which:
 - ▶ builds on the strengths of the BASIS-32 and other available instruments;
 - ▶ covers domains considered of relevance to consumers including 'Quality of Life'; Functioning; Physical Health and Health Risks; Relationships; Illness Symptoms; Coping and Recovering from Illness; and Satisfaction with Service Quality; and
 - ▶ is designed to be 'consumer friendly' in all respects, including its instructions, content, language, and item format.
2. That development of the instrument occur from the outset with maximum participation by consumers and involve other stakeholders and academics with expertise in instrument design.
3. That Victoria negotiate with other jurisdictions and seek funding from the Commonwealth to develop the instrument on a national basis. An indicative budget in the range \$250,000 - \$300,000 will be required.
4. That the BASIS-32 be retained within the standard suite of outcome measures until a new instrument is available.
5. That future training programs and communication about the outcome measurement strategy promote a 'good practice' approach to consumer self-assessment that emphasises the importance of process in building consumer confidence in routine outcome assessment.

1 INTRODUCTION

1.1 Context

Along with other States and Territories, Victoria is introducing a system of outcome measurement designed to regularly monitor changes in the health and well being of the consumers of mental health services. The process commenced in 1996 with the conduct of field trials and was followed by further consultation and planning aimed at establishing both a system and culture to enable consumer outcome measurement to become a routine part of mental health service delivery.

Nationally, the introduction of routine outcome measurement was foreshadowed in the National Mental Health Strategy when it was adopted by all governments in 1992. With the renewal of the Strategy under the Second National Mental Health Plan (1998-2003) funds have been made available to support the initiatives of States and Territories to develop systems for the introduction and use of a nationally agreed, core set of outcome measures. These comprise measures completed by clinicians as well as measures completed by consumers. While Victoria commenced the process earlier than its other state counterparts, it is expected that by 2003, the vast majority of Australia's publicly-funded adult mental health services will be using outcome measures on a regular basis.

The Victorian Mental Health Outcomes Strategy has been articulated in a number of documents¹ and has the following objectives:

- to ensure that the mental health sector undertakes continuous quality improvement;
- to enable consumer health status to be monitored by consumers and clinicians;
- to enable the comparison of services;
- to foster an ethos of routine outcome measurement to provide the basis for the ongoing development of health status and outcome measurement; and
- to better inform clinical decision making through interaction and discussion between the consumer and their clinician.

To assist in the implementation process, the Department engaged the Centre for Health Service Development (CHSD) at the University of

¹ See in particular Aged, Community and Mental Health Division, Department of Human Services. *Health Status and Outcomes in Victoria's Mental Health Services*. Victoria, February 1999.

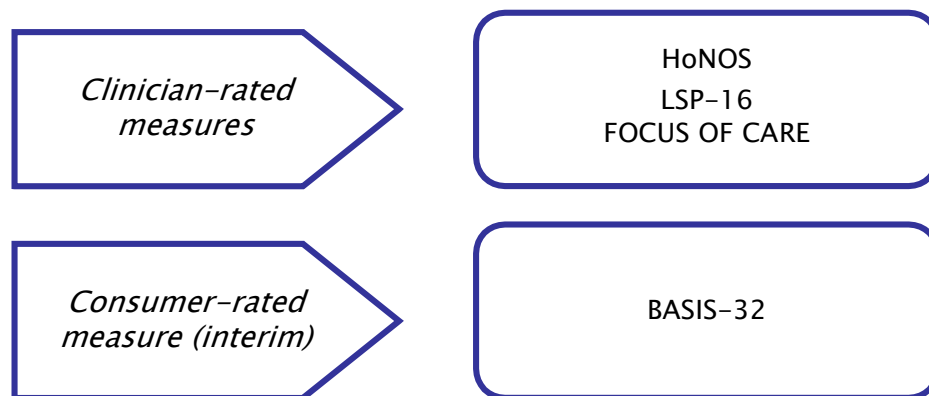
Wollongong. The Centre's brief was to develop training resource materials² and provide training and support to introduce routine outcome measurement in four 'round one' Area Mental Health Services (AMHS) which agreed to act as pilot agencies (Barwon Health; Grampians Psychiatric Services; St Vincents Area MHS; Maroondah/Outer East MHS). This work was completed in the latter half of 2000 and is expected to be expanded to cover all adult AMHS over the course of 2001.

The role of the Centre changed as the project developed and was expanded to include consultation with consumers regarding their views about both the interim consumer self-rated specific measure adopted by Victoria and the overall process of outcome measurement. This report represents the result of those consultations.

1.2 The Consumer Outcome Measures

Consistent with the national approach, Victoria is introducing both clinician and consumer self-rated measures of outcome. Table 1 summarises the outcome measures that the Department will be using in all adult AMHS.

Table 1: Summary of the outcome measures



The HoNOS (Health of the Nation Outcomes Scales) and LSP (Life Skills Profile) are rated by the clinician and focus on (1) the severity of the consumer's clinical symptoms and (2) the level of disability, defined as those aspects of the consumer's personal functioning which may be

² See Eagar K, Buckingham B, Coombs T, Trauer T, Graham C, Eagar L and Callaly T. *Outcome Measurement in Adult Area Mental Health Services: Implementation Resource Manual*. 2000, Department of Human Services Victoria.

disrupted by mental illness. Both of these measures have been agreed for national adoption.³

Selection of a consumer self-rating measure was one of the more difficult aspects of the Victorian Strategy as no single instrument was believed to capture all areas considered by consumers to be important. Nationally, three instruments were trialed for routine use.⁴ The Commonwealth recommended that States and Territories use the Mental Health Inventory (MHI) as the national standard measure but acknowledged that '*... limited Australian work has been undertaken on consumer-rated measures, additional work is required in this area*'.³ Subsequently, the Commonwealth resolved that States and Territories could decide individually on which measure to use on the grounds that experience in a range of measures would contribute to future development of a 'national standard'.

The measure selected by Victoria as an interim tool for use by consumers is the Behaviour and Symptom Checklist (BASIS-32). The BASIS was developed in the early 1990's by a team in the United States for use in outcome assessment. It is described by its authors as being derived from consumer perspectives and covers the major symptoms and functioning difficulties often experienced by people as a result of a mental illness.⁵

The BASIS-32 asks the consumer to respond to 32 questions that assess the extent to which the person has been experiencing difficulties on a range of dimensions. The items differ slightly in their format but each one offers a choice of five responses. The consumer can respond by simply ticking the box to indicate whether they are having no difficulty; a little difficulty; moderate difficulty; quite a bit of difficulty; and extreme difficulty. A full copy of the BASIS-32 is provided at Attachment A.

The 32 items are grouped into five domains, representing:

- Relation to self and others;
- Daily living and role functioning;
- Depression and anxiety;
- Impulsive and addictive behaviour; and

³ See Commonwealth Department of Health and Aged Care. *Mental Health Information Development: National Information Priorities and Strategies under the Second National Mental Health Plan 1998-2003 (First Edition June 1999)*. Commonwealth of Australia, Canberra, 1999

⁴ Stedman, T, Yellowlees P, Mellsop G, Clarke R & Drake S. *Measuring Consumer Outcomes in Mental Health*. Canberra: Department of Health and Family Services, 1997

⁵ Eisen SV, Dill, DL. & Grob MC. Reliability and validity of a brief patient-report instrument for psychiatric patient outcome evaluation. *Hospital and Community Psychiatry*, 1994, 45, 242-247

- Psychosis.

Scores can be derived for each of these groups, and for the whole scale.

The decision by Victoria to include the BASIS-32 in its outcome 'suite' was due to its better coverage of the range of mental health disorders experienced by consumers of public mental health services. Whereas the content of instruments such as the MHI is structured around broader 'psychological distress', the BASIS-32 was seen to specifically survey the types of symptoms and experiences of public mental health consumers.

It is beyond the scope of this report to review the technical aspects of the instrument but in summary terms, it has been found to have adequate psychometric properties (reliability, validity etc) and is sensitive to change in consumers. The issue of interest in the current project is whether it is acceptable to Victorian consumers.

1.3 Consumer Consultation Project

Concern amongst consumer representatives about both the outcomes measurement strategy and the selection of the specific consumer self-rated instrument (BASIS) emerged throughout the course of the consultancy. In part this reflected the lack of information available to consumer representatives about the Strategy overall and a perceived lack of opportunity to influence its implementation. Previous consumer consultation carried out by the Department in the development of the Strategy was not regarded as sufficient to support comprehensive introduction of such a significant initiative. Concerns voiced by consumers in regard to the BASIS-32 ranged from the absence of consumer input into its selection; the perceived inappropriateness of some of its content; the fact that it appeared to be driven by academics with minimal input from consumers; and its non-coverage of areas regarded as important to reflect consumer's experience of their mental health.

In embarking on the Outcomes Strategy, the Department of Human Services recognised that choosing an appropriate measure for consumers to make assessments of their own health and well being is a relatively unexplored area. It is also aware that some consumer groups have advocated the need to develop a new approach based on significant consumer input, and which is customised to reflect both the Victorian mental health service delivery environment and consumer perspectives.

For these reasons, the Department commissioned the current project team to consult with a representative group of consumers to more specifically understand their concerns about the BASIS-32, the range of areas that should be covered in a self-rating instrument and the process of outcome measurement more generally. Arising from these consultations, the Centre was requested to prepare a report for consideration by the Department that:

(1) describes Victorian consumer views on:

- the domains that should be captured in a self-rating instrument;
- the suitability of the BASIS-32 in relation to these domains;
- how the process of consumer assessment should be undertaken; and
- any other views offered in relation to the process and utility of outcome measurement.

(2) recommends the domains that should be covered in a self-rating instrument; and

(3) identifies the steps that should be taken by the Department in:

- implementing an existing instrument if one is found to be suitable; or
- developing a new instrument, including partnership arrangements with the Commonwealth to progress the development on a national basis.

2 FINDINGS FROM PREVIOUS WORK

Limited Australian work has been undertaken in this field. Similarly, while the international literature on measurement of consumer outcomes in mental health is extensive, the bulk reflects the views and interests of clinicians and researchers. This is not to underestimate the importance of that work but only to highlight the relative paucity of similar endeavours that set out explicitly to represent consumer perspectives.

In the Australian context, two reports have presented the views of consumers about the content and process of outcome measurement, both funded under the National Mental Health Strategy. Stedman and colleagues at the University of Queensland conducted consumer focus groups as part of a larger project to field-test six adult outcome measures in a range of private and public sector clinical practice settings.⁶ Their report concluded that, overall, consumers are positive about the introduction of outcome measures but have a range of concerns about the content, language and incomplete scope of the instruments reviewed (BASIS-32, MHI, SF-36). They concluded that the process of measuring consumer outcomes (i.e. how outcomes are measured and used in practice) is as important as the selection of the measures themselves.

Of particular relevance to the current project, Stedman *et al* sought the comments of consumers who had completed the BASIS-32 about the appropriateness of the instrument. Table 2 summarises these views.

Table 2: Summary of issues raised by consumers about the BASIS-32 in previous field testing of outcome instruments

POSITIVE	NEGATIVE
<ul style="list-style-type: none"> • Format helpful • One week is an appropriate time frame. • Comprehensive • User friendly, i.e., short, simple and easily understood • Format and content of this questionnaire allows for independent completion • Relevant questionnaire on a personal level • Useful in providing the service provider with information that may not be covered comprehensively during a clinical interview • Can provide feedback on a personal level as to changes in your condition 	<ul style="list-style-type: none"> • Some responses were too restrictive • Some of the language was difficult to comprehend and/or open to individual alternative interpretations • An interviewer would be necessary in order to assist the completion of the questionnaire • Questions predictable; may effect validity of information obtained • Not relevant in an inpatient environment • Not perceived as relevant by some participants • Will be responded to depending on wellness. • May have a negative impact on affect during the completion process

Source: Stedman *et al* (1997)

⁶ Stedman T, Yellowlees P, Mellsop G, Clarke R, and Drake, S. *Measuring consumer outcomes in mental health: Field testing of selected measures of consumer outcome in mental health*. Canberra: Commonwealth Department of Health and Family Services, 1997.

