
Continence Clinic Project

Outcome Measurement for Victorian Continence Clinic Services



National Ageing Research Institute

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NARI staff:

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Key Terms:

Continence:

International Continence Society (ICS) - New Definition:

Urinary incontinence is the complaint of any involuntary leakage of urine.

International Continence Society (ICS) - Old Definition:

Urinary incontinence is the involuntary loss of urine that is a social or hygienic problem.

The ICS (2001) recommend both definitions be adopted. "Two definitions of incontinence are necessary firstly to reflect the true prevalence of incontinence (new definition) and secondly to describe the prevalence of troublesome incontinence that is likely to lead the sufferer to seek advice and treatment (old definition)" (ICS 2001)

Health outcome: "A change in an individual, a group, or population, which is attributable to an intervention or series of interventions" (AHMAC, 1993)

Victorian Continence Clinic Service:

".. an accessible multidisciplinary clinical service specialising in incontinence and other bladder and/or bowel function difficulties providing assessment, diagnosis, management, education and support to improve continence for clients. The service will also provide consultancy, education and support to carers, relatives and professional service providers" (Continence Clinic Program Guidelines and Performance Indicators, 2001)

List of Abbreviations:

D.H.S Department of Human Services

N.A.R.I National Ageing Research Institute

Executive Summary:

Background:

Incontinence is increasingly growing as one of the largest health issues confronting the Australian community. Incontinence affects people of all ages, both sexes, and people of every social and economic level. From an economic perspective, Australians spend over \$1 billion dollars each year on incontinence. A far greater cost is associated with the direct impact incontinence can have on people's self-esteem, dignity and level of independence.

The Victorian Department of Human Services (DHS) fund 17 Continence Clinic Services throughout the state. Continence Clinic Services provide "... professional advice, support and information to all on the promotion of continence and the management of incontinence" (DHS, 2001, p. 7).

In 2000/2001, a Continence Clinic program guidelines and performance indicators document (DHS 2001) was developed and published by a working party established by the Aged Care Branch of the Department of Human Services. This document was developed to:

- Assist service providers in setting minimum service requirements; and
- Enable purchasers to determine what constitutes a quality service.
- Help the public to understand the main components of the services they receive

This document was in the process of being reviewed by the Victorian Department of Human services and a DRAFT document was developed and provided to the National Ageing Research Institute in 2003 (unpublished 2003).

Project Aims:

The DHS commissioned the National Ageing Research Institute (NARI) to *seek feedback from experts in the field on the DRAFT best practice guideline document and to finalise this report given the feedback provided*. The final version of the Best Practice guideline document is provided as a separate report.

In the early stages of the NARI/ DHS project implementation, a significant body of work on Outcome Measures (DRAFT form) was identified (project undertaken by LaTrobe University Faculty of Health Sciences for the Commonwealth Department of Health and Ageing, November 2003). Following consultation with representatives from both LaTrobe University and the Commonwealth Department of Health and Ageing, it was agreed by the NARI/ DHS project steering committee that the 'best practice guideline project' would also include a service field test of some of the measures identified within the LaTrobe university DRAFT report. This was therefore incorporated into the methodology and a second project aim was developed - *To field-test outcome measures as identified within the Continence Outcome Measurement Suite Project DRAFT report to further determine their clinical acceptability and practicability for use within Victorian Continence Clinic services*.

Project Methodology and Results:

A workshop was held with experts from the field and the outcome measures as identified within the DRAFT Continence Outcomes Measurement Suite project report (LaTrobe 2003) were reviewed. Three tools were recommended for field-testing within Victorian Continence Clinic services. These tools were the Wexner/ Cleveland Clinic Faecal Incontinence Score; the Urogenital Distress Inventory – Short form and the Kings Health Questionnaire. A standard bladder diary incorporating recommendations from the 2nd ICS/ WHO Consultation on Incontinence was recommended for trial, as too the Modified Care-giver Strain Index – a tool not reviewed in the Continence Outcomes Measurement Suite project DRAFT report (LaTrobe 2003).

Fourteen services were recruited and were involved in an information session where the tools were presented and the demands of the research project considered. These 14 services then field-tested the tools on a consecutive series of clients for an approximate one-month period. Feedback was provided on the applicability and practicability of these tools via focus groups with Continence Service staff and via data collection sheets completed by practitioners post use of the assessment with each client.

An outcome measurement survey was also developed and sent to all Victorian DHS funded Continence Clinic Services. The survey aimed to identify current outcome measurement use, and staff opinion about relevant outcome measure domains and tools, to help inform the development of an outcome measurement framework.

There was considerable variability in the use of outcome measurement tools across services. No outcome measures were being consistently used across services or across client groups. Outcome measurement was seen by all services as a minimum expectation in today's evidence based health service environment and as required in order to better judge the efficiency and effectiveness of Continence Clinic Services and client outcomes.

Outcome measures were identified as needing to be simple to use and time efficient to administer if they are to be accepted by practitioners. Traits such as the tool's ability to be translated into different languages and its ability to be administered in different ways were also valued. Most services identified benefits in having commonality in core outcome measurement across the state. Having one or a few tools to use with all clients across all services and then having a suite of tools to draw upon to meet individual service or client needs was a concept largely valued.

All services identified benefits and weaknesses for all of the outcome measures trialed in this project and all services identified that no tool or selection of tools could replace existing assessment practice. Whilst assessment practice was not considered as part of this project, this finding has important implications as, if recommended, any of the outcome measures trialed will need to be implemented in addition to existing service demands. Concern was also expressed by most services about how data collected by the outcome measures would be interpreted and used, and most services identified a need for a longer trial and evaluation period to further determine any of the tools measurement merits.

In the future, five regional and rural services identified that they would consider using the Wexner/ Cleveland Clinic Faecal Incontinence Score, Kings Health Questionnaire and the Modified Caregiver strain index on admission and discharge for all clients presenting to a Continence Clinic service. Six additional services identified that the Wexner/ Cleveland Clinic Faecal Incontinence Score and the Urogenital Distress Inventory short form could be used by all clients presenting with faecal and urinary incontinence respectively. Most services identified that the Kings Health Questionnaire should be used for a target population presenting with urinary incontinence (mostly described as younger in age and cognitively able) and for research purposes.

Project critique:

The results described above need to be interpreted in the context of limitations including the following:

- The project aimed only to field test tools as identified within the Continence Outcomes Measurement Suite project DRAFT report – with the aim of exploring issues related to tool applicability and practicability. The tool's ability to detect change related to Continence Clinic health service intervention can therefore not be reported on in this project report.
- This project did not consider tools or outcome measurement domains outside of those identified within the Continence Outcomes measurement suite project DRAFT report (LaTrobe 2003). As

such, domains including client goal attainment and satisfaction (measurement domains identified within the outcome measurement survey as important by many services) were not considered.

- A context was established at the beginning of the project for the development of a suite of core outcome measures to use across all client groups and all services, and then recommended tools that could be drawn upon to meet local needs and interests. A 'one size fits all approach' could be considered a limitation to this project.

Recommendations:

There were two aims for this project. The recommendations detailed in this report only relate to Project Aim Two. Project Aim One was to finalise the best practice guideline document post feedback from an expert steering committee – the outcome of this aim is provided in a separate report. Project Aim two was to field test outcome measures as identified within the Continence Outcomes Measurement Suite project DRAFT report (LaTrobe 2003) to further determine their clinical acceptability and practicability for use within Victorian Continence Clinic services. The recommendations identified as a result of the project methodology adopted to meet Project Aim Two are as follows:

- Recommend the development of a minimum set of core outcome measures to use across all Continence Clinic services and all client groups in the context of a broader suite of tools to draw upon to meet local needs and interests.
- Where there is a desire to use a common measurement approach for all clients presenting to Continence Clinic Services in Victoria the following tools should be considered as part of a more formal trial given their general field acceptance from a practicability and usability perspective: The Wexner/ Cleveland Clinic Faecal Incontinence Score and the Urogenital Distress Inventory – Short Form. The King's Health Questionnaire was considered beneficial for research purposes.