In a related project reviewing outcome measures in the child and adolescent field, Bickman *et al* consulted consumer, parents and clinicians on a wide range of issues including desirable outcome measurement domains, measurement processes and the perceived benefits and risks of routine outcome measurement.⁷ While there was some concordance between providers and consumers, clear differences are apparent throughout the report on many key issues.

Internationally, United States Ohio Department of Mental Health has extensively documented on its website an approach to routine outcome measurement that is built on consumer perspectives and the concept of recovery.⁸ The developments in Ohio are relevant to Victoria (and Australia more generally) because it is one of the few jurisdictions known to the current project team where a systematic effort is being made to comprehensively introduce a standard approach to outcome measurement, backed by training, manuals and wide system support.

The Ohio Department states as a fundamental of its approach that:

'Outcomes should be measured primarily from the perspective of consumers and in a manner that complements rather than replaces the clinical judgment of practitioners.'

'Recovery is the foundation of (the) current initiatives. The Ohio Mental Health Consumer Outcomes System builds upon that foundation. Recovery can be defined as "a personal process of overcoming the negative impact of a psychiatric disability despite its continued presence." Recovery involves a personal transformation that involves acceptance of the illness, a sense of responsibility or control over one's life, hope, the support of others, and treatment and rehabilitation in collaboration with providers. The above aspects of recovery are reflected in the (Department's) values, the outcomes instruments, and the measurement process.'

The outcomes approach being implemented in Ohio for adult consumers was developed over a three year period by a state-level task force comprising consumers, carers, researchers and clinicians. The final set of outcome instruments represent a hybrid of several existing instruments by combining selected items and scales from those instruments as well as additional items deemed by the task force to be essential but not included in available measures. The instruments covers the following domains:

⁷ Bickman L., Nurcombe B, Townsend C., Belle M, Schut J & Karver, M. *Consumer Measurement Systems for Child and Adolescent Mental Health*. Canberra: Commonwealth Department of Health & Aged Care, 1999.

⁸ See <http://www.mh.state.oh.us/initiatives/outcomes/outcomes.html>

- Clinical Status
- Quality of Life (Life Satisfaction, Fulfilment, and Empowerment)
- Functional Status
- Safety and Health

Separate instruments have been developed for completion by consumers and clinicians.

Closer to home, similar themes to those driving the Ohio model have been advocated by New Zealand outcome researchers attempting to design an outcome measure from consumer perspective, particularly for Maori consumers. For example, Bridgman and colleagues⁹ argue that the concept of recovery is rarely transformed into an outcome measure. To do so requires incorporation of the notion of 'wellness' to balance the traditional focus on illness. Significant work along these lines has been completed by Durie and Kingi at Massey University in the development of 'Hua Oranga' – an outcome measure derived from Maori cultural views of health and well being and which reflects aspects of mental health outcome relevant to Maori consumers.¹⁰ The scale looks very different from scales developed by clinical researchers and covers four domains:

- Spiritual
- Mental
- Physical
- Family

Based on our review of the literature, we believe that there are six key themes emerging from previous research and consultations with consumers that provide a context for the current project.

2.1 Outcomes for consumers are about more than relief from symptoms

Consumers and clinicians have different perspectives on what constitutes valued health outcomes. For the clinician, the emphasis is often on the symptoms of illness and their relief. For the consumer, an outcome is only relevant when it includes measures of the impact of

⁹ Bridgman G, Dyal L, Bidois A, Gurney H, Hawira J, Tangitu P, Huata W, Webster S, Heron M *The assessment of wellness – an outcomes tool drawn from the participant perspectives in Māori and Mainstream mental health*, Invited presentation to the Mental Health Outcomes Research Conference, Wellington. New Zealand, September 2000

¹⁰ Durie MH & Kingi TK *A framework for measuring Māori mental health outcomes*. Massey University, Department of Māori Studies. Te Pūmanawa Hauora, Palmerston North. 1997

the illness and its treatment on the person's life. For them, a symptom-centred assessment of outcome is not compatible with the recovery process. For example:

"Health professionals often disrupt the normalisation process (that emphasises abilities and recovery) by continually introducing a problem saturated perspective which services the illness rather than providing the help one needs for getting on with your life ... The participants focussed on their strengths and used them to help themselves recover. A major problem with health professionals was their focus on deficits, on symptoms, on what the person could not do, resulting in the stripping of hope." ¹¹

In reviewing the literature, Campbell concluded that the following core consumer outcomes need to be considered for inclusion in a consumer-rated outcome measure.¹²

- *Well-being*, including, for example, good health, food, decent housing, meaningful work, satisfying social life and social integration in the community, and basic human freedoms and rights such as privacy, dignity and respect.
- *Personhood*, including feeling listened to, validated and respected, being given information relevant to services and tolerance for individual differences.
- *Empowerment*, or the process of gaining control over one's life which builds self esteem, autonomy and personal optimism about the future.
- *Recovery*, referring not only to minimisation of the effects of illness but also the development of coping strategies and finding meaning in one's experience of mental illness.
- *Minimising the detrimental effects of treatment and care regimes*, including loss of freedom and dignity though involuntary commitment, drug side effects and resultant feelings such as anger, fear, alienation and confusion.

Outcomes in mental health are therefore considerably more complex than the simple notion of *cure*. A good outcome cannot be achieved until the consumer reports that the illness no longer interferes with their life, or has reached a point where they feel they have minimised its impact as much as possible, or that they are on the path to recovery.

¹¹ Tooth BA, Kalyanansundaram V, Glover H *Recovery from Schizophrenia: A Consumer Perspective: Final Report to Health and Human Services Research Development Grants Program*. Department of Health and Aged Care, Canberra, 1997

¹² Campbell J *Consumerism, Outcomes, and Satisfaction: A Review of the Literature*. See www.madnation.org/citations/consumerism.htm

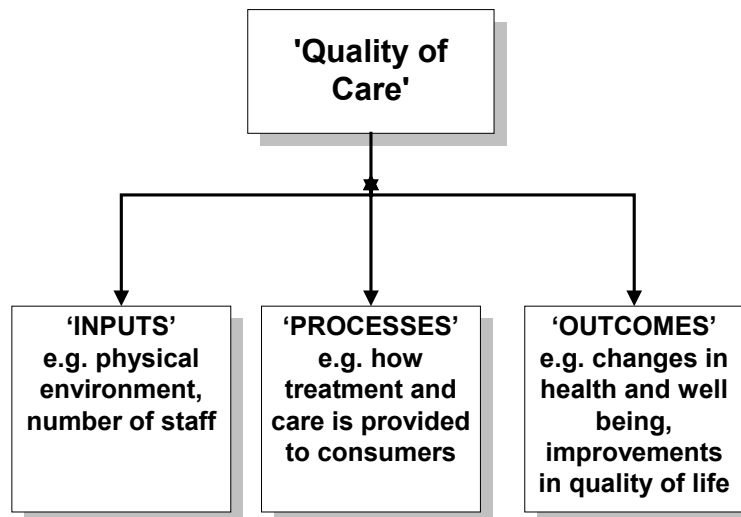
The Victorian outcomes strategy responds to this complexity by including a 'suite' of instruments that cover both clinical (symptom-based) measures and measures of the impact of illness on the person's functioning. The inclusion of consumer self-ratings within the suite acknowledges the importance of the individual's subjective experience and provides scope to broaden outcome concepts to embrace consumer concerns. The issue being addressed in the current project is whether the measurement instrument and process makes best use of that opportunity.

2.2 Consumers want the link between health outcome and service quality to be recognised in self-assessment measures

This is a related issue but deserves separate consideration. A concern raised by consumers about outcome measures that focus on health and wellbeing is that they do not capture their experience of being a consumer of services. For many, the quality of the services they receive is *the* critical ingredient to whether they have a successful outcome. Thus, if they are going to be surveyed regularly through a standard form, consumers have asserted that they want to see the inclusion of questions concerned with service quality sitting alongside questions about the current status of their illness.

This approach does not fit comfortably with current definitions and approaches to 'consumer outcomes' which are based on the distinction between inputs, processes and outcomes. Outcomes represent the visible or practical result of inputs and processes. For example, in Australia, the definition accepted by the Australian Health Ministers' Advisory Council (known as the AHMAC 'Sunshine Statement') defines a health outcome as "*a change in the health of an individual or group of individuals which is attributable to an intervention or a series of interventions*". Within this model, outcomes form one

Table 3: Aspects of 'Quality of Care'



component of an overall framework for evaluating quality of care, as shown in Table 3 below.

Instruments designed to measure outcomes adopt this separation of concepts and rarely include questions designed to survey the consumer's views about the 'input' and 'process' aspects of the

treatment they receive. These are usually evaluated through separate measures of consumer satisfaction. Victoria has followed this approach and is the only Australian jurisdiction to regularly conduct satisfaction surveys within the consumers of mental health services.

In parallel, Victoria is introducing an accreditation process to ensure all services meet the requirements of the *National Standards for Mental Health Services*. These standards give meaning to the concept of 'good quality care' by using criteria that cover all input and process aspects of a service, including its structure, procedures and interactions with consumers and carers.

The issue to be explored in the current project is whether this separation of concepts and measurement processes is compatible with Victorian consumer perspectives. Put simply, the question is whether it is meaningful to consumers to gather information about their health outcome without also asking whether they regard the service being provided to them as meeting their needs.

2.3 Consumers rate their outcomes differently from clinicians

Previous research has suggested that even when clinicians and consumers rate the same aspect of outcome they frequently differ in their views. This does not mean that one is right and the other is wrong – instead, it means that both parties approach the task from different perspectives and that these need to be brought together for a full understanding.¹³

In recognising the importance of consumer-rated outcomes, the challenge is how to best capture the consumer's unique experience and insight in a relevant outcome measurement process.

2.4 No single measure is universally accepted as the best measure

This may seem self-evident but needs to be stated. Where consumers have been asked for their views about specific instruments, they have been generally positive about the idea but critical of one or more aspects of specific measures. Examples of concerns voiced by consumers about specific measures include:

¹³ Trauer T. *Self assessment in adult mental health*. Report to the Aged, Community and Mental Health Division, Department of Human Services Victoria 2000.

- the idea that rating your wellness by a standard form that reduces to a set of numbers is overly simplified;
- the language of some questionnaires is not seen as 'consumer friendly', or is judgemental;
- it is unrealistic for a single instrument to be relevant to all consumers, or it fails to respect each consumer's individuality;
- questions may be ambiguous or not asked in a clear manner;

The work by Stedman *et al* asked a group of approximately 50 consumers to indicate their preferences in a comparison of two instruments. They found that no clear candidate emerged. Their results showed:

- BASIS-32 vs MHI - 56% preferred the MHI
- BASIS-32 vs SF-36 - 58% preferred the BASIS-32
- MHI vs SF-36 - 71% preferred the MHI

It is also significant that even when instruments are developed collaboratively with consumers (e.g., SOAP, the Ohio instruments) they differ in their coverage and item content.

The simple point from previous research is that no single measure has emerged as being widely accepted by consumers. They all have their individual strengths and weaknesses and the choice of which measure to use depends on what you are trying to achieve. The political and cultural context of the instrument development is also important – for example, a consumer measure developed by Victorian consumers may not be acceptable to those in other jurisdictions, or those from other cultures.

The literature makes clear that the work involved in the development of a comprehensive new instrument is substantial and there is no guarantee that such a new instrument would not also be seen to have faults.

2.5 The process of measurement is as important as the outcome measure

As indicated earlier, the University of Queensland research emphasised that the process of gathering information about consumer outcomes is as important as the measure chosen. Process here refers to questions about *how* rather than *what* – for example, how consumers are approached for information, how their information is used by clinicians, how it influences treatment planning, how privacy is protected and so forth.

Issues raised in previous studies by consumers about the process have included:

- how their self-ratings will improve the treatment they receive;
- whether they will have access to the clinician's ratings;
- whether anonymity and confidentiality can be guaranteed; and

- how the possible negative impact of completing an assessment of one's own health will be dealt with.

The Ohio Procedural Manual makes the following important point:

“Item and sub-scale scores provide critical perceptions of the responding consumer that, directly or through deduction or inference, can be used as a barometer of the recovery process. The scores indicate the relative strength of these perceptions, but they do NOT indicate the relative importance or priority of these perceptions to the consumer. That is why thorough discussion is required with the consumer before deriving implications or devising recommendations.”¹⁴

A key focus of the current project was to hear from consumers about their views on how the process of outcome measurement should be implemented so that it is appropriate to their needs. Ideas coming from the project may then be incorporated in the further development of consumer measures as well as clinician training programs.

2.6 Comprehensiveness needs to be balanced by brevity

Finally, previous work on consumer outcome measurement has emphasised two potentially conflicting requirements:

- to be meaningful, the instrument must be comprehensive,
- but to be practical, it must also be brief.

We have included this issue here because it is a critical factor to consider when reviewing the options. The BASIS-32 takes about 10 minutes to complete and this is considered to be 'about right' in terms of what the 'average consumer' considers acceptable. Acceptable instrument length sets the broad parameters for deciding many aspects about what content areas can be covered in a self-rating measure that is intended for routine use.

¹⁴ Ohio Department of Mental Health. *The Ohio Mental Health Consumer Outcomes System Procedural Manual Fourth Edition (Revised)*. September 2000

3 METHODOLOGY

The method used in the current project was developed through a process of discussion with consumers, consumer representatives and Departmental officers. CHSD team members refined the final plan.

3.1 Sample

It was understood at the planning stage that making contact with people with a mental illness and gaining their interest and trust to participate in a project is always a challenge. Furthermore, we were aware that personal contact is a useful strategy for instilling consumer confidence in the project facilitators. However project resources required that initial contact with consumers was made by letter. Every effort was made to ensure that the information in the letter was written in plain English, that it was not ambiguous and that consumers could clearly understand what they were being asked to contribute and what they could expect back as a result of participating in the project. Copies of the letters of invitation are provided in the Appendices.

On the basis of the consultation aims a purposive sample was used comprising two groups.

Group 1 were consumers of the four 'round one' agencies who had completed a BASIS-32 within their area mental health service. The aim was to identify individuals who had first-hand experience of consumer self-ratings and to discuss with them their perceptions of the relevance of the instrument used and the overall process. Letters of invitation to attend a focus group were distributed to consumers via their local AMHS. It is estimated that approximately 40-50 consumers were invited through this channel.

Group 2 were consumer representative groups and consumer consultants who it was assumed had no personal experience of the BASIS-32 and none or only limited information about the Victorian Mental Health Outcome Strategy. A letter inviting a representative to participate firstly in an information workshop and at a later date in a focus group was sent to the following individuals and/or groups:

- Consumer Consultants, invited from the 22 Area Mental Health Services;
- the 72 consumer groups located around the state that are affiliated with the Victorian Mental Illness Awareness Council (VMIAAC);
- the Victorian Consumer Advisory Group; and

- specific mental illness support organisations. VMIAC; Schizophrenia Fellowship; Barwon Psychiatric Resources Council; Richmond Fellowship; Prahran Mission; Melbourne Consumer Consultants group and NEAMI.

A total of 112 letters of invitation were sent to individuals in Group 2. In addition, all consumer consultants employed within the AMHS were personally contacted by telephone to encourage them to attend a workshop.

An important limitation in our sampling approach needs to be acknowledged. It was not possible within the project to specifically sample the views of Koorie mental health consumers, nor people from non-English speaking backgrounds. Special issues in relation to outcome measurement for these groups are therefore not addressed.

3.2 Information workshops

Given that consumers in Group 2 were coming to the project with none or limited understanding about the outcome measures or the Victorian Outcomes Strategy, it was critical that an information workshop was held prior to the gathering of consumers' opinions.

The aim of the two and a half-hour information workshop was to orient participants to the task, provide relevant background information and describe the issues upon which we were seeking their views. An information kit was prepared to support the sessions, covering:

- the background to the project and overview of the Victorian Outcome strategy;
- key concepts;
- the current instruments available, focusing on the BASIS 32 and the rationale for its selection as an interim measure in Victoria;
- experience elsewhere in the use of consumer self-ratings, drawing on the literature and local experience; and
- an indicative list of questions to be addressed in the consultations.

Two facilitators from the CHSD team (CG and TC) conducted the information workshops.¹⁵ The venue was in central Melbourne and thus close to both trains and trams.

Twenty-two consumers attended the first workshop (late August 2000) while eighteen attended the second workshop (October 2000). Of the total of 40 workshop participants, fourteen were consumer consultants working within an AMHS. Of the remaining participants, thirteen were from rural Victoria and thirteen from around Melbourne.

The conceptual nature and jargon of outcome measures initially made it difficult for most participants to follow the concept. However, once the facilitators decided to talk in terms of mental health *change* rather than outcomes, increased understanding followed. At various times within both workshops some consumers reacted in a negative manner to both the strategy and to the BASIS-32. However they were encouraged to save these opinions for the focus groups. These opinions served to demonstrate to other participants the types of areas they might reflect on prior to the focus group. Participants made some suggestions at the workshops about additional questions to be asked during the focus groups. Those seen as relevant were incorporated into the interview schedule.

3.3 Focus groups

A focus group methodology was used to collect information from consumers. A total of 10 focus group was conducted with 58 participants.

At the end of both information workshops facilitators negotiated with participants on the dates/times and venues for the focus groups. Approximately five weeks after the first information workshop consumers chose to participate in one of the four focus group times offered. The first focus group was conducted in late August with pilot group participants in the Barwon region. This was followed by three centrally-based focus groups in Melbourne and one in Ballarat, the latter including both Group 1 and Group 2 participants.

Participants from the second workshop chose to participate in one of three focus groups convened a month from the workshop date (November 2000). Consumers who had attended an information workshop were all keen to have time to reflect on the workshop and materials distributed and to have sufficient time to discuss the issues with other consumers. In early November focus groups with the two

¹⁵ One facilitator (CG) was the consumer consultant team-member who has a research background. The other facilitator (TC) has a psychiatric nursing background and is currently working in staff education and mental health service development.

outstanding trial sites, Maroondah and St Vincents were also conducted.

Table 4: Summary of consumer participation in information workshops and focus groups

	<i>Number of invitations</i>	<i>Number of participants</i>	<i>Number of sessions</i>
Information workshops	112	40	2
Focus groups:			
• Consumers at 'round one' sites	40-50	27	4
• Consumer representatives	40	31	6
TOTAL		58	10

Participants attending sessions who are not on salary were paid at the standard Department rate (\$20 per hour) and travel costs were reimbursed.

Indicative questions to be asked at the focus group (see Appendix 4) were developed by the project team in consultation with the Victorian Mental Illness Awareness Council (peak mental health consumer organisation) and a consumer consultant. Questions were grouped under three general headings: content areas (or domains) to be covered in a consumer self-assessment measure; the process of outcome measurement; and the suitability of BASIS-32. The questions were distributed to consumers prior to participation in a focus group. In all focus groups the three general areas were covered, although the order that they were discussed varied.

A thematic analysis was undertaken based on the discussions. Results are presented in the following section.

4 FINDINGS FROM FOCUS GROUPS

Wide ranging views were expressed by participants within the focus groups. In the sections that follow, we have organised these views around the four key areas nominated by the Department:

- the domains that should be captured in a self-rating instrument;
- the suitability of the BASIS-32 in relation to these domains;
- how the process of consumer assessment should be undertaken; and
- any other views offered in relation to the process and utility of outcome measurement.

We have attempted to represent consumers views as accurately as possible as this was fundamental to our brief. In so doing, we are aware that there are diverse viewpoints within other stakeholder groups on several of the issues and that, ultimately, these need to be reconciled. Consultation with other stakeholders was beyond the scope of the current project.

As a preliminary, it is important to acknowledge three overarching assertions made during the focus groups that provide a context for understanding consumers' thinking on outcome measurement.

First, there was general support for a consumer self-report instrument with several potential benefits identified:

- it provides a basis for feedback to a consumer on their progress and areas they want to improve on;
- it provides a record of change over time which overcomes the problem if a consumer has poor memory;
- it is empowering because the consumer can state how they experience their illness;
- it provides a basis for more 'grounded dialogue' with a case manager; and
- it empowers the consumer to reflect on their own experience.

Second, participants argued strongly that these benefits do not flow automatically simply from the administration of a self-rating measure. They argued that for a consumer self-report instrument to be useful to both the consumer and clinician, two preconditions need to be in place. First, a service culture needs to exist that values the consumer as

a person and recognises that he/she has a good knowledge of his/her own health. And secondly, the process is seen to be worthwhile only if the consumer has developed trust in their case manager. Participants stated consistently that only when they felt listened to, believed and supported did they develop such trust with the clinician. For them, this is the most significant factor mediating their mental health outcome. While the use of routine outcome measures may contribute to the consumer's recovery, it does not in itself substitute for the trustful and therapeutic alliance that is the foundation of all good mental health practice.

And finally, participants were sceptical about whether the use of a consumer-rated measure would result in the desired changes to service provision. From their perspective, there is a risk that the current culture of mental health services will stifle the potential of outcome measures to produce genuine collaborative dialogue between consumers and clinicians.

4.1 Consumers' views about the domains to be captured in a self-rating instrument

To explore this question, participants in all focus groups were asked to think about what they personally use as indicators of the state of their mental health and when changes occur. It was hoped that by asking this question early in the focus group consumers would initially reflect and respond from their own experience. However, most participants found this question difficult without an external reference point. Consequently the BASIS-32 was often used as the starting point to prompt consideration of the issues.

Clearly, there are many ways in which items relevant to consumer outcomes can be categorised. This may be achieved on the basis of statistical techniques (e.g., factor analysis) or simply on the basis of item content. Where the latter approach is used, there is no right or wrong way of approaching the task. How content areas are 'packaged' depends as much upon the issues and values that instrument designers want to promote as upon any underlying 'truth'.

We have used a summary framework comprising seven content domains to present consumers' views. Both the framework and content areas are offered as indicative only rather than as the definitive model for the future. However, every effort has been made to ensure that the framework faithfully reflects the views of consumers interviewed.

➤ 'Quality of Life'

Many definitions have been offered of this broad ranging concept. As stated by Andrews et al¹⁶, most definitions have in common the idea that quality of life is a multidimensional concept, covering physical, cognitive, affective, social and economic domains. While some definitions emphasise objective elements of the individual's life (e.g., economic, housing etc.), others focus on the person's subjective experience. Specific instruments promoted as 'quality of life' measurement tools typically cover dimensions that overlap with measures of more specific domains, such as disability and functioning outcome instruments, which makes them difficult to categorise within a mutually exclusive classification of measures.