Project activity recommended as a result of this project:

- This project considered evaluation related to tool acceptability and usability. There is a need for a formal trial of any recommended measures for a sufficient period in order to profile clients who access continence services, and to identify the usefulness of the recommended measures in identifying change in response to intervention. Throughout this time, there is a need to monitor the effect of any additional demands placed on services – for example implementation of the Service Co-Ordination Tool Templates on issues regarding measure acceptability and practicability. All tools field-tested were identified as being inappropriate for administration with some clients – for example, clients accessing a service for a repeat prescription of continence aides or clients presenting with impaired cognition. It is recommended that a profile of these clients be collected to determine if other measures are more appropriate to identify change associated with intervention for these client groups.
- This project only considered outcome measures recommended within the Continence Outcomes Measurement Suite project DRAFT report (LaTrobe 2003). Additional measurement domains were identified by practitioners as needing to be incorporated into an outcome measurement framework but were not included in this project activity. Examples of such domains include - measures or a process for documenting and evaluating client goals, measures addressing client and caregiver satisfaction and measures addressing constipation and quality of life related to faecal incontinence. These measurement domains would benefit from further exploration.
- Reducing continence related caregiver strain and demand is commonly reported as a goal requiring continence service intervention. Most services identified the need for further research in this area.

- That the outcome measurement process remain a dynamic one with opportunities provided for continual review – including consideration of recommendations and discussion from the 3rd International Consultation on Incontinence in Monaco July 2004. Further investigation of work completed by the Continence Physicians group on outcome measurement (1998) is recommended.

Background:

How big is the incontinence problem?

It is estimated that over 2 million Australians have some degree of incontinence (McCallum 2003). That's over 1 in 10 people! (Australian Institute of Health and Welfare 2002). Incontinence affects all ages, both sexes, and people of every social and economic level - it is increasingly growing as one of the largest health issues confronting the Australian community. It is estimated that at any time 1 in 3 adult woman in the Australian population (Chiarelli et al 1999) have some degree of incontinence and one in ten men, with the prevalence of incontinence increasing with age (72% of residents in aged care facilities (Pearson et al 2002); up to 40% of the over 75 age group) and increasing amongst Aboriginal and Torres Strait Islander Communities (Bruce et al 1998). Women comprise 70% of the incontinent population with problems arising primarily after childbirth and menopause. Almost half of all women aged 26 – 39 will exhibit some form of incontinence at least once during this period of their lives.

What is the cost to the community?

Australians spend over \$1 billion each year on incontinence, including around \$200 million on pads and continence aides. Incontinence can result in prolonged hospital stays in both acute and extended care settings, and can incur additional costs when considering the treatment of associated factors such as skin breakdowns and urinary tract infections. Bladder control problems have been estimated as trebling the cost of care in nursing homes, with 60% of nursing time in these homes being directed towards incontinence management.

Notwithstanding the financial costs, there are many hidden costs which whilst often difficult to measure are important to consider. Incontinence has an impact on people's self-esteem, dignity and level of independence. It has been linked with early withdrawal from the work force and with withdrawal from family activities and social participation in the community.

Who's there to help?

Continence care can be accessed through a variety of means. A person's general practitioner (GP) or pharmacist is often the first point of contact for someone experiencing a continence problem.

The Department of Human Services Victoria fund 17 Continence Clinic services throughout the state. These services aim:

"to be an accessible multidisciplinary clinical service specialising in incontinence and other bladder and/or bowel function difficulties providing assessment, diagnosis, management, education and support to improve continence for clients. The service will also provide consultancy, education and support to carers, relatives and professional service providers" (DHS 2001).

What is the purpose of this project?

The National Ageing Research Institute (NARI) was commissioned by the Victorian Department of Human Services (DHS) to assist in finalising the extensive work already completed by the Department of Human Services and an expert steering committee, reviewing the Continence Clinics Program Guidelines and Performance Indicators document (2001). The NARI/ DHS project had one primary aim:

Aim One:

1. To obtain feedback from representatives of the field, incorporate the feedback and complete the best practice guidelines document for Victorian Continence Clinic services.

In the early stages of the NARI/ DHS project implementation, a significant body of work on Outcome Measures (DRAFT form) was identified (project undertaken by LaTrobe University Faculty of Health Sciences for the Commonwealth Department of Health and Ageing November 2003). Following consultation with representatives from both LaTrobe University and the Commonwealth Department of Health and Ageing, it was agreed by the NARI/ DHS project steering committee that the 'best practice guideline project' would also include a Continence clinic service field test of some of the measures identified within the LaTrobe university DRAFT report. This was therefore incorporated into the methodology and a second project aim was developed.

Aim Two:

2. To field-test outcome measures as identified within the Continence Outcome Measurement Suite Project DRAFT report to further determine their clinical acceptability and practicability for use within Victorian Continence Clinic services.

The following report outlines the methodology and results of the outcome measures component of the project.

Project Activities:

The following project activities were undertaken: (Appendix One: Project Proposal)

Phase One: Project Development and Preparation

- Established Project Steering Committee and Working Committee including DHS project staff, field representatives across a number of disciplines, and regional and metropolitan representatives.
- Developed and disseminated a survey (Appendix Two: Outcome Measurement survey) to determine current use of outcome measures across DHS funded Victorian Continence Clinic services. Seventeen surveys posted. Eleven returned (65% response rate).
- Disseminated the existing DRAFT best practice guideline document (not published 2003) for steering committee review and comment. Disseminated the existing Best Practice guideline document (DHS 2001).

Phase Two: Field testing of Outcome Measures

- NARI facilitated a working group with steering committee members to review measures as identified within the Continence Outcomes Measurement Suite DRAFT report (LaTrobe University, 2003). Steering committee identified four measures for field-testing (Appendix Three: Measures for field-testing) and expressed interest in field testing the Modified Caregiver strain index (Thornton et al 2003).
- Recruited services to field-test the Outcome Measures as identified by the project steering committee. Fourteen services recruited representing metropolitan, rural and regional Victoria.
- Information session for recruited Continence Clinic services to present Outcome Measures and consider project requirements. Eight information sessions conducted averaging two hours in length. Information sessions included: Background to project; Presentation of tools to be trialed; Implementation and evaluation issues.
- Outcome Measures field-tested in fourteen Continence Clinic services. Field-testing occurred for 4-6 weeks. Practitioners were encouraged to use the outcome measures with a consecutive number of new clients being admitted to the service during the established time period. The Wexner/ Cleveland Clinic Faecal Incontinence Score was recommended for use with all consecutively admitted clients presenting with faecal incontinence symptoms. The UDI and the Kings Health questionnaire was recommended for use with all consecutively admitted clients presenting with urinary incontinence symptoms. The Modified Caregiver strain index was recommended for use with all clients who had a primary carer attend the assessment visit. The bladder diary was recommended for use with all clients presenting with urinary incontinence symptoms. A de-identified client-tracking sheet was provided to each service. Some measures were not considered appropriate by practitioners for administration to some clients. Services were asked to document reasons why a client was not administered a particular tool.

Phase Three: Outcome Measurement evaluation

- Received and analysed responses from Outcome Measures survey – presented to steering committee for their expert opinion and review.
- Focus groups (Appendix Four: Focus group questions) with recruited Continence Clinic services regarding the acceptability of the Outcome measures used. Eleven services were involved in the focus groups, one additional service provided written feedback to focus group questions. Presented findings to the steering committee for their expert opinion and review.
- Report provided to the steering committee on the Outcome Measures component of the NARI/ DHS project.

Phase Four: Finalisation of Best Practice guideline document

- Steering committee provided feedback about the existing Best Practice guideline document.
- Feedback incorporated to assimilate a FINAL Best Practice guideline document.

Summary of Timelines:

Key Tasks	Time Lines
Established Steering Committee	November 2003
Developed, Disseminated and assimilated results from Outcome Measures survey	December 2003 – February 2004
Steering Committee meeting reviewed revised project proposal, discussed limitations, reviewed terms of reference for working group, discussed preliminary results of outcome measures survey, DHS disseminated DRAFT best practice guidelines document and existing best practice guidelines document.	February 2004
Compiled a manual of outcome measures as recommended in the DRAFT Commonwealth Department of Health and Ageing report (LaTrobe University 2003)	February 2004
Workshop with steering committee - reviewed recommended measures/ selected measures for field testing/ considered field testing protocol and carer measures	March 2004
Recruited Continence Clinic services	March 2004
Information sessions for Continence Clinic services	March 2004
Continence Services Field tested measures	April 2004
Continence service Focus Groups	May 2004
Assimilated results from focus groups. Presented results to steering committee. Assimilated feedback. Provided report on Outcome measures project.	June 2004
Assimilated feedback of DRAFT best practice guidelines document	June 2004
Steering committee reviewed reports	July 2004
Presentation of final report	July 2004

Results:

Outcome Measures Survey

An outcome measurement survey was developed by the National Ageing Research Institute and sent to seventeen DHS funded Continence Clinic services.

The survey was conducted for two reasons. Firstly to identify outcome measurement tools that were being used currently within all Victorian DHS funded Continence Clinic services and secondly to identify domains or specific measures considered necessary to be included in an outcome measurement framework. Practitioners were asked to consider outcome measurement in relation to measures/ domains recommended for use on a 'routine basis' and measures/ domains recommended for use on an 'as needed basis'.