Recognising the multiple definitions that abound, and the potentially all-embracing nature of the quality of life concept, we are using the term here to refer to the individual's sense of satisfaction across various life domains, including housing, finance, employment, recreation, spiritual fulfilment and empowerment.

Indicative content areas relevant to this domain suggested by participants are summarised in Table 5.

Table 5: 'Quality of Life' - Indicative content areas suggested by focus group participants

<i>Level of consumer's satisfaction with:</i>	
• 'Suitable accommodation'	★
• 'Sense of happiness'	
• 'Enjoyment of activities/life'	★
• 'The way you spend your leisure time'	
• 'Undertaking of meaningful work (paid/unpaid)'	★
• 'Spiritual values and fulfilment'	★
• 'Creative activities'	
• 'Capacity to have choices'	
• 'Sense of responsibility and control over one's life'	
• 'Meaningful occupation of time'	★
• 'Level of self esteem and self confidence'	
• 'Hope for the future'	

★ Asterisks signify those areas most frequently identified by participants

➤ **Functioning**

We use this term to incorporate aspects of day-to-day functioning required by the person to perform the various roles entailed in

¹⁶ Andrews G, Peters L and Teesson M. *The Measurement of Consumer Outcome in Mental Health*. Sydney, Clinical Research Unit for Anxiety Disorders, 1994.

maintaining independence in the community. The concept of functioning is broad and encompasses social, occupational, recreational and self-care aspects. Difficulties in these areas are often referred to under the title 'psychosocial disability'.

As opposed to the 'quality of life' domain which focuses on the individual's sense of fulfilment and satisfaction, the content of the functional domain is focused on the actual abilities (and difficulties) experienced by the consumer in specific areas. Because mental illness may affect any or all areas of functioning, it is a focus for a number of specific outcome scales, albeit ones that are primarily completed by clinicians. In their 1994 review of available outcome instruments, Andrews and colleagues made the point that self-report measures of functioning were undeveloped or lacking in their psychometric properties.¹⁶ It is significant to note in this context that the approach recently developed in Ohio includes measures of the consumer's functional status but the items are collected via clinicians rather than through self-report.

The relevance of the functioning domain was endorsed by workshop participants. Indicative content areas suggested by participants and relevant to the domain are summarised in Table 6.

Table 6: 'Functioning' - Indicative content areas suggested by focus group participants

<i>Abilities reported by consumers in:</i>	
• 'Maintaining your house'	★
• 'Cooking'	
• 'Maintaining appearance/demeanour'	
• 'Handling money, meeting financial obligations/budgeting'	★
• 'Social activities'	★
• 'Ability to work'	
• 'Ability to manage medication and side effects'	
• 'Maintaining friendships'	

★ Asterisks signify those areas most frequently identified by participants

➤ **Physical Health and Health Risks**

Participants identified their overall physical health and risks to health as important content areas to be included in any self-report measure of outcome. Indicative content areas suggested by participants and relevant to the domain are summarised in Table 7.

Table 7: 'Physical health' – Indicative content areas suggested by focus group participants

Consumer assessment of extent to which the following compromise their overall well-being:

- 'Medication, level and side effects' *
- 'Sleeping habits' *
- 'Eating habits and diet' *
- 'Energy levels' *
- 'Level of cigarette smoking'

* Asterisks signify those areas most frequently identified by participants

➤ **Relationships**

By this term, we are referring to both the quantity and quality of relationships. This was widely identified by participants as a key dimension of outcome for inclusion in a consumer self-rating measure. Technically, this domain forms a sub-domain of 'quality of life' but we have listed it separately because of the significance attributed by the group participants. Note also that this domain refers to the consumers *perceptions* of their situation, rather than a self-assessment of their relationship abilities. The latter is included within the Functioning domain.

Indicative content areas suggested by participants that is relevant to the domain are summarised in Table 8.

Table 8: 'Relationships' – Indicative content areas suggested by focus group participants

Level of consumer's satisfaction with:

- 'Quality of relationships with family and friends' *
- 'Extent of social networks and activities' *
- 'Amount of friendships'
- 'Level of support from family, friends'

* Asterisks signify those areas most frequently identified by participants

➤ **Illness Symptoms**

Participants recognised the importance of this area, the core focus of most clinician-rated outcome assessments, and identified many potential content items. However, the reservation was expressed frequently that an exclusive focus on illness as the only outcome domain of interest ignores areas of equal or more importance to the consumer and is not a sound basis for the development a individualised recovery plan. This issue is taken up later in this report.

Indicative symptom-related areas are shown in Table 9.

Table 9: ‘Symptoms’ – Indicative content areas suggested by focus group participants

<i>How does the consumer rate their current situation in regard to:</i>	
• ‘Anxiety levels’	★
• ‘Memory’	★
• ‘Level of concentration’	
• ‘Ability to break habits/cycles’	★
• ‘Depression’	★
• ‘Number of nightmares’	
• ‘Understand things going on around you’	
• ‘Thought disturbances’	

★ Asterisks signify those areas most frequently identified by participants

➤ **Coping and Recovering from Illness**

This domain refers to the impact of illness upon the consumer as well as his/her personal development in dealing with its implications across all areas of life. Participants emphasised that understanding ‘how we deal with stress and change’ should be a foundation for designing both the content and process of outcome measurement. This was argued to be the case for consumers with persistent conditions, for whom symptom change scores provide little insight into the ongoing personal adjustment of the individual, and consumers with conditions where active symptoms move through remission and relapse cycles.

Indicative content areas arising from the focus groups are summarised in Table 10.

Table 10: ‘Coping and Recovering from Illness’ - Indicative content areas suggested by focus group participants

<i>How does the consumer feel about their progress on:</i>	
• ‘Dealing with the impact of the illness’	
• ‘Responding to how people treat you (stigma)’	
• ‘Coping in return to work’	
• ‘Ability to recognise and take action on early warning signs (e.g., depression, mood swings, hearing voices)’	★
• ‘Having a strategy to break habits/cycles’	★
• ‘Minimising any detrimental effects of treatment and care’	★
• ‘Adjusting to the effects of medication’	★
• ‘Coping with day-to-day stress and change’	★
• ‘Developing a recovery plan and ability to initiate action’	

★ Asterisks signify those areas most frequently identified by participants

➤ **Satisfaction with Service Quality**

The final domain concerns consumers' perceptions of the quality of care they have received. As discussed earlier in this report, technically this is regarded as a process rather than an outcome domain. This issue drew the most strongly expressed views of all issues discussed within the focus groups.

Participants did not see a difference between outcome measurement, satisfaction with service delivery or the quality of care provided. They suggested the distinction was based on the views of providers and planners rather than reflecting consumer perspectives. For them, the consumers' experience of service delivery was identified as the most important area to regularly monitor. The question was asked frequently: *'isn't satisfaction with the service a good outcome?'*

Participants argued that there is a relationship between a consumer's self-rating of outcome and his/her perceptions of service quality. Unless consumers are routinely surveyed about their experience of services received, in parallel with the assessment of outcomes, the Department will not be in a position to understand this relationship nor to respond to service inadequacies that underlie poor outcomes. This approach was seen to be fundamentally different from the Department's current method of monitoring consumer satisfaction (i.e. annual or biennial surveys of a sample of consumers).

Overwhelmingly, participants argued that including questions about the consumers satisfaction with services within an outcome instrument is a pre-condition to achieving full involvement of consumers. For them, it is a sign that consumers are being regarded as genuine and respected partners in the outcome monitoring process.

Indicative content areas arising from the focus groups are summarised in Table 11.

Table 11: 'Satisfaction with Service Quality' - Indicative content areas suggested by focus group participants

<i>How satisfied is the consumer with:</i>	
• 'The help you have been able to get from the service'	★
• 'The information given by the service about your mental illness, medication and your rights as a consumer of the programs'	★
• 'The attitude of staff toward you and whether you have been treated with dignity'	★
• 'Staff listening to your opinion'	★
• 'Feeling confident to express yourself to your mental health worker'	★
• 'Being able to advocate for yourself to the Mental Health Review Board'	

★ Asterisks signify those areas most frequently identified by participants

4.2 Consumers' views on the suitability of the BASIS-32

There was a mixed reaction to the suitability of the BASIS-32 by the consumers who participated in the consultation. Approximately half of the sample suggested that it should be discarded and replaced by a new, consumer-appropriate instrument. The remainder of participants believed that BASIS-32 is a reasonable start but requires modification.

Specific comments on the BASIS-32 are outlined below.

4.2.1 Overall content

Consumers in the main believe that the domains covered are relevant but not sufficiently comprehensive. Table 12 summarises the BASIS-32 coverage of the seven content domains identified by workshop participants.

Consumers recommended that additional items would need to be added to the BASIS-32 to cover the outcome domains relevant to them. There was also strong support for including a minimum of one open-ended question at the end to tap concerns held by the consumer that are not covered in a standard instrument. This might be worded along the lines of: *'In what ways do you think that you have made progress in the past six months?'*

Table 12: Suitability of the BASIS-32 in collecting content domains relevant to consumers

Content Domain	BASIS-32 coverage of domain
'Quality of Life'	<ul style="list-style-type: none"> • BASIS includes some items relevant to this domain (e.g., several items on the 'relation to self/others'; Item 32 – <i>'To what extent are you experiencing difficulty with ... Feeling satisfaction with life'</i>) but excludes critical areas (e.g., accommodation, employment, spirituality) • Main problem is the wording of the instrument (<i>'to what extent are you experiencing difficulty with ...'</i>). Focus on problems is not conducive to quality of life assessment. <i>Possible alternatives:</i> <i>'To what extent are you happy with ...'</i> or <i>'how do you feel about ...'</i>
Functioning	<ul style="list-style-type: none"> • Regarded as strong in this domain, with a specific 'Daily Living/Role Functioning' scale.
Physical Health and Health Risks	<ul style="list-style-type: none"> • Inadequate coverage – only Item 19 addresses this domain (<i>'To what extent are you experiencing difficulty with physical symptoms eg. headaches, aches and pains, sleep disturbance, stomach aches, dizziness'</i>) • Participants believe key physical concerns affecting mental health consumers (sleep disturbance, eating habits) should be separately itemised.
Relationships	<ul style="list-style-type: none"> • Regarded as strong in this domain, with a specific 'Daily

	Living/Role Functioning' scale. <ul style="list-style-type: none"> • Comments re Quality of Life apply here – does not identify strengths.
Illness Symptoms	<ul style="list-style-type: none"> • Regarded as strong in this domain, covering all major symptom categories.
Coping and Recovering from Illness	<ul style="list-style-type: none"> • Inadequate coverage of this domain – includes one relevant item only (Item 6 - <i>'To what extent are you experiencing difficulty with ... adjusting to major life stresses eg. separation, divorce, moving, new job, new school, a death'</i>)
Satisfaction with Service Quality	<ul style="list-style-type: none"> • No coverage of this domain

4.2.2 *Rephrase in positive language*

Most concern about the BASIS-32 was directed at its focus on difficulties. The leading question to all items (“to what extent are you experiencing difficulty in the area of ...”) was regarded as negative and disheartening for the individual completing the instrument.

Strong support was voiced for re-framing the overarching question in positive or neutral terms, for example: “to what extent are you satisfied with ...”, “to what extent have you improved in relation to ...” or “how do you feel about ...” This was seen as more likely to inspire cooperative feedback and gives the consumer an opportunity to report on their perceived strengths. As one consumer stated *“I would like to see a questionnaire that realistically emphasises achievement while still identifying areas to be worked on”*.

4.2.3 *Explanatory notes*

Participants recommended that the guidelines for consumers need to be rewritten so that they:

- are in ‘plain English’;
- include an explanation of the purpose of the instrument
- inform consumers about how the data will be used and who will have access;
- stress that completion of the instrument is voluntary; and
- repeat the instruction that ‘If the item is not applicable or not known, please leave it blank’ across all pages.

4.2.4 *Format and presentation*

The length and presentation of the BASIS-32 were regarded as reasonable. In general, participants suggested that *“no more than two*

pages” was a useful guideline for any consumer self-rated measure but the font size should be “*big enough to see*”.

A suggestion relevant to all measures was to include a method to allow the consumer to identify priorities from their perspective and whether they wanted assistance with a particular area.

4.2.5 Specific items

Concerns were expressed about several specific items which were seen as ‘irrelevant’, ‘intrusive’, ‘offensive’ or reflecting judgemental values. Items identified in this category were:

- *Item 27: “To what extent are you experiencing difficulty with ... Sexual activity or preoccupation”.* All women participants and most men viewed this question as offensive and believe that it should be deleted.
- *Item 29: “To what extent are you experiencing difficulty with ... Taking illegal drugs, misusing drugs”.* Some suggested that this item should be deleted because of its sensitivity. Use of tobacco was seen as a more relevant outcome measure.
- *Item 22: “To what extent are you experiencing difficulty with ... Disturbing or unreal thoughts or beliefs”.* Some participants argued that ‘everybody’s beliefs are real’ and thus the second part of the question should be deleted.
- *Item 4: “To what extent are you experiencing difficulty with ... School (e.g., academic performance, completing assignments, attendance)”.* This was seen to be irrelevant to adult consumers and should be deleted..
- *Items with multiple content:* There was a consistent view that questions need to be specific because in its current form, many BASIS-32 questions are regarded as ambiguous. For example Item 19 covers a range of physical symptoms (*‘Headaches, aches and pains, sleep disturbance, stomach aches and dizziness*). Participants suggested that sleep disturbance should have a separate question as it is such a strong indicator to consumers of their mental health. Similarly it was argued that the Item 21 (*‘Confusion, concentration, memory’*) descriptors should each be a separate question.

Item 7 (*“To what extent are you experiencing difficulty with ... Relationships with family members”*) was the item over which there was most disagreement about whether the content was appropriate to outcome measurement as it has variable interpretation. Differences of opinion in the groups appeared to reflect the strong family support

some people receive and the anger others feel at their rejection by family members.

4.3 Consumer views on the process of consumer self-assessment

Participants were asked to share their views on the overall process of outcome measurement. The aim was to identify those factors likely to increase consumer participation as well as perceived barriers from the consumer perspective.

4.3.1 How the instrument is offered to consumers

This emerged as a central issue with several components. Participants' views on each of these are outlined below.

➤ Explanation of purpose

Several consumers shared their experience of having the BASIS-32 offered in an off-hand way, or as *'just another piece of paper work'*. They were not made aware of its relevance to their treatment, nor its potential to contribute to case managers understanding of their situation.

Case managers should be positive in their invitation to consumers to complete the instrument, explaining clearly its purpose and relevance. The explanation should highlight how the information will contribute to the consumer's treatment and care as well as being useful *"to make the system function better"*. Benefits to the consumer should indicate how the information will help the clinician better understand the consumer's perspective of their current life situation as well as to monitor changes in their health and well-being. A commitment by the clinician to discuss the consumer's responses and share the results of the clinical rating measures will build consumer confidence in the process.

➤ Consumers right to refuse

Concern was often raised that failure or refusal to complete the consumer rated measure would have a detrimental effect on the services the consumer receives. They want to be reassured that there will be not be a negative impact on service provision as a result of refusal or partial completion of the measure. The explanation should therefore include reassurance that completing the instrument (or refusal to do so) would not have any detrimental effect.

➤ **Offer of assistance**

Once the consumer has been informed about the measure, participants suggested that the invitation to the consumer to complete the measure should be backed by an offer to sit down with the consumer and go through it step by step if necessary. For some consumers, this may involve reading out the questions individually, or completing the first few items together. However, some consumers will prefer to complete the instrument in private to allow time to reflect, and may want to take the measure away. Participants recommended that the consumers should be offered the choice of approaches.

In summary, consumers identified that the above issues need to be discussed as a first step in developing collaboration between clinicians and consumers in routine outcome monitoring. The invitation to consumers should be planned on the basis that consumers want to know:

- Why it is important
- It is optional and refusal to complete will not have any detrimental effect on treatment
- Who is going to use it
- How it is going to be used
- That information will be shared and the course of action if disagreement over ratings occur

4.3.2 Where and when to invite consumer self-ratings

This was vigorously debated within the focus groups. Approximately half of the participants believed that the consumer-rated measure should be offered in all mental health service settings, including acute inpatient units. They argued that while this may present difficulties to both consumers and clinicians in some situations, by not offering the consumer rated measure in all settings “*control of the process would be maintained with the clinician*”. Moreover, clinicians could lose the opportunity of collecting valuable information at this time.

Overall, they encouraged the measure to be offered in as wide a variety of service settings as possible, as often as possible. They argued that the more you asked the consumer their point of view, the better the clinicians understanding of the consumers' situation. A caveat to this approach is that asking questions is only the first part of the process - there is a follow-through implication for the clinician who is expected to respond to the information reported by the consumer and assist them with identified need or problem areas.

The opposing view was that consumer self-rating measures be confined to ambulatory settings because they are not appropriate in inpatient settings, particularly acute units, where most consumers are too ill to comprehend a measurement tool. When first admitted to an inpatient unit, the process of admission and the consumer's ability to make sense of information, especially written information is limited. As one person said *"I just wouldn't understand this"*. The primary concern was that imposing a survey form at a time of personal crisis could alienate and frustrate the consumer, compromising their treatment.

On balance, participants supported the principle that the consumer rated measure be offered at every mental health service site, with the rider that clinical judgement is required to determine the best time to offer the measure. However consumers felt that this clinical judgement should err on the side of offering the measure rather than not.

Furthermore, if the consumer initially refused to complete the measure then it should be offered again at another time. This may be several weeks later in the community or in the case of inpatient units, it should be offered around the third day of the inpatient stay because *"about the third day you start to feel better"*.

4.3.3 Strengthening therapeutic dialogue through sharing of ratings

Consumers wanted maximum exchange of information and believe that the introduction of routine outcome measurement should be used as an opportunity to begin a deeper dialogue with clinicians. There was strong support for clinicians discussing with the consumer the results of the clinical measures (HoNOS and LSP) as well as the BASIS-32. This was seen to *"put the power back to us, give us the chance to consider their (clinicians) arguments"*.

Sharing information highlighted for participants the importance of developing a trusting relationship with clinicians. Where the clinician did not discuss the ratings, this would undermine the person's confidence that the clinician was working in their best interests. Participants argued that clinicians should be aware that sharing information can have 'massive repercussions' for consumers and remember that for many, *"the last bit of paper that they saw with their name on it, got them committed"*. Some felt that the sharing of ratings *"should be mandated by the department"*. They were concerned that a great deal of personal information was being collected at present but not shared. If this tradition was extended to outcome measures, consumers would view the process with suspicion and scepticism.

To support the completion of the consumer rated measure, clinicians should involve consumers in a dialogue around the rating of both the

clinical and consumer-rated measures. This should include discussion of the similarities and differences between the clinician and consumer perspective's of ratings. It was recognised that this process may prove difficult for some consumers at certain times in their lives, but the opportunities for the majority of consumers and clinicians to strengthen the collaborative relationship outweigh the difficulties.

Consumers also indicated that this dialogue should not only include discussion around the current ratings of clinician and consumer measures but previous ratings as well. This will give consumers a sense of “*moving on*” and clinicians the opportunity to reflect on practice.

Consumers also want clinicians to be aware that if you ask a question, “*you have to follow through*”. For example, the BASIS-32 includes questions about difficulties in relationships. Participants want to know “*if I have problems, what help will you give me?*” They suggested that to ask questions in a collaborative manner is simply a “*good first step*”.

4.3.4 Need for clinician training

Participants suggested that clinicians would benefit from specific training to incorporate consumer self-ratings within their clinical practice. This should encourage them to use the information in way that provides benefit to the consumer as well as the overall service.

4.3.5 Role of Consumer Consultants

Some participants suggested that consumer consultants may be best placed to offer the consumer rated measure. Given their experience and position, they were seen to be better able to develop rapport with consumers, explain the questions and provide support to the consumer in completion of the measure. However, it was recognised that this may not be appropriate in many cases because of confidential issues, the potential blurring of boundaries between consumer and carer roles and the extra strain that this may place on the consumer consultant.

4.3.6 Using consumer self-ratings to improve service accountability

The introduction of regular consumer self-reporting measures creates a new form of service accountability when consumers' feedback is aggregated and reviewed at the agency level. Participants argued that the combined information provided by an agency's consumers should be reviewed regularly to identify and address service deficiencies. As an example, the story was told at one focus group an AMHS where the majority in consumers attending a group do not have cooking skills and their case managers have long known that this has

caused difficulties. The particular service has a large kitchen with several stoves, yet a cooking class has not been offered. Regular review and use of the aggregate results of consumer self-ratings should be used to highlight these issues and prompt appropriate program development.

5 DISCUSSION AND RECOMMENDATIONS

Three broad conclusions can be drawn from the focus groups that are central to the current project.

First, consumers support the introduction of routine outcome assessments and see the process as having potential to contribute to the treatment they receive. Reservations expressed in this report concern primarily the suitability of the current measure (BASIS-32) to meet consumer needs and the capacity of mental health services to engage in 'good process'.

Second, consumers articulate a broad range of content areas that they believe are essential to an understanding of their personal outcomes. Only some of these are covered in the BASIS-32.

Third, consumers are seeking a different approach to implementation of consumer self-ratings than has been the case to date. In particular, they want to see strong consumer involvement at all stages, commencing with the design of a new instrument that reflects their views.

The views expressed by consumers contributing to the current project echo those from previous work and documented earlier in this report.

A number of issues arise from the focus group consultations that are critical to the path forward. The remainder of this report presents our analysis of the issues and spells out recommendations to guide future work.

5.1 The content domains for consumer self-assessment

There is considerable overlap in domains covered by the consumer self-rated instruments that have been considered as candidates for routine use. These typically cover: functioning, general health status, specific clinical symptoms, and life satisfaction ('quality of life').

Our qualitative analysis of the ideas emerging from the focus groups identified seven content areas as being important to Victorian consumers. These have been structured to provide an indicative summary of the type of item content considered important to Victorian consumers rather than as a definitive set of domains. Refinement and consolidation is likely to occur if this work is taken to further stages.

There are two aspects to note about the content areas suggested by consumers participating in the current project. The first is the similarity to

the domains of the various consumer-based instruments that have been developed elsewhere for routine application.

Table 13 compares the seven content areas with the domains of a select number of instruments.