'Routine basis' in the context of the survey, referred to measurement tools or domains recommended to be used for all clients presenting to the service on their admission and discharge to the Continence Clinic service. 'As needed basis' referred to measurement tools/ domains recommended for use on an 'as needed basis' to use on a selected subset of clients to address local needs and interests.

Eleven out of seventeen DHS funded Continence Clinic services returned the questionnaire (65% Response Rate). Of these services, four were from Regional Victoria.

Measures currently used on either a 'routine' or 'as needed' basis

The first question asked services to list all of the Outcome Measures they were using on either a 'routine' or 'as needed' basis. (Table 1).

The results for this question need to be interpreted carefully as some Continence services included various *assessment* tools they were using on admission rather than specific outcome measures being used at two or more time points to measure change. For example, three services indicated that they used the Bladder and Bowel symptom questionnaire. This questionnaire was developed as an assessment tool by the Continence Physicians Group (1998). The questionnaire has various outcome measures within it – some validated and some not and the purpose when developing the questionnaire was for these outcome measures to be completed again on a client's discharge. The focus group results suggested that at least five of the recruited services were using the questionnaire, but as most services indicated the outcome measures within it were not being used at two time points, they did not include the questionnaire within their Outcome Measure survey results. It was not the purpose of this project to review assessment practices in Victorian Continence Clinic Services.

For thoroughness, a summary of all of the responses has been included in Table 1.

Table 1: Outcome measures used in Victorian Continence Clinic Services**(n=11)**

Measure	Routine	As needed
Bladder diary	9	1
Accident diary	2	3
Bladder scan	1	1
Flow rates (including Uroflow)	-	2
Pad weight (for 1, including paper towel test – “stress test”)	-	2
Urodynamics (including Urodynamics questionnaire (1))	-	2
Bladder ultrasound	-	1
Urinalysis	1	-
Bladder and Bowel Symptom Questionnaire	3	-
Food and Bowel Chart	-	1
Bowel chart (1stool chart, 1 bowel diary)	-	4
Constipation scoring system		1
Wexner/ Cleveland Clinic Faecal Incontinence Score	1	2
Bristol Stool Scale	-	2
Service Co-Ordination Tool templates - Functional screen (SCOT)	-	1
Mini Mental State Examination (MMSE)	-	2
Barthel Index	-	2
Abbreviated Mental Test Score (AMTS)	-	1
Pelvic floor measure (Oxford,1)	2	2
Physiotherapy Pelvic Floor Assessment – Part A & B	1	-
Physiotherapy Minimum Data Set	1	-
Goal Attainment Scale	-	1
Evaluation of Short term and Long term goals	1	-
QoL* Assessment follow up	-	1
Incontinence Impact Questionnaire – 7SF	2	-
QoL WHO 1-7 (WHO)	3	-
ICIQ-SF (ICS)	1	1

* = Quality of Life QoL

Specific tools or assessment domains being considered by services for use:

The second question asked services to list any outcome measures that were not currently being used, but which services were considering using or trialing in the future. Ten out of eleven services commented on this question. The results are provided in Table 2.

Table 2: Tools or assessment domains being considered for service use

(n=10)

Specific Measure:	Number of services
Bladder and Bowel symptom questionnaire	3
24 hour pad weight	2
Kings Health Questionnaire	2
Urogenital Distress Inventory - long form	1
Constipation scoring system	1
Faecal incontinence QoL scale (Rockwood)	1
Continence Scale	1
Functional Independence Measure	1
Domain	
Quality of Life (QoL)	4 (1 service reported the need for such a measure to be client administered)
Faecal incontinence QoL scale	1
Goal attainment	2
Client satisfaction	2
Functional assessment	1
Number of diagnosis	1

In relation to specific measures services were considering trialing, the 24 hour pad weight, the Kings Health questionnaire and the Bladder and Bowel Symptom questionnaire were the most commonly reported.

Quality of Life, goal attainment and client satisfaction were the most commonly reported domains services were investigating for outcome measurement purposes.

Domains considered important to include in a measurement framework:

The third question asked services to indicate whether they would consider measuring various domains on either a 'routine' basis or 'as needed basis' for clients. Whilst some domains were specified (Continence Clinics – Program Guidelines and Performance Indicators 2000, p14), services were encouraged to list any other domains as required. The domains provided included: patient symptom measures, practitioner measures, anatomical measures, patient function measures, carer measures, quality of life measures, client specific measures and socio-economic measures.

Services were also encouraged to list any specific outcome measures they considered were appropriate within these domains in the consideration of the development of a core set of outcome measures or a suite of tools for recommended use by Continence Clinic services.

The following results were obtained:

1. Patient symptoms:

(N=11)

Measure	Routine	As needed
Number of incontinence episodes	2	1
Number of pads used	2	1
Type of pad used	1	-
Pad Weight	1	4
Bladder diary	2	-
Voiding diary	5	1
Bowel chart/ diary	2	2
Accident diary	1	1
Bowel assessment	1	-
Specific Measures recommended		
Modified Queen Victoria chart	1	-
Bristol Stool Scale	2	-
Wexner/ Cleveland Clinic Faecal Incontinence Scoreore	-	1
Not specified but identified as an important measurement domain	1	-

2. Practitioner Measures

(N=11)

Measure	Routine	As needed
Pelvic floor strength	6	2
Continence assessment tool	1	-
PR	1	-
PV	1	-
PBFB/EMG	-	1
MSV	-	1
DRE	-	1
Perionometer	-	1
Physical assessment (abdominal, vulva, rectal, prostate)	1	-
Specific measures recommended		
Oxford Scale	2	-
Modified Oxford	-	1
For PV and PR see C. Nortons work	-	1
Not specified but identified as an important measurement domain	-	1

3. Anatomical measures

(N=11)

Measure	Routine	As needed
Bladder scan	4	1
Ultrasound	4	3 (3x pelvic specified)
Urodynamics	-	8
Urine dipstick	1	-
Urinalysis	4	-
Post void residual	1	-
Uroflowmetry (including voiding flow rate ²)	1	5
X-rays (including Abdominal)	-	2
Biofeedback	-	1
MSU	-	1
Bloods (including +/- PSA)	-	1
Electrical stimulation	-	1
Not specified but identified as an important measurement domain	-	-

One service specifically indicated that anatomical measures should *not* be incorporated into an outcome measurement framework.

4. Functional Measures:

(N=11)

Measure	Routine	As needed
General function, not a scale or tool	2	-
Specific measures recommended:		
Mini Mental State Examination	-	5
Abbreviated Mental Test Score	-	1
Falls risk assessment tool	-	1
Barthel Index	-	4
Timed up and go	-	1
Not specified but identified as an important measurement domain	-	-

Two services specifically indicated that functional measures should *not* be included as part of a routine outcome measurement framework.

5. Carer Measures:

(N=11)

Measure	Routine	As needed
Carer satisfaction survey	-	2
Specific measures recommended:		
Care giver demand scale	-	1
Not specified but identified as an important measurement domain	2	3

Six services indicated the importance of including carer measures within a Continence service Outcome measurement framework. Few specific carer measures were identified.

6. Quality of Life measures

(N=11)

Measure	Routine	As needed
Continence specific QoL	1	-
"Bother" factors	1	-
Depression scale		1
Specific measure recommended:		
WHO QoL	-	1
ICI SF	1	1
IIQ 7SF	1	-
Bladder and Bowel symptom questionnaire 'degree of bother'	1	-
The Short Form 36 Health Survey Questionnaire	1	1
Patient Oriented Outcomes Tool (POOT) developed by service ("needs validation and further field testing")	-	1
Not specified but identified as an important measurement domain	2	-

7. Client measures

(N=11)

Measure	Routine	As needed
Client satisfaction survey	3	3 (2 indicating validation required)
Client goal attainment	2	-
Subjective appraisal	1	-
Specific Measures recommended:		
Bladder and Bowel Symptom questionnaire	1	-
Not specified but identified as an important measurement domain	2	-

One service indicated that the concept of incorporating client measures was valued but that it should not form part of a routine outcome measurement framework.

8. Social economic measure

(N=11)

Measure	Routine	As needed
Costs of social containment	1	-
Pad/ product usage	1	-
Funding (ability to self fund/ Need for Aides and Equipment programme funding etc)	3	1
Specific Measure recommended		
Nil	-	-
Not specified but identified as an important measurement domain	1	-

Outcome measures used in the past and discontinued:

The fourth question encouraged services to discuss outcome measures they have used in the past. Services were asked to list any outcome measures used in the past and not found useful as well as any outcome measures used in the past/ found useful but discontinued.