Table 13: Comparison of content domains of selected consumer outcome measures with those emerging from focus groups

<p>CURRENT PROJECT FOCUS GROUPS</p> <ul style="list-style-type: none"> • 'Quality of Life' • Functioning • Physical Health and Health Risks • Relationships • Illness Symptoms • Coping and Recovering from Illness • Satisfaction with Service Quality 	<p>BASIS-32</p> <ul style="list-style-type: none"> • Relation to Self and Others • Daily Living And Role Functioning • Depression and Anxiety • Impulsive and Addictive Behaviour • Psychosis
<p>MENTAL HEALTH INVENTORY¹⁷</p> <ul style="list-style-type: none"> • Anxiety • Depression • Behavioural/Emotional Control • General Positive Affect • Emotional Ties • Life Satisfaction • Psychological Distress and Well-Being 	<p>S.O.A.P.¹⁸</p> <ul style="list-style-type: none"> • Satisfaction • Self-concept • Work/Role • Mental Health • Interpersonal • Medication Effects • Activities of Daily Living • Physical Function
<p>SF-36¹⁹</p> <ul style="list-style-type: none"> • Physical Health • Role Limitations due to Physical Health Problems • Role Limitations due to Emotional Problems • Bodily Pain • Social Functioning • General Mental Health (psychological distress) • Psychological Well-Being • Vitality (Energy/Fatigue) • General Health 	<p>OHIO MENTAL HEALTH CONSUMER OUTCOMES SYSTEM²⁰</p> <ul style="list-style-type: none"> • Clinical Status • Quality of Life (Life Satisfaction, Fulfilment, Empowerment) • Functional Status • Safety and Health
<p>BICKMAN et al (child/adolescent)²¹</p> <ul style="list-style-type: none"> • Symptoms • Functional impairment and competence • Family functioning • Satisfaction 	<p>ROLE FUNCTIONING SCALE²²</p> <ul style="list-style-type: none"> • Working • Independent Living and Self-Care • Immediate Social Network Relationships • Extended Social Network Relationships

¹⁷ Veit CT and Ware JE. The structure of psychological distress and well-being in general populations. *Journal of Consulting and Clinical Psychology*, 1983, 51, 730-742

¹⁸ Barr J. Development and validation of a self administered survey for individuals with schizophrenia living in the community. *16th Annual Meeting of Academy for Health Services Research and Health Policy*, 1999. See <http://www.ahsr.aa.psiweb.com/1999/abstracts/barr.htm>

¹⁹ Ware JE. and Sherbourne CD. The MOS 36-item Short Form Health Status Survey (SF-36): I. Conceptual framework and item selection. *Medical Care* 30, 1992, 473-483

²⁰ See Footnote 8.

<ul style="list-style-type: none">• Self-esteem• Quality of life• Goal attainment	<ul style="list-style-type: none">• Global Role Functioning
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²¹ See Footnote 7. This is not an outcome measure as such but provides recommendations on the domains to be covered in outcome measures for child/adolescent mental health services.

²² Goodman SH., Sewell DR, Cooley EL. and Leavitt N. Assessing levels of adaptive functioning: the Role Functioning Scale. *Community Mental Health Journal*, 1993 29 (2): 119-131.

There is 'face-level' concordance with at least two other measures on five of the content areas: Functioning; Clinical Status/Symptoms; Life Satisfaction/'Quality of Life'; Relationships; Physical Health. This is not surprising given that these emerge consistently in the outcomes literature.

Of the remaining two - Coping/Recovering from Illness and Satisfaction with Service Quality- these are not well represented in available instruments. The former derives from more modern notions of consumer empowerment and recovery that were not foreground issues when several of the available scales were developed.

We believe that inclusion of items to tap the concepts underlying all domains is both desirable from an outcome measurement perspective and necessary to incorporate consumer views.

5.2 The inclusion of consumers' perceptions of service quality in outcome assessment

Consumer opinion that routine outcome measures include items to assess their perception of service quality is at odds with the established definition and scope of outcome measures. The challenge is how to reconcile this with the strong view expressed by consumers that inclusion of questions about consumer satisfaction alongside questions about personal outcomes is a pre-condition to achieving their full engagement.

There are two options. The first is to regard the challenge as educational in nature. This assumes that with further consultation and experience, consumers and their representatives will also recognise the need to separate the measurement of outcome from measurement of consumer's perception of service quality.

The alternative approach responds to consumer views by adding items to the consumer self-assessment scale to explicitly seek their views about the adequacy of the services they have received. This approach recognises that definitional purity is different from the process of information collection and analysis. Information gathered about consumers' perceptions of service quality would be analysed in its own right, to assist in interpreting the analysis of the more traditional outcome domains.

We believe that the advantages in taking the second approach far outweigh the retention of the status quo.

- It would reinforce Victoria's commitment to collaborative development with consumers that has been evident in other major

policy initiatives. The alternative approach would signal lack of commitment and become a rallying point for opposition to outcome measurement within the consumer sector.

- Information gathered on a routine basis about consumers' perception of the quality of services is valuable in its own right because it contributes to a better understanding of the outcome data. For example, it allows exploration of the relationship between consumer satisfaction and outcome which is not possible under the current approach that periodically samples the views of a limited number of consumers.
- It would contribute additional information to the responsible clinician about the consumer's experience that would assist in refining individual care plans to better meet needs.
- It would complement the existing approach to consumer satisfaction by providing consumer perspectives on service delivery, collected on a routine basis for the majority of clients.

It is important to clarify what pursuing this option might involve. We envisage only a small number of additional items that capture the essence of the consumer's experience of service delivery. It would not mirror the more lengthy Consumer Satisfaction Survey used periodically throughout Victorian mental health services. Selecting items that represent the 'essence' will be difficult but should occur in collaboration with consumer groups (see below).

Victoria would not be alone if it pursues this approach. The Ohio definition of outcomes also distinguishes health and outcome indicators of well-being from input and process measures of service delivery:

"Consumer Outcomes are indicators of health or well-being for an individual or family, as measured by statements or characteristics of the consumer/family, not the service system." ²³

Yet the introduction to the Ohio consumer instrument (Adult Consumer Form A) states that:

"We are very interested in how you are doing, and how our services may or may not be helping you." ²⁴ (our emphasis)

The Ohio measure also includes the following indicator of the consumer's perception of service delivery:

²³ See Footnote 14.

²⁴ The Ohio Adult Consumer Form A is attached at Appendix 5.

I have been treated with dignity and respect at this agency.

- Never
- Seldom/rarely
- Sometimes
- Often
- Always

Admittedly, this is only a single item which is grouped under the domain of 'Safety and Health' but, in view of Ohio's adherence to a consumer-centred value system, it points to the need to be flexible in settling on the content of a consumer measure.

Similarly, in their comprehensive analysis of an Australian approach to outcome measurement in child and adolescent services, Bickman *et al* recommend the inclusion of 'Satisfaction' as a central domain. They state that "*Satisfaction with services is either an outcome domain or a process domain ... Satisfaction is measured ... according to satisfaction with specific aspects of treatment (e.g., adequacy of facilities, accessibility of treatment).*"²⁵

Obvious risks are introduced if the consumer self-rating measure invites the consumer to comment about the adequacy of the care they receive. The process is potentially threatening to both the consumer and the clinician. The uneven distribution of power in the treatment relationship may induce fear on the part of the consumer, or defensive posturing by the clinician. We believe that taking these risks is a necessary step to developing a mature service system, an aspiration that is intrinsic to routine outcome measurement more generally.

5.3 The suitability of the BASIS-32

Consumers participating in this project gave the BASIS-32 a mixed report. The instrument is seen to be relevant in its content and brief to complete. Its failings were identified as lack of coverage of key content areas, its exclusive focus on difficulties, the inclusion of several items regarded as invasive or insensitive, the ambiguity of several items and inadequate instructions about the purpose of the instrument. Similar comments were made by consumers who participated in the Stedman *et al* field trial of the instrument.²⁶

On the positive side, the instrument has been established to have satisfactory psychometric properties and a growing research knowledge base that can guide interpretation of results. However, we believe that these attributes are insufficient to retain the BASIS-32 in an

²⁵ See Footnote 7.

²⁶ See Footnote 6.

unmodified form for the long term. At a minimum, modifications are required to accommodate the requirements of consumers. These would include a re-working of items, addition of new content areas and reframing the style of questioning to be positive or open ended. We anticipate that the amended instrument would differ substantially from the original.

We outline a process below for developing a 'consumer friendly' instrument that uses the BASIS-32, amongst other instruments, as a starting point. The process will be lengthy (2 years minimum), raising the issue of whether Victoria should continue with the BASIS-32 as an interim instrument. We believe that the BASIS-32 should be retained until a better alternative has been devised. Victoria's original rationale for introducing the BASIS-32 as an interim measure remains valid – that is, it allows valuable experience to be gained while new measures are explored, as well as provide consumers with an opportunity to participate from the outset in this early phase of routine outcome measurement.

5.4 Consumer ownership

A key conclusion arising from the current project is that the process for engaging stakeholders is as important as the choice of the instrument. As the principal stakeholders in the mental health industry, consumers are entitled to expect that a measurement tool inviting them to regularly assess their own health and well-being is both relevant and acceptable. The fact that the current project was initiated in the first place, and the findings emerging, indicate that many Victorian consumers do not believe that this fundamental condition has been met.

This is not intended as implicit criticism of the approach taken by Victoria. The outcomes implementation has been based on the best information available and occurred against the background of previous consumer consultations, at state and national levels, and within the context of a national agreement to begin routine outcome measurement. Rather, is intended to highlight that the critical task ahead is to work together with consumer representatives in a way that ensures they are full partners in the further development of the outcome measurement strategy.

5.5 Steps towards development of a new instrument

For Victoria to marry its dual commitment to consumer participation and outcome assessment, it should initiate a process to design a new consumer self-rating instrument. This would involve:

- *Establishing a consultative forum with consumer representatives, clinicians and academics with expertise in instrument development*

This group would act as the key advisory body. Consumer and service provider representation is desirable because any new instrument must ultimately reconcile the different perspectives and be useful to all parties. Representatives from the academic sector with expertise in instrument design will also be necessary. The current Victorian Outcomes Reference Group may be a suitable body to serve this function but we believe a new group needs to be set up with substantial consumer representation.

- *Identify content domains for a future consumer self-rating measure.*

Identifying the desirable content domains sets the parameters for instrument development. We anticipate this occurring through broadly-based consultation and review of the literature. Circulation of the current project report for comment by stakeholder groups would be a useful catalyst to the consultation process.

- *Review available measures to identify suitable items and construct initial instrument*

Items and subscales within existing instruments provide a rich source of options for developing a 'first cut' of the new instrument. As indicated above, the BASIS-32 provides a good starting point but will need complementing by additional content. Items would be selected, or modified to ensure their wording is 'consumer friendly' as well as covering the required outcome domains.

We anticipate that a composite instrument will be developed that incorporates components from other scales as well as additional items deemed necessary.

- *Pilot test and refine instrument*

This is likely to require several iterations and involves evaluating the scale from the perspective of its technical properties as well as consumer acceptability.

- *Ongoing evaluation of BASIS-32 data*

This should occur as a parallel task to inform item selection and construction of the final instrument. Substantial quantitative and qualitative data on the BASIS-32 will be collected over the course of developing a new instrument. Analysis should address critical issues including rates of completion, concordance between clinician and consumer ratings and the performance of individual items.

A similar approach was taken by the Ohio Department of Mental Health and extended over a three year period. It is useful to note that the final instruments developed for routine use represent a hybrid 'mix and match' of existing scales with modifications made to incorporate new elements not covered in available measures.

There are several ways in which the work might proceed but it will need a project manager to coordinate the various elements. Consumer consultants should also be employed to work alongside the Department. Involvement of the academic sector to assist in instrument development and technical design aspects will be required.

We anticipate a period of two years to complete the initial development work, which would need to be followed by work thereafter to further establish the new instrument.

An indicative budget in the range of \$250,000 - \$300,000 would be appropriate and comprise the following components:

Project Manager (2 years)	\$ 120,000
Consumer Consultant (s)	\$ 50,000
Technical Support (academic subcontract)	\$ 60,000
Operating costs (include travel, printing etc)	\$ 60,000
<i>Total (estimate only)</i>	<i>\$ 290,000</i>

5.6 Victorian or national instrument?

We anticipate that the issues facing Victoria in relation to the selection and use of the consumer self-rating measure will be raised in other jurisdictions as they move to introduce routine outcome assessment within public mental health services. While there is variation between the States and Territories in the consumer measure selected, with the majority using the Mental Health Inventory, our assessment is that none of the alternative instruments addresses adequately the issues raised by consumers in this project. Additional issues may also be of concern to consumers in other jurisdictions.

The possibility that each State and Territory develops its own measure is neither efficient nor sensible from the perspective of building an outcome measurement national knowledge base. The Commonwealth has foreshadowed its interest in being a partner in the development of a consumer self-rating measure that meets the needs of Australian consumers. Funding for this could be negotiated under the Information Development Agreement component of the Australian Health Care Agreements.

Given the work previously undertaken in Victoria, it is the logical jurisdiction to lead the national development. The process we have outlined above would apply but with a considerably wider consultation base. Our indicative budget incorporates this.

Negotiation will be required with both the Commonwealth and other jurisdictions to gauge their interest and agreement to Victoria undertaking the project on a national basis.

5.7 Promoting ‘good practice’ in routine outcome assessment

Consumers raised many issues about the process of outcome measurement that are not addressed simply through choosing the ‘right’ instrument. Their concerns support the findings of Stedman *et al* who argued that how outcomes are measured and used in practice process is as important as the selection of the measures themselves.

The incorporation of a consumer self-rated measure within the outcome suite has the potential to change the culture of services by providing a means for clients to become partners in the design of their care and how it is provided. For many clinicians, this does not come naturally. Also, staff movement in the industry is high making it difficult for new staff to receive procedural induction or training in the process aspects of outcome assessment.

The training approach designed in Victoria with the four ‘round one’ agencies advocates a ‘good practice’ approach to outcome assessment’ that includes key elements of the views expressed by consumers (see Table 14). It is important that in the ongoing roll-out of outcome measurement, future training programs give emphasis to these issues.

Table 14: Aspects of ‘good practice’ outcome assessment²⁷

- Inviting the consumer to self-rate their own health status and being genuinely interested in the responses that the consumer gives.
- Following up the self-rating with an invitation to the consumer to discuss their answers, elaborate on how they feel and discuss how it might impact on their individual treatment plan.
- Identifying any discrepancies between consumer and clinician ratings and using this information to reassess perceptions.
- Sharing the knowledge gained from both single and multiple ratings with the consumer themselves and integrating the results into the individual treatment plan.

5.8 Recommendations

1. That Victoria initiate the development of a new consumer self-rating instrument which:

²⁷ Based on Victorian Implementation Resource Manual. See footnote 2.

- ▶ builds on the strengths of the BASIS-32 and other available instruments;
 - ▶ covers domains considered of relevance to consumers including 'Quality of Life'; Functioning; Physical Health and Health Risks; Relationships; Illness Symptoms; Coping and Recovering from Illness; and Satisfaction with Service Quality; and
 - ▶ is designed to be 'consumer friendly' in all respects, including its instructions, content, language, and item format.
2. That development of the instrument occur from the outset with maximum participation by consumers and involve other stakeholders and academics with expertise in instrument design.
 3. That Victoria negotiate with other jurisdictions and seek funding from the Commonwealth to develop the instrument on a national basis. An indicative budget in the range \$250,000 - \$300,000 will be required.
 4. That the BASIS-32 be retained within the standard suite of outcome measures until a new instrument is available.
 5. That future training programs and communication about the outcome measurement strategy promote a 'good practice' approach to consumer self-assessment that emphasises the importance of process in building consumer confidence in routine outcome assessment.

APPENDICES

Appendix 1 - BASIS-32

Instructions:

On the following pages are a list of problems, and areas of life functioning, in which some people experience difficulties.

Put a tick in the box that best describes the degree of difficulty you have been experiencing in each area during the past two weeks.

For instance, Question 1 asks you "To what extent have you been experiencing difficulties in the area of: Managing you day to day life."

You should respond by placing a tick in the box which corresponds to the choices of No Difficulty; A little; Moderate; Quite a bit; or Extreme.

The BEHAVIOUR and SYMPTOM IDENTIFICATION SCALE (BASIS - 32)						
Put a tick in the box which best describes the degree of difficulty you have been experiencing in each area during the PAST TWO WEEKS.						
		No Difficulty	A Little Difficulty	Moderate Difficulty	Quite a Bit	Extreme Difficulty
To what extent are you experiencing difficulty in the area of:-						
1	Managing day-to-day life <i>(eg. getting to places on time, handling money, making everyday decisions)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	Household responsibilities <i>(eg. shopping, cooking, laundry, keeping room clean, other chores)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Work <i>(eg. completing tasks, performance level, finding / keeping a job)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	School <i>(eg. academic performance, completing assignments, attendance)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To what extent are you experiencing difficulty in the area of:-						
5	Leisure time or recreational activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Adjusting to major life stresses <i>(eg. separation, divorce, moving, new job, new school, a death)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	Relationships with family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	Getting along with people outside of the family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	Isolation or feelings of loneliness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To what extent are you experiencing difficulty in the area of:-						
10	Being able to feel close to others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	Being realistic about yourself or others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	Recognising and expressing emotions appropriately	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	Developing independence, autonomy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14	Goals or direction in life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	Lack of self-confidence, feeling bad about yourself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The BEHAVIOUR and SYMPTOM IDENTIFICATION SCALE (BASIS - 32)						
Put a tick in the box which best describes the degree of difficulty you have been experiencing in each area during the PAST TWO WEEKS.						
		No Difficulty	A Little Difficulty	Moderate Difficulty	Quite a Bit	Extreme Difficulty
To what extent are you experiencing difficulty in the area of:-						
16	Apathy, lack of interest in things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17	Depression, hopelessness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18	Suicidal feeling or behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19	Physical symptoms <i>(eg. headaches, aches and pains, sleep disturbance, stomach aches, dizziness)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20	Fear, anxiety or panic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To what extent are you experiencing difficulty in the area of:-						
21	Confusion, concentration, memory	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22	Disturbing or unreal thoughts of beliefs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23	Hearing voices, seeing things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24	Manic, bizarre behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25	Mood swings, unstable moods	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26	Uncontrollable, compulsive behaviour <i>(eg. eating disorder, hand-washing, hurting yourself)</i> Please specify:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<hr/>						
<hr/>						
<hr/>						
<hr/>						
To what extent are you experiencing difficulty in the area of:-						
27	Sexual activity or preoccupation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28	Drinking alcoholic beverages	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29	Taking illegal drugs, misusing drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30	Controlling temper, outbursts of anger, violence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31	Impulsive, illegal or reckless behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32	Feeling satisfaction with your life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix 2 – Letter of invitation to Consumers to attend Focus Groups

8 August 2000

Dear Consumer

As you are probably aware over the next twelve months all public adult mental health services will be required to implement a new consumer assessment process to measure consumer outcomes. It is part of the Victorian Mental Health Outcomes Strategy. This strategy will put a standard process in place to measure changes in consumers' health status over specific periods of time.

Two types of outcome measures are to be introduced to assess consumer's health status. The first will be completed by a clinician (depending on the setting the clinician will rate the consumer's health status using two agreed outcome measures) and the second type will be an optional self-assessment measure that is completed by the consumer.

Your area mental health service has been part of the project to try out the outcome measures before they are introduced across the rest of the State. The project is being implemented by an independent team from the Centre for Health Services Development Part of this project is to have a consultation to get consumers' views on:

- how the process of consumer outcome assessment should be undertaken;
- whether consumers wish to undertake self-assessment;
- the questions or areas that should be covered in a self-rating measure;
- the process and suitability of the consumer self-assessment measure that will initially be used (called BASIS – 32) in relation to the above questions;
- any other views in relation to the process, utility and outcome measurement.

I understand that you have been offered the opportunity to complete a BASIS-32. Whether you chose to fill it out or not we would like to invite you to participate in a focus group to gain your ideas on the dot points listed above. The focus group will be held on Wednesday, 23 August from 2.00pm to 3.30pm at , Ballarat and will be facilitated by Carolyn Graham, a consumer. Payment to unwaged participants will be \$20 per hour with reimbursement of transport costs on presentation of receipts for train, tram or petrol.

As you will appreciate the introduction of outcome measures in mental health services is going to impact on us, the consumer. Thus we urge you to participate in the focus group and ensure the inclusion of consumers' views in the outcome measures strategy.

If you have any queries at all please do not hesitate to ring me on ... and reverse the charges. Please note that individuals and groups confidentiality will be protected throughout the project with no names mentioned in the final report.

Yours sincerely

Carolyn Graham

(Consumer Consultant and on behalf of CHSD team)

APPENDIX 3 - Letter of invitation to Consumers to attend Information Workshops

30 July 2000

Dear VicCAG member

As you may be aware over the next twelve months all public adult mental health services will be required to implement a new consumer assessment process to measure consumer outcomes. It is part of the Victorian Mental Health Outcomes Strategy. This strategy will put a standard process in place to measure changes in consumers' health status over specific periods of time.

In the past it could be said that health professionals were making their own individual assessment of consumers health status (and thus outcome) continually in the course of their daily work. One of the limitations of this approach is that generally there was no provision for obtaining routine, systematic and comparable information about consumers. Under the new strategy a variety of measurement tools and instruments have been developed to measure changes in consumers' health status

Two types of outcome measures are to be introduced to assess consumer's health status. The first type will be completed by a clinician (depending on the setting the clinician will rate the consumer's health status using two agreed outcome measures) and the second type will be an optional self assessment measure that is completed by the consumer.

The Department of Human Services has chosen the outcome measures that all clinicians are to use. However it has chosen only an interim consumer self-assessment measure called BASIS - 32. This is because a consumer consultation is to be conducted over the next two months. This consultation will be organised by an independent team from the Centre for Health Service Development (names attached). The objectives of this consultation are to obtain a range of consumer views on:

- how the process of consumer outcome assessment should be undertaken;
- whether consumers wish to undertake self-assessment;
- the questions or areas that should be captured in a self-rating measure;
- the process and suitability of the consumer self-assessment measure that will initially be used (called BASIS – 32) in relation to the above questions that are suggested;
- any other views in relation to the process, utility and outcome measurement.

Five target groups have been identified for participation in the consumer consultation. VicCAG members are one of these as well as consumer consultants, consumer groups, consumers from four project pilot agencies and some representative organisations.

We would like to invite you to participate in the consultation project, which is to have two stages. Stage 1 is the conduct of information workshops. The workshops will include explanation of the Victorian Outcomes Strategy, key concepts to do with

outcome measures, to experience and discuss the interim consumer self-rating measure, BASIS – 32, and to indicate the type of questions that will be asked in the consultation. At the conclusion of the workshop participants will be provided with an information package. This will reinforce the areas covered in the workshop and should assist you in discussing the issues with consumers that are your constituency.

A number of weeks following the information workshop you will be asked to participate in Stage 2, a focus group. Here your opinions about consumer self-rating measure/s and those of the consumers that you represent, will be gathered.

Information workshops will be held on Monday, August 21 from 1.00pm to 3.30p.m or Tuesday, August 22 from 1.00pm to 3.30p.m at Ross House, 4th floor, 247 Flinders Lane, Melbourne. Payment to unwaged participants will be \$20 per hour with reimbursement of transport costs on presentation of receipts for train, tram or petrol. Focus groups will probably be conducted in Melbourne, Bendigo, Geelong and Traralgon, although we would like to discuss this with participants at the information workshops.