The following table provides a summary of the comments provided by five services:

Table 3: Measures used in the past

Measure	Used in the past, not found useful	Used in the past, found useful but not using anymore. With reason.
King's Health Questionnaire	-	1, Difficult scoring system
Patient Oriented Outcomes Tool (POOT)		1, Needs validation
Bladder and Bowel Symptom questionnaire		3, - Difficult to administer on clients with cognitive impairment. Not validated - Tried for 6 months in 1998/99. Issues included: lack of administration staff to input data; Not useful at the time as the service had no recurrent funding - One service, still using although not using all parts routinely for all clients e.g. QOL section. Symptoms as described were seen to be overly "medical and artificial" and as not applicable for many clients. The urinary symptoms which aren't rated in terms of frequency, bother etc (e.g. nocturia) were often seen as more relevant to this service's clientele. The diagnoses section was seen as 'medicalized' and as rarely appropriate. The need to find a minimum data set and broader nomenclature was seen as necessary. The outcome measure re number of incontinence episodes was identified as needing to be developed to include things such as urinary and bowel frequency. The 24 hour time frame was also seen as inadequate given it could be only 1 episode per week which the client and service is concerned with.
Quality of Life		

Additional comments regarding outcome measurement:

The fifth question asked services to provide any additional comments regarding the topic of outcome measurement. Seven of eleven services responded. The following provides a summary of the comments provided. The summary details comments provided about outcome measurement/assessment practice and key performance indicators.

Recommendations regarding outcome measurement were described as needing to be "meaningful" (1) and able to be used by all practitioners across the state (1). Uniformity in assessment was considered advantageous as long as it did not become too prescriptive (1). Whilst many domains were considered as important to measure for many clients, not all were seen as appropriate to include within an outcome measurement framework for all clients across all services for example, client goal attainment (1). The need for a tool to be clinically useful was valued (1) in addition to the tool's utility as an outcome measure (1). The need for measures to be simple to use and administer, without an excessive time requirement was considered necessary (1) particularly for services with limited resources (1).

Final data collection was identified as needing to be "integrated" and "relevant" to existing assessment practices and not simply a collation of pages of individual tools (1). The need to view the measures in a co-ordinated manner was valued as opposed to considering change in individual measures (1).

One service suggested the Continence Assessment Minimum Data 1998 was a useful starting point in considering outcome measurement for Continence Clinic services, but indicated it would need to be further refined requiring field consultation. Another valued the need for a simple quality of life tool.

Gathering demographic information on client's attending the service was valued (1) with examples of age; ethnicity and area in which the client was residing provided. This information was seen as beneficial for planning and funding purposes (1) and was seen as necessary for interpreting outcome measurement results. This service described limitations of the existing DHS Key Performance Indicators, indicating that additional information such as type of urinary incontinence; treatment and investigations required should also be captured to determine the personal requirements needed within a service.

Workshop with field representatives:

An expert steering committee that also acted as a working party was developed in the early phases of this project. This group comprised nursing practitioners, physiotherapists, medical staff and service co-ordinators from both regional and metropolitan Victoria.

As part of the methodology, the working group attended a workshop to review the outcome measures identified within the Continence Outcomes Measurement Suite Project – DRAFT report (LaTrobe 2003). Working party members were asked to review the tools with respect to how *applicable* the tools were for their client population and how *practicably* the tools could be incorporated into existing Continence Clinic services.

Concerning applicability, working party members considered factors including the relevance of the domains assessed in each tool; the appropriateness of the depth of information gained to meet service needs and the extent to which the tool would complement or duplicate existing assessment processes. In relation to the practicability issues, working party members considered factors including the perceived need for staff training in tool use and the ability to incorporate the new measurement demand given existing resources.

The following tools were considered within the workshop:

Faecal Incontinence Symptom Severity Measures

- Wexner/ Cleveland Clinic Faecal Incontinence Symptom Severity Scoring System.

Urinary Incontinence Symptom Severity Measures

- Incontinence Severity Index (ISI)
- Kings Health Questionnaire
- Urogenital Distress Inventory (UDI) – Long and Short form
- Bristol Female Lower Urinary Tract Symptoms (BFLUTS) Questionnaire

Frequency Volume Charts and Bladder Diaries

Multi-Attribute Quality of Life Measures

- Assessment of Quality of Life Scale (AQoL)
- EuroQol 5D
- Health Utilities Index, Mark 3 (HUI3)

Generic Quality of Life Measures

- The Short Form – 36 Health Survey Questionnaire (SF-36). Version 1 and 2

Functional Outcome Measures

- Functional Independence Measure (FIM)
- Barthel Index

Summary and Recommendations from workshop:

- That every service recruited would field-test the same outcome measures.
- That it would not be possible to practicably incorporate an outcome measure from each of the domains identified above as part of a measurement approach for every client presenting to a Continence Clinic service.
- That outcome measures should be chosen in the context that they were to be used for all clients presenting to a Continence Clinic service rather than specific client groups
- That none of the Functional Outcome Measures or Quality of Life Outcome Measures should be field tested as all would be unlikely to be sensitive enough to detect change directly related to continence specific intervention.
- In consideration of issues related to practicability and applicability, the following tools were recommended for field-testing.

Faecal Incontinence Symptom severity measure:

- Wexner/ Cleveland Clinic Faecal Incontinence Symptom Severity Scoring System. This was the only measurement tool in this category recommended within the Continence Outcomes measurement suite project (LaTrobe 2003), as such it was included for field-testing.

Urinary Incontinence Symptom severity measure:

- Kings Health Questionnaire. This tool was seen as relatively comprehensive measuring symptoms and quality of life for males and females with urinary incontinence, its use internationally and its excellent psychometric properties was seen as advantageous. It was therefore recommended for inclusion in the field-testing.
- The standard Urogenital Distress Inventories (UDI) both short and long form were reviewed by the working group. The Incontinence Impact Questionnaire (IIQ) was developed at the same time as the UDI with the aim of assessing the impact of urinary incontinence symptoms upon quality of life for women. This was not reviewed by the working party as it was not considered by the authors of the DRAFT Continence Outcomes measurement suite project report (LaTrobe 2003). Similarly, the male UDI and the modified UDI for urge incontinence were also not

reviewed. Of the inventories considered, the UDI short form was recommended for field-testing.

- Bristol Female Lower Urinary Tract Symptom Questionnaire. This tool was seen as holding no advantage over the Kings Health questionnaire and was therefore not included as a tool recommended for service field-testing.
- Incontinence Severity Index. This tool was identified as being more of a screening tool to be recommended for use by primary care practitioners. As such, it was not included as a tool recommended for specialist service field-testing.

Frequency Volume Chart and Bladder diary:

- A trial of uniform recording standards in relation to Frequency Volume Charts and Bladder diaries was recommended. A uniform bladder diary was therefore included for field-testing.
- A recommendation was made to include a measure of caregiver strain for field-testing. A literature review was not conducted to identify appropriate measures. The working group considered four measures - The Care giver demand scale; The care giver strain index (Robinson 1983); The Care-giving Burden Scale (Gerritsen et al 1994) and a Carer profile developed by the Primary Care Partnerships in the Western Metropolitan Region. A recommendation was made to include a Modified version of the Caregiver strain index (Thornton et al 2003) as part of the field-testing.
- In summary, in consideration of issues related to practicability and applicability, the following tools were recommended for field-testing: The Wexner/ Cleveland Clinic Faecal Incontinence Score; The Urogenital Distress Inventory – Short Form; The Kings Health Questionnaire; The modified care-giver strain index and a uniform bladder diary.

Focus Groups Results:

Fourteen services were involved in the field testing of outcome measures. Six focus groups were conducted with representatives from eleven services. Three services were unable to participate in the focus group, one of these services provided feedback on the summary of the focus group from their health service. One service has yet to participate in a focus group due to staff absence and one service did not participate as their participant was on annual leave during the focus group period. After each focus group a summary was provided to participants for their review to ensure accuracy of data recorded. Of the eleven services involved, three did not provide feedback about their summary – these three services were rural services. All six focus groups conducted had at least one service endorse that the summary provided an accurate record of the discussion held – as such, all six summaries representing *twelve services* (including one service that only gave written feedback) were used in the analysis and summary of results described below.

Appendix five details the questions considered in each focus group. In summary, the questions considered current outcome measure use, desirable outcome measure features and then separate feedback on each of the tools trialed. The current use of outcome measures was reviewed in addition to the outcome measure survey sent in order to clarify responses provided.

Current outcome measures:

Apart from bladder and bowel diaries and a subjective rating of client/ carer goals, there were no outcome measures being used on a consistent basis by all services across all client groups. Some outcome measures were being used for some client's on their admission to the service - for example the Mini Mental State Examination and Barthel Index but were not scored again on a client's discharge. It was seen as likely that such measures were being used to help inform assessment rather than being

used as variables that may change with Continence Clinic service intervention. Various other measures were being used for some clients and by some practitioners – for example the Wexner/ Cleveland Clinic Faecal Incontinence Score, Goal Attainment Scale and Pad tests (see survey results), but were often not reassessed at discharge to determine change related to intervention.

The Bladder and Bowel symptom questionnaire developed by the Continence Physicians Group (1998) was being used as an assessment tool for some or all clients by at least five services (no rural services). This questionnaire has some validated outcome measures within it but these were not being re-administered at discharge by any service. Not knowing how data collected would be interpreted and used was one reason cited for not completing the outcome measures again at discharge. (Note one practitioner in one service identified completing the WHO QoL at admission and discharge as a minimum requirement for all of her clients).

As indicated above, bladder and bowel diaries were regularly used by all services. They were mostly described as being used on admission and discharge for all clients presenting with urinary and faecal incontinence respectively.

All services identified that they also routinely assessed what the client and/or carer wanted to achieve on the admission to their service and reassessed whether this had been achieved on the client's discharge. This was completed informally but more often than not was recorded as part of both the admission and discharge summaries for their service.

For example:

- Admission: Carer wants to stop changing the bed at night-time.
Discharge: Carer is no longer needing to change the bed-clothes at night time due to the provision of client pads and bed aides.
- Admission: Client wants to be able to play netball without leaking and being worried about the smell.
Discharge: Client reports being able to play netball without being concerned about leaking or smell.

Outcome measurement was seen as important by all services and as being required in today's evidence based health service environment. As there will always be a compromise between the ability to use an outcome measure across all services and for all client groups with practical issues such as time and resources, participants were asked whether they would prefer outcome measurement recommendations to be in the form of a suite of tools to draw upon to meet local needs and interests or in the form of a tool, or a selection of tools to be used by all services for all client groups. Eleven services indicated that the ideal would be the development of a "short" list of outcome measures to be used across all services and all client groups and then a suite of accepted tools to draw upon for use as required. Whilst this was the ideal, all services questioned whether there were tools available that would have the desired features to use for all client groups presenting to all Victorian Continence Clinic services. In relation to this point, most (8) services identified that despite not being able to find the 'ideal' measure(s), there was still merit in using what was available and having consistency in measurement across services and across client groups. One participant commented on the practicability of using outcome measures saying "it's much easier to do it (use an outcome measure) with everyone rather than using it with some clients and not others". Another participant commented on the difficulty of selecting target groups for measurement. One service identified that it was unrealistic given the tools available to adopt a 'one size fits all approach' and that having a suite of accepted tools for each service to draw upon was the only way to go forward at this stage.

Services were also asked to comment on whether they wanted to use outcome measures to help inform their assessment process. Practitioners held mixed views about this, and no clear summary

could be made. Some practitioners wanted an outcome measure that could be incorporated into an assessment process and could aide clinical assessment and intervention, others wanted the two components of service provision to be kept mutually exclusive.

Desired outcome measure features:

Services were asked to describe features seen as needing to be considered with respect to implementing outcome measures.

The following features were described and are included in Table 4. They are not presented in order of priority rather they are presented in order of frequency mentioned.

Table 4: Features considered important to consider in relation to outcome measurement

Feature	Service
Simple to administer and score (incl: comments such as short, something that doesn't take too much time, etc)	11
Sensitive to change	11
Minimal to no training required	7
Different administration methods (phone, client, clinician)	7
Comprehensive	5
Easy to interpret	5
Translations readily available, cross cultural norms available	4
Able to be used across adult age range and with both genders	1

Whilst reliability and validity are commonly reported in the published literature as variables needing to be considered in the selection of outcome measures, practitioners were more likely to comment on variables related to practicability, acceptability and applicability.

The need for a tool to be simple to administer and score with minimum training requirements was seen as a necessary feature by all services particularly in services with a high turnover of staff or agency staff. All services identified being pressured by time and tools that were perceived to be time onerous were largely rejected.

One discussion held regarding practicability issues surrounded the method of administration. A tool that held good psychometric properties when administered in different ways was valued by most services. Two common issues were discussed in relation to this point. Firstly many services commented that their clients would often not attend for a discharge visit, therefore a tool that could be administered over the phone was valued. Secondly, many services commented on the ideal of having a tool that could be self administered but recognised that for many clients self administration was not possible due to reasons including client cognition, vision and motor skills. As such, a tool that held good psychometric properties for different methods of administration was valued.

Services were asked to identify if there was anything unique about their service that would need to be considered in an outcome measurement framework. Most services identified the majority of their work as being tailored toward an older age population despite the wide age range of people presenting to their service. Factors including poor cognition and multiple co-morbidities were commonly cited as variables that may impact on how a tool can be administered and factors that may confound outcome measurement results and interpretation. Two services described a high proportion of clients seen from

culturally and linguistically diverse backgrounds, a tool with cross cultural norms was therefore seen as an advantage for these services.

Specific feedback on the tools trialed:

Wexner/ Cleveland Clinic Faecal Incontinence Score:

Services report a smaller proportion of clients presenting with faecal incontinence symptoms than with urinary incontinence symptoms. As such the Wexner was not frequently used by some services. When used, the tool was identified as simple and easy to use and score (12). Three services identified the need for additional descriptions for each category (3) to ensure adequate rater reliability and one service commented that they would like to change the terminology of gas to add the terms "wind" and "flatulence".

Because of the tool's simplicity, an advantage was that the tool could be administered over the phone (3). This was seen as beneficial for some clients who did not attend discharge visits.

It was likely that the tool would be clinician administered if used again in the future (8). Administering the tool in this way would not be too burdensome for practitioners (12). Self-administration was difficult for clients with cognitive deficits. Also, some clients would not adequately represent the true nature of their problem usually underestimating the severity of their incontinence symptoms. As such, clinician administration was a preferred option for most practitioners. Four services identified that the tool would ideally be self administered as a first option and then clinician administered as required.

Twelve services indicated that a limitation of the tool was that it didn't consider constipation (12). Service staff reported that a high number of people accessing continence services present with constipation. Not including constipation in an outcome measure would mean that change related to the service's intervention for these clients would not be detected.

The tool was perceived as likely to detect change (6) but probably more so for clients presenting with severe faecal incontinence (1). Data regarding change scores were not collected in this research project and six services did not comment on the tool's ability to detect change (6).

The Wexner was *not* perceived by any service to be an adequate assessment tool (12). For example 'it doesn't tell you about the patients "normal pattern" – for example, frequency, volume, usual bowel habits and diet.'

Eleven of the twelve services would consider trialing the Wexner longer term for all clients presenting with faecal incontinence symptoms. Five of these services identified value in administering the tool to everyone admitted to the service as the tool often helped to initiate discussion around an often embarrassing problem that many clients wouldn't confess to having unless the tool was used as part of routine assessment.

There were different opinions about whether the tool would be included within the assessment form or whether it would be administered separately. It was generally felt that this would need to be left to service discretion.

No services reported that training was required however, three services identified that the tool would benefit from modification to the tool's definitions as described above.

Urogenital Distress Inventory (UDI) – Short Form:

The UDI was seen as reasonably quick to administer and score, requiring no training to use (10). The tool was often described as “simple” but not comprehensive enough for all clients - for example, it did not assess nocturnal incontinence; incontinence related to poor mobility, passive incontinence and vaginal pain (7).

The tool would need to be used in addition to standard assessment practice (12). For example it missed a lot of the detail required for assessment purposes such as fluid intake and frequency (1). The tool was not seen as adequate to “drive intervention” (1). One service identified that it could be easily incorporated into standard assessment practice if it was to be adopted in the future.

Seven services perceived that most of their clients would be able to self administer the tool. Three services identified the need for a clinician to administer the tool due to differences in client interpretation of the questions - related to client variables such as insight and cognition. One service identified that the method of administration would need to be left to practitioner’s discretion. All services identified that it would not take a great deal of additional time or resources for this tool to be administered and scored by the clinician (12).

Questions about the bother attributed to incontinence symptoms were perceived by practitioners to be repetitive – sometimes confusing the client (9). Two services commented that because of the repetitive nature of the ‘bother’ questions, practitioners were tempted to inappropriately influence the result when they were administering the tool – sometimes skipping questions or assuming the client response. One service liked the consideration of bother in this tool (1).

One question in particular was difficult to understand. This question was ‘do you experience small amounts of urine leakage’. Clients and practitioners were unsure how this question should be answered if the client experienced large amounts of urine leakage or ‘flooding’ (7).

Three services felt more information was required regarding score interpretation.

Eight services would use the tool again for all clients presenting with urinary incontinence symptoms. Four services would not use the tool again because it lacked comprehensiveness and was seen as insensitive enough to detect change for most of their client population (4).

One service that would not use the tool again for outcome measurement purposes identified its potential value as a screening tool (1).

In comparison to the Kings Health Questionnaire, eight services would prefer to use the UDI on a day to day basis, as it is quick and easy to administer and score.

Kings Health Questionnaire:

The measure was identified as a “good screening tool” - “(it) covers most assessment bases”(6) and ‘helps to initiate conversation in areas that are often embarrassing for clients to talk about’ (1). It was also identified as being readily able to ‘screen’ where more in-depth assessment was warranted (6). One service valued the tool’s ability to describe the patient versus the clinician perspective of the problem. While this was always a service aim, it was sometimes not achieved in usual assessment practice (1).

The first page of the Kings Health Questionnaire was considered to have the most essential information required for assessment for all clients presenting with urinary incontinence symptoms (5).

Most clients in five services were perceived as being able to adequately self-administer this tool (5). Six services indicated that the tool would need to be clinician administered for the majority of their clients (6) and one service indicated that method of administration would need to be left to practitioner discretion dependent on variables such as client cognition and vision. For those clients unable to self administer, clinician administering would be time onerous particularly if the tool was used in addition to usual assessment practice (9). The measure was described as duplicating current assessment practice which would need to be reviewed if the tool was incorporated in the future. Practical issues were described if the intention was to incorporate the tool into existing assessment forms (7). The tool couldn't replace existing assessment forms as more information about the urinary symptoms was required (11) for example, fluid intake, type of pad used and pain on urinating. Five services felt that it could be incorporated into assessment practices even though it may be a challenge (8). Two services commented that the tool was too detailed for use as an outcome measure to be used with all clients, but not detailed enough to use as an assessment instrument for any client (2).

Questions also arose about the ability to complete the assessment on discharge, particularly for those clients who did not attend their discharge appointment ("a large proportion (2)"). The tool was considered inappropriate for phone administration (11) and unlikely to be returned if posted out at discharge (4).

Questions regarding personal relationships and emotions were valued (5) although considered not applicable for some clients by some services. Three services commented that much of the information captured in the tool may not be relevant for the majority of the clients seen by their nursing staff (1) for example, information regarding sexual and physical activity and emotions (3). Two of these services commented that many of their clients would find questions of this nature mostly irrelevant, intrusive and confusing. One service described these clients as those with multiple medical conditions, those living in supported residential services or nursing homes and those with poor cognition. For these client groups, administering the Kings Health questionnaire was perceived to be a "waste of time and resources (2)" (3). One additional service identified that the "tool was much too lengthy to use practicably for all clients".

Scoring the Kings Health Questionnaire was identified to be difficult and time consuming by all services (11) with inadequate training provided. Scoring instructions were also not identified to be consistent - for example, in the first section if the client doesn't experience the urinary problem they leave it blank and in the following section if the client doesn't experience the urinary problem they mark "not at all". This was described as being confusing for many clients and as often needing practitioner clarification (1). Two services identified the need for further training regarding score interpretation (2).

Six services questioned why similar questions to that of the Kings Health Questionnaire weren't asked about the bowel (6).

Five services identified that the King's Health questionnaire was a better outcome measure than the UDI (note one of these services indicated that they would use either the UDI or the Kings Health Questionnaire routinely). **All of these services indicated if the scoring could be clarified and was not too time intensive they would consider using the tool at admission and discharge for all clients presenting with urinary incontinence (5).** For practicability purposes, these services indicated that the Wexner could be added to the Kings Health questionnaire and sent out to all clients prior to their first visit.

The tool was seen as a good outcome measure for the younger client group without cognitive impairment - usually seen by physiotherapists (6 additional services to the 5 described above) but not appropriate for use by all clients (7). Two services identified that the tool would be useful for research purposes or to address local needs and interests but was not practical for use with all clients presenting with urinary incontinence symptoms.

Training was identified as being required for this tool (10).

Modified Care – giver strain index:

The modified care giver strain index was described as a good generic assessment tool that helped to detect care giver strain (10). It was described as “practical” by one service and as “simple and easy to use” by others (2). Seven services perceived the tool was unlikely to measure change related to intervention provided by Continence Clinic services (7). One service felt the tool would detect change in intervention if used as an outcome measure (1). Four services were unsure about the tool’s use as an outcome measure but felt the tool’s value was in its ability to detect carer strain and not necessarily in its use as an outcome measure (4). One participant commented on the value of using the tool but recommended adding a preface to each question something in the order of “... relating to the incontinence the person you provide care for is experiencing ...” so that change related specifically to continence intervention could be captured. One service that reported that the tool would not reflect change identified that the tool may help to explain why variances in other outcome measurement results.

The tool was seen as useful in helping to identify when additional referrals were required - for example to an Aged Care Assessment Service (10). Seven of these services identified that standard practice identified this anyway although five services identified that the tool provided structure to this process, which was seen as beneficial. The care-giver strain index was also seen as a useful aide for encouraging carer participation (1), carers were described by practitioners as valuing the opportunity to talk about issues relating to them rather than the client (6). Six of these services perceived that the tool often validated how carers were feeling – allowing carers to ‘see it on paper’ and hear that other carers often experienced similar worries.

Two services identified that Continence Clinic services often don’t have the resources available (including time and expertise) to address issues that the tool identified (2). They therefore questioned the value of assessing this domain (1). Another service identified that it was important to “remember who the client is” indicating that caregiver strain was not relevant to consider in a Continence Clinic Service outcome measurement framework (1). This was in conflict to all other services that identified the carer as integral to the assessment and care planning process.

The tool was identified as needing to be clinician administered without the client present (6). Five services identified that carer guilt often influenced how carers answered the questions and, as such the tool needed to be administered in a confidential interview format. Some services identified that the examples used within the measure were often misleading which contributed to carers misrepresenting what was actually happening despite the instructions. Five services identified that the tool’s results could be misleading - for example, a carer could rate that something was a high physical strain but that this was not causing a ‘bother’ for them.

There was no need for training identified in use of the tool or its scoring (5).

Three services would not use this tool again, one specified ‘not in its current form’. Two of these services felt the tool held no benefit over standard practice with respect to identifying and acting

on the detection of caregiver strain and felt it lacked the ability to detect change in care giver strain related to continence service provision. **One service would use this tool again for some clients. Five services identified that they would use the tool again “across the board”. All of these five services were from regional and rural Victoria.** Participants in these five services identified that it was good to use the tool for all carers because ‘some will cover up and not acknowledge their issues and problems’. This measure was perceived to assist this problem.

All services identified the need to find a better tool to detect change in caregiver strain related to continence service provision.

Bladder Diary:

Use of a bladder diary was seen as an important tool to use with all clients presenting with urinary incontinence symptoms (12). Most services reported using bladder diaries similar to that used within the trial project (12) although the diary used within the trial project was seen as more complex than most. About half of the services reported using bladder diaries on a person’s admission to the service, their discharge and at interim points throughout their episode of care (6), other services reported using a bladder diary on admission only, or as required dependent on patient need and clinic resources.

Patient compliance in completing the diary was identified as an issue for all services. Practitioners reported that between 30 and 90% of their patients will complete the bladder diary. A number of strategies have been adopted by many services to improve compliance rates. One service reported that they no longer posted out the bladder diary, rather explained its use with the client on their first visit. This was felt to improve patient compliance in completing the tool. Another service described having three different bladder diaries graded in terms of level of detail required and level of complexity to complete. Other services described the benefit of using larger font; simple instructions at the end (or back) of the diary rather than at the start (2); organising the layout so that one page relates to one day and providing clients with a measuring ‘jug’ - as helping to aide compliance. In general, bladder diaries were perceived as being completed by most clients, if they were seen as being simple to use. Most services valued at least getting a minimum amount of data from as many clients as possible so the need to keep the tool simple was generally endorsed (10). All services identified that further information could often be gained once the client had completed a simple diary and understood the benefit of the diary for their own treatment. Nine services described the minimum data required in a bladder diary as: fluid input (type, time, amount); fluid output (time, volume) and comments (e.g. activity participating in when leaked). One service reported that they had reverted to sending clients a simple bladder diary that documented frequency only and then upgraded the information that they wanted throughout the person’s episode of care.

Whilst three consecutive days were valued as an ideal by all services, most services identified that they would accept whatever they could obtain from clients. Consecutive days was often difficult particularly for client’s who worked. The major benefit of the bladder diary was in it’s objectivity in detailing patient symptoms. Even patients with good cognition were often described as having some difficulty in accurately self-reporting their symptoms. The bladder diary was also described, as a tool that helped client’s to take ownership of their treatment and outcome. For example, two services described clients who would look at their interim bladder diaries and comment on the correlation of their fluid type with their level of incontinence.

Particular problems with the bladder diary as used within the trial were: ‘scoring of urge incontinence (3) (‘didn’t make practical sense’); instructions were perceived as being too long and detailed (4) and font/ layout was felt not to be user friendly (2). The bladder diary was also seen as being “ideal” but too detailed for use by many clients.

Conflicting views were expressed about the benefit of incorporating information obtained in bladder diaries in to an outcome measurement framework. Obtaining discharge information was a difficulty reported by most services. Most services were receptive to using a similar bladder diary across services.

Outcome measurement domains not reviewed in this process:

Eight services identified the need for a tool that assessed and measured change related to constipation and six identified the need to measure quality of life related to faecal incontinence and not just urinary incontinence.

Five services felt a suite of tools needed to be developed for children as well as adults.

Five services identified that client goals or 'the client's primary reason for accessing the service' and whether this had been achieved, needed to be considered in any outcome measurement framework.

Three services identified there may be benefit in using some or all of the three quality of life questions as found in the bladder and bowel symptom questionnaire.

Two services identified the need for a carer measure that was more continence specific.

Summary:

There was considerable variability in the use of outcome measurement tools across services. Outcome measurement was seen as being expected by all services in today's evidence based health service environment and as required to better judge the efficiency and effectiveness of services and client outcomes.

Outcome measures need to be simple to use and time efficient to administer if they are to be accepted by practitioners. Traits such as the tool's ability to be translated into different languages and its ability to be administered in different ways were also valued.

Most services identified benefits in having commonality in core outcome measurement across the state. Having one or a few tools to use with all clients across all services and then having a suite of tools to draw upon to meet individual service or client needs was valued. Most services identified that given this approach, there will be a minority of people for whom the core tools will not be appropriate. As long as the core tool(s) chosen were not too time onerous to administer this was not seen to be too problematic from a resource perspective by most services. Most services reported a profile of those clients for whom the tools weren't appropriate was warranted.

All services identified benefits and weaknesses for all of the tools trialed in this project and all services identified that no tool or tools could replace existing assessment practice.

Concern was expressed by most services about how data collected would be interpreted and used, and most services identified a need for a longer trial and evaluation period to further determine any of the tools measurement merits.

Five regional and rural services identified that they would consider using the Wexner, Kings Health questionnaire and the Caregiver strain index on admission and discharge for all clients.

Six services identified that the Wexner and the Urogenital Distress Inventory short form could be used by all clients presenting with faecal and urinary incontinence respectively.

Most services identified that the Kings Health Questionnaire should be used for a target population (younger, cognitively able) or for research purposes.

Limitations:

The methodology adopted for this project did not include the collection of change scores – as such tool ability to detect change related to intervention provided by DHS funded Victorian Continence Clinic services cannot be reported on. The project aimed to explore issues regarding the acceptability and practicability of the tools for use within Continence Clinic services. The tools were chosen from recommendations made within a DRAFT report document (LaTrobe 2003), a substantial body of work reviewing outcome measures internationally. Within the Continence Outcomes measurement suite DRAFT report (LaTrobe 2003), the authors drew their recommendations from a series of data gathering activities. These included – consultations with clinical experts and practitioners; literature reviews of the tools and measures and their application in incontinence outcome measurement and deliberations by an expert panel of measurement specialists. Each tool reviewed, was considered by expert

measurement specialists with respect to various criteria. An associated scoring system was developed by the team and made explicit within their project report. In addition, the evaluation included the availability of comparison data/ usage; evidence of reliability and validity and other psychometric/ utility axioms.

Many practitioners identified a desire to continue to use various outcome measures field-tested within the project for at least a longer trial period. This appeared in part, to reflect practitioner's genuine enthusiasm to 'give anything a go' but it also appeared to reflect the value practitioners perceived the tools would have on service processes and practice. All practitioners identified the need for a longer trial period and remained wary about the ability of any of the tools chosen to adequately reflect the value of their service's intervention.

The time lines of the project were short. Services had limited time to familiarise themselves with the tools before having to provide feedback about the tools usability. Despite the perceived time constraint, most practitioners within most services identified having trialed the tool enough to provide relevant feedback.

The project team did not review tools or assessment domains that lay outside of the areas considered within the Commonwealth project. The project identified additional domains considered by clinicians as necessary to be included in an outcome measurement framework but these were not considered - for example, client goal attainment and client satisfaction. A carer measure was incorporated into the project methodology on advice from the steering committee. A thorough literature review was not conducted on carer measures to help inform the process of choosing this carer measure and further investigation may identify a more suitable tool. In addition, practitioners identified some common outcome measures they would consider using on a routine basis for all clients across all client groups - for example the ICI and the IIQ as found in the Bladder and Bowel symptom questionnaire developed by the Continence Physicians Group (1998). These tools were not field tested due to the project methodology adopted.

Practitioners largely provided feedback on the tools in the context that one/ or a few tools were to be considered for measurement with all clients presenting to a Continence Clinic service. Whilst this was a mostly valued context, it did influence how practitioners provided feedback. Given current work practices, incorporation of any outcome measures will be completed in addition to existing workload. As such, time taken to clinician administer was often the overriding factor influencing whether the tool was considered appropriate for future use.

Feedback indicated that further training in relation to scoring the Kings Health Questionnaire was required. Whilst most practitioners did not feel the level of training influenced their overall feedback about the tool, it was considered a limitation in the study design. In addition, a bladder template was designed that incorporated recommended criteria from the 2nd ICS/ WHO Consultation on Incontinence. As font/ layout etc was the work of NARI any criticism regarding this needs to be considered a limitation and needs to be considered with respect to the final feedback provided on this tool.

Recommendations:

There were two aims for this project. The recommendations detailed in this report only relate to Project Aim Two. Project Aim One was to finalise the best practice guideline document post feedback from an expert steering committee – the outcome of this aim is provided in a separate report. Project Aim Two was to field test outcome measures as identified within the Continence Outcomes Measurement Suite project DRAFT report (LaTrobe 2003) to further determine their clinical acceptability and practicability for use within Victorian Continence Clinic services. The recommendations identified as a result of the project methodology adopted to meet Project Aim Two are as follows:

- Currently there is considerable diversity in the number and range of outcome measures used by Victorian Continence Clinic services. Although there are benefits to having diversity across Continence Clinic services, there are also benefits in having at least a small amount of common measurement. This project recommends the use of a common approach to outcome measurement across services. Use of common core outcome measurements can be used to share information between services, to use as a basis for ensuring best practice, and could have potential for use in multi-clinic research. Implementing core common outcome measures should not be considered prescriptive or limiting to the range of measures used by services. Services should still have the capacity to add additional measures to address local needs and interests.
- Where there is a desire to use a common measurement approach for all clients presenting to Continence Clinic services in Victoria the following tools should be considered as part of a more formal trial given their general field acceptance from a practicability and usability perspective: The Wexner/ Cleveland Clinic Faecal Incontinence Scale and the Urogenital Distress Inventory – Short Form.

The King's Health Questionnaire was considered beneficial for research purposes or for use with a target population mainly described as younger in age and cognitively alert.

Project activity recommended as a result of this project:

- This project only considered outcome measures recommended within the Continence Outcomes Measurement Suite project DRAFT report (LaTrobe 2003). Additional measurement domains were identified by practitioners as needing to be incorporated into an outcome measurement framework but were not included in this project activity. Examples of such domains include - measures or a process for documenting and evaluating client goals, measures addressing client and caregiver satisfaction and measures addressing constipation and quality of life particularly related to faecal incontinence. These measurement domains would benefit from further exploration. In writing this report, NARI was aware of a concurrent project considering patient satisfaction in the context of incontinence being conducted by Associate Professor Graeme Hawthorne at Melbourne University.
- Reducing continence related caregiver strain and demand is commonly reported as a goal requiring continence service intervention. Most services identified the need for further research in this area.
- Recommend use of a bladder diary incorporating at a minimum factors including: fluid input (type, time, amount); fluid output (time, volume) and comments (e.g. activity participating in when leaked). Recommend bladder diaries be used at admission, discharge and at interim points throughout a person's episode of care and be used ideally for three consecutive days.

- Recommend that the outcome measurement process remain a dynamic one with opportunities provided for continual review – including consideration of recommendations and discussion from the 3rd International Consultation on Incontinence in Monaco July 2004. Recommend further investigation of work completed by the Continence Physicians group on outcome measurement (1998).

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Appendices:

Appendix One: Project Proposal

Key Tasks	Timelines
Establish Project Steering Committee including DHS project staff, field representatives across a number of disciplines, rural and metropolitan representatives.	November 2003
Develop survey of current outcome measures used in DHS funded Continence Clinic services across Victoria.	December 2003
Disseminate survey, receive responses, assimilate results	January - February 2004
Steering Committee to consider revised project proposal, review terms of reference for committee members, discuss preliminary results of outcome measures survey as available	02/02/04
Disseminate to the steering committee, the DRAFT best practice guidelines excluding the current project activity. Disseminate the agreed on DHS/ NARI project proposal to the field.	February 2004
Development of a manual for use of the Outcome measures recommended by report titled: Continence Outcomes Measurement Suite Project, commissioned by the Commonwealth Department of Health and Ageing	February 2004
Recruitment of Continence clinics to participate in the pilot testing of these measures	February 2004
Workshop with steering committee members to review Commonwealth recommended measures and provide feedback to help inform the field testing stage of the project	March 2004
Provide training as indicated, for recruited service participants with respect to use of these measures.	March 2004
Pilot test the tools. Support role by project staff at NARI	March – April 2004
Assimilate feedback from the steering committee regarding the DRAFT best practice guidelines excluding the current project activity.	April 2004
Conduct focus groups with participating clinical and administrative staff to investigate the utility of the tools and make recommendations for ongoing use	May 2004
Disseminate to the steering committee the revised best practice document for Continence Clinic services including the DRAFT report of the findings of the current project activity.	June 2004
Steering Committee Meeting to receive and provide feedback to the best practice document in it's entirety	July 2004
Workshop for Continence service staff to hear outcomes of the project activity and provide feedback	July 2004
Outcomes	
Final project report and presentation	July 2004

Appendix Two: Outcome Measurement Survey

Continence Clinic Outcome Measures Questionnaire

Dear Colleagues,

The National Ageing Research Institute has been commissioned by the Victorian Department of Human Services to assist in finalising the extensive work already completed reviewing and developing performance indicators and best practice guidelines for Victorian Continence Clinic services.

A component of the work to be finalised includes the identification and trial of outcome measures to help inform the development of a minimum outcome data set to be used in Continence Clinic services across the state. The National Ageing Research Institute and the Victorian Department of Human Services are aware of the recent activities undertaken by the Commonwealth Department of Health and Ageing in relation to Continence Outcome Measures. Work conducted within Victoria will seek to complement any previous project activity.

Although there are benefits to having diversity across Continence Services, there are also benefits in having at least a small amount of common assessment. A minimum data set (MDS) can be used to share information between services, to use as a basis for ensuring best practice and could have potential for use in multi-Clinic research. Such a data set would form the basis of a continence clinic service assessment and could for example be included within current data collection programmes. It would not however be considered prescriptive or limiting to the additional measures sometimes required to address local needs and interests. A minimum data set may need to be developed as a complement to a suite of accepted tools that could be pooled upon by continence clinic services to meet such needs and interests.

To commence this body of work, we have attached a questionnaire. The aim of the questionnaire is two fold: Firstly to identify outcome measurement tools that are currently being used within all Victorian Continence Clinic services and secondly to identify domains or specific measures considered necessary to be included in an outcome measurement framework to be used on either a routine or as needed basis.

The questionnaire is 4 pages in length and should take approximately 5-10 minutes of your time. We would welcome the combined input from all clinicians within your team when completing it. The questionnaire is being sent to all Victorian Continence Clinics funded by the Department of Human Services.

If you have any queries about the survey please contact Fiona Bremner at the National Ageing Research Institute on 8387 2377. If you have any queries regarding the broader project or would like a copy of the Continence clinic project plan please contact Fiona Bremner or Linda Muller at the Department of Human Services on 9616 1336.

A steering committee has been established to oversee this project. Steering committee members are also happy to discuss this project with you as required. Please find their contact details below – listed in alphabetical order.

Thank you for your time,

With kind regards,

Fiona Bremner, Project Officer
National Ageing Research Institute

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3. Please indicate whether you would consider assessing the following domains on either a 'routine' or 'as needed basis' for your clients. Please indicate any specific assessment tools that you feel may be appropriate to consider in the development of a MDS or suite of tools for recommended use in Continence Clinic services. (you may like to consider urinary and faecal incontinence separately for some domains)

Domain	Routine (please provide measure suggestions if appropriate)	As needed (please provide measure suggestions if appropriate)
Patient Symptoms <i>(Example: number of incontinence episodes; number of pad numbers used, voiding diary)</i>		
Practitioner Measures <i>(Example: pad weighting; pelvic floor strength)</i>		
Anatomical Measures <i>(Example: urodynamics; ultrasound)</i>		
Functional Measures <i>(Example: Barthel Index; Functional Independence Measure)</i>		
Carer Measures <i>(Example: Care giver demand scale, Carer burden interview, Carer satisfaction)</i>		
Quality of life Measures <i>(Example: AqoL; SF36)</i>		
Client Measures <i>(Example: Goal attainment scale; client satisfaction)</i>		
Socio- economic measures <i>(Example: hours of lost employment)</i>		
Other		

Other:		
Other		

4. Please list any outcome measures that you:

- may have used in the past and not found useful
- may have used in the past/ found useful but are not using anymore (please list reasons for discontinuing use)

5. Please provide any additional comments you may have

Thank you for returning the questionnaire by Friday 16th January - we have included a self-addressed envelope for your convenience.

Please include a copy of any data forms you are currently using.

Name of Service:	<input style="width: 80%;" type="text"/>
Contact Name:	<input style="width: 100%;" type="text"/>
Ph:	<input style="width: 30%;" type="text"/>
Email:	<input style="width: 70%;" type="text"/>

Thank you for completing this questionnaire.



Appendix Three: Tools trialed in field testing

Wexner/ Cleveland Clinic Faecal Incontinence Symptom Severity Scoring System

Name: _____

Score: **/20**

Type of Incontinence	Frequency				
	Never	Rarely < 1/month	Sometimes < 1/week, > or equal 1/month	Usually < 1/day, > or equal to 1/week	Always > or equal to 1/day
Solid	0	1	2	3	4
Liquid	0	1	2	3	4
Gas	0	1	2	3	4
Wears Pad	0	1	2	3	4
Lifestyle Alteration	0	1	2	3	4

This score takes into account the type and frequency of incontinence and the extent to which it alters the patient's life.

0 = Never
20 = Complete Incontinence

Kings Health Questionnaire

Name:

Today's Date:

1. How would you describe your health at present? (please tick)

Very Good

Good

Fair

Poor

Very Poor

2. How much do you think your bladder problem affects your life?

Not at all

A little

Moderately

A Lot

What are your bladder problems and how much do they affect you?

From the list below choose ONLY THOSE PROBLEMS that you have at present. LEAVE OUT those that do not apply to you.

To choose, please tick the appropriate box.

	A little	Moderately	A Lot	Office Use
Frequency: (going to the toilet very often)				
Nocturia: (getting up at night to pass urine)				
Urgency: (a strong and difficult to control desire to pass urine)				
Urge Incontinence: (urinary leakage associated with a strong desire to pass urine)				
Stress Incontinence: (urinary leakage with physical activity e.g. coughing, sneezing or running)				
Nocturnal Enuresis: (wetting the bed at night)				
Intercourse Incontinence: (urinary leakage with sexual intercourse)				
Frequent waterworks infections				
Bladder pain				
Difficulty passing urine				
Other, Specify:				

Below are some daily activities that can be affected by bladder problems. How much does your bladder problem affect you?

3. Role Limitations (Tick the box that applies to you)

	Not at all	Slightly	Moderately	A lot
a. To what extent does your bladder problem affect your household tasks (e.g. cleaning, shopping)				
b. does your bladder problem affect your job or your normal activities outside the home				

4. Physical Limitations (Tick the box that applies to you)

	Not at all	Slightly	Moderately	A lot
a. Does your bladder problem affect your physical activities (e.g. going for a walk, run, sport, gym etc.)				
b. Does your bladder problem limit your ability to travel?				

5. Social Limitations (Tick the box that applies to you)

	Not at all	Slightly	Moderately	A lot
a. Does your bladder problem limit your social life?				
b. Does your bladder problem limit your ability to see/visit friends?				

6. Personal Relationships (Tick the box that applies to you)

	N/A	