As you will appreciate the introduction of outcome measures in mental health services is going to impact on us, the consumer. Thus we urge your participation in the project to ensure the inclusion of consumers' views in the outcome measures strategy.

To register your participation or non-participation please return the attached slip by mail to or email or ring me on by Wednesday, August 16.

Ensure that you indicate which information session that you would like to attend.

If you have any queries at all please do not hesitate to ring me on. Please note that individuals and groups confidentiality will be protected throughout the project with no names mentioned in the final report.

Yours sincerely

Carolyn Graham

(Consumer Consultant and on behalf of CHSD team).

Attachment: names of Consultancy Team

APPENDIX 4 - Focus Groups Questions

CONTENT AREAS THAT NEED TO BE COVERED IN A CONSUMER SELF-RATING OF OUTCOME

- As a consumer there is some expectation that mental health services will help to minimise the effects of mental illness. What are the areas you think of when assessing the changes that have occurred as a result of care you are receiving?
Areas that might be considered include:
 - The severity of symptoms and disability
 - Social contacts and meaningful work
 - Ability to ask to be treated with respect and following a recovery plan
 - Minimisation of the detrimental effects of treatment and care
- Are some areas more important than others? If so which ones?
- Is it meaningful to gather information about a change in a consumer's mental health (outcomes) without also asking about:
 - A consumer's views on the quality of the services received; and
 - The extent to which the service meet the consumers' needs?
- What other questions should be asked?
- What happens outside of the clinical area that results in a change in a consumer's mental health?

THE PROCESS OF OUTCOME MEASUREMENT

- How should staff approach consumers to get them to complete outcome measures
- What helps (helped you) consumers complete these outcome measures?
- What stops (stopped you) consumers completing these outcome measures?
- Should the results of clinician rated measures be shared with consumers? How should this happen?
- Who should have access to the information contained in outcome measures?
- What things need to happen within the system to make outcome measurement work best for consumers?
- When you were offered the BASIS to complete what was it about the way that it was given to you made you want or not want to complete it?

THE SUITABILITY OF THE BASIS

- To what extent does the BASIS capture the content areas important to consumers? Are there key areas that are not covered?

- Are the questions easy to understand?
- Is the language appropriate to consumers?
- Are there any changes that you can suggest?

APPENDIX 5 - Ohio Mental Health Consumer Outcomes System Adult Consumer Form A



Ohio Mental Health Consumer Outcomes System Adult Consumer Form A

A

Today's Date ____/____/____ Name _____ Date of Birth ____/____/____ Gender (check one): Male <input type="checkbox"/> Female <input type="checkbox"/>	<p style="text-align: center;">Agency Use Only</p> Client's Medical Record Number: _____
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We are very interested in how you are doing, and how our services may or may not be helping you. Please answer all of the questions below, then give the questionnaire to your case manager or another staff person at the mental health agency.

Part 1

Below are some questions about how satisfied you are with various aspects of your life in ***the past 6 months***. For each question, checkmark the answer that best describes how you feel.

How do you feel about:

1. The amount of friendship in your life?

- Terrible
- Mostly dissatisfied
- Equally satisfied/dissatisfied
- Mostly satisfied
- Very pleased

2. The amount of money you get?

- Terrible
- Mostly dissatisfied
- Equally satisfied/dissatisfied
- Mostly satisfied
- Very pleased

3. How comfortable and well-off you are financially?

- Terrible
- Mostly dissatisfied
- Equally satisfied/dissatisfied
- Mostly satisfied
- Very pleased

4. How much money you have to spend for fun?

- Terrible
- Mostly dissatisfied
- Equally satisfied/dissatisfied
- Mostly satisfied
- Very pleased

5. The amount of meaningful activity in your life (such as work, school, volunteer activity, leisure activity)?

- Terrible
- Mostly dissatisfied
- Equally satisfied/dissatisfied
- Mostly satisfied
- Very pleased

6. The amount of freedom you have?

- Terrible
- Mostly dissatisfied
- Equally satisfied/dissatisfied
- Mostly satisfied
- Very pleased

7. The way you and your family act toward each other?

- Terrible
- Mostly dissatisfied
- Equally satisfied/dissatisfied
- Mostly satisfied
- Very pleased
- Does not apply

Please turn to the next page ➔

8. Your personal safety?

- Terrible
- Mostly dissatisfied
- Equally satisfied/dissatisfied
- Mostly satisfied
- Very pleased

9. The neighborhood in which you live?

- Terrible
- Mostly dissatisfied
- Equally satisfied/dissatisfied
- Mostly satisfied
- Very pleased

10. Your housing/living arrangements?

- Terrible
- Mostly dissatisfied
- Equally satisfied/dissatisfied
- Mostly satisfied
- Very pleased

11. Your health in general?

- Terrible
- Mostly dissatisfied
- Equally satisfied/dissatisfied
- Mostly satisfied
- Very pleased

12. How often do you have the opportunity to spend time with people you really like?

- Never
- Seldom/rarely
- Sometimes
- Often
- Always

Part 2

These next few items ask you about your health and medications *within the past 6 months*.

13. How often does your physical condition interfere with your day-to-day functioning?

- Never
- Seldom/rarely
- Sometimes
- Often
- Always

14. Concerns about my medications (such as side effects, dosage, type of medication) are addressed:

- Never
- Seldom/rarely
- Sometimes
- Often
- Always
- Not applicable/no medications

The next two items deal with how you have been treated by other people.

15. I have been treated with dignity and respect at this agency.

- Never
- Seldom/rarely
- Sometimes
- Often
- Always

16. How often do you feel threatened by people's reactions to your mental health problems?

- Never
- Seldom/rarely
- Sometimes
- Often
- Always

Part 3

The following questions ask you about how much you were distressed or bothered by some things *during the last seven days*. Please mark the answer that best describes how you feel.

During the past 7 days, about how much were you distressed or bothered by:

17. Nervousness or shakiness inside

- Not at all
- A little bit
- Some
- Quite a bit
- Extremely

18. Being suddenly scared for no reason

- Not at all
- A little bit
- Some
- Quite a bit
- Extremely

19. Feeling fearful

- Not at all
- A little bit
- Some
- Quite a bit
- Extremely

20. Feeling tense or keyed up

- Not at all
- A little bit
- Some
- Quite a bit
- Extremely

21. Spells of terror or panic

- Not at all
- A little bit
- Some
- Quite a bit
- Extremely

22. Feeling so restless you couldn't sit still

- Not at all
- A little bit
- Some
- Quite a bit
- Extremely

23. Heavy feelings in arms or legs

- Not at all
- A little bit
- Some
- Quite a bit
- Extremely

24. Feeling afraid to go out of your home alone

- Not at all
- A little bit
- Some
- Quite a bit
- Extremely

25. Feeling of worthlessness

- Not at all
- A little bit
- Some
- Quite a bit
- Extremely

26. Feeling lonely even when you are with people

- Not at all
- A little bit
- Some
- Quite a bit
- Extremely

27. Feeling weak in parts of your body

- Not at all
- A little bit
- Some
- Quite a bit
- Extremely

28. Feeling blue

- Not at all
- A little bit
- Some
- Quite a bit
- Extremely

29. Feeling lonely

- Not at all
- A little bit
- Some
- Quite a bit
- Extremely

30. Feeling no interest in things

- Not at all
- A little bit
- Some
- Quite a bit
- Extremely

31. Feeling afraid in open spaces or on the streets

- Not at all
- A little bit
- Some
- Quite a bit
- Extremely

32. How often can you tell when mental or emotional problems are about to occur?

- Never
- Seldom/rarely
- Sometimes
- Often
- Always

33. When you can tell, how often can you take care of the problems before they become worse?

- Never
- Seldom/rarely
- Sometimes
- Often
- Always

Part 4

Below are several statements relating to one's view about life and having to make decisions. Please check the response that is closest to how you feel about the statement. Check the word or words that best describes how you feel now.

34. I can pretty much determine what will happen in my life.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

35. People are limited only by what they think is possible.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

36. People have more power if they join together as a group.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

37. Getting angry about something never helps.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

38. I have a positive attitude toward myself.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

39. I am usually confident about the decisions I make.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

40. People have no right to get angry just because they don't like something.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

41. Most of the misfortunes in my life were due to bad luck.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

42. I see myself as a capable person.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

43. Making waves never gets you anywhere.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

44. People working together can have an effect on their community.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

45. I am often able to overcome barriers.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

46. I am generally optimistic about the future.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

47. When I make plans, I am almost certain to make them work.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

48. Getting angry about something is often the first step toward changing it.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

49. Usually I feel alone.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

50. Experts are in the best position to decide what people should do or learn.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

51. I am able to do things as well as most other people.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

52. I generally accomplish what I set out to do.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

53. People should try to live their lives the way they want to.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

54. You can't fight city hall (authority).

- Strongly agree
- Agree
- Disagree
- Strongly disagree

55. I feel powerless most of the time.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

56. When I am unsure about something, I usually go along with the rest of the group.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

57. I feel I am a person of worth, at least on an equal basis with others.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

58. People have a right to make their own decisions, even if they are bad ones.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

59. I feel I have a number of good qualities.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

60. Very often a problem can be solved by taking action.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

61. Working with others in my community can help to change things for the better.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

Part 5
Please tell us some things about yourself.

62. What was the last school grade you completed?

- | | |
|--|--|
| <input type="checkbox"/> Less than 1 st grade | <input type="checkbox"/> 10 th grade |
| <input type="checkbox"/> 1 st grade | <input type="checkbox"/> 11 th grade |
| <input type="checkbox"/> 2 nd grade | <input type="checkbox"/> High school diploma/GED |
| <input type="checkbox"/> 3 rd grade | <input type="checkbox"/> Trade/Tech school |
| <input type="checkbox"/> 4 th grade | <input type="checkbox"/> Some college |
| <input type="checkbox"/> 5 th grade | <input type="checkbox"/> 2 yr college/Associate degree |
| <input type="checkbox"/> 6 th grade | <input type="checkbox"/> 4 yr college/Undergraduate degree |
| <input type="checkbox"/> 7 th grade | <input type="checkbox"/> Graduate school courses |
| <input type="checkbox"/> 8 th grade | <input type="checkbox"/> Graduate degree |
| <input type="checkbox"/> 9 th grade | <input type="checkbox"/> Post-graduate studies |
| | <input type="checkbox"/> Further special studies |

63. Race (check all that apply):

- | | |
|---|--|
| <input type="checkbox"/> White | <input type="checkbox"/> Hispanic/Latino |
| <input type="checkbox"/> Native American/Pacific Islander | <input type="checkbox"/> Asian |
| <input type="checkbox"/> Black/African-American | <input type="checkbox"/> Other _____ |

64. What is your marital status?

- Never married
- Married
- Separated
- Divorced
- Widowed
- Living together

65. What is your current living situation?

- Your own house/apartment
- Friend's home
- Relative's home
- Supervised group living
- Supervised apartment
- Boarding home
- Crisis residential
- Child foster care
- Adult foster care
- Intermediate care facility
- Skilled nursing facility
- Respite care
- MR intermediate care facility
- Licensed MR facility
- State MR institution
- State MH institution
- Hospital
- Correctional facility
- Homeless
- Rest home
- Other _____

66. What is your employment status?

- Employed full time
- Employed part time
- Sheltered employment
- Unemployed
- Homemaker
- Retired
- Disabled
- Inmate of institution

67. Are you in treatment because you want to be?

- Yes
- No

Please stop here. Thanks!!

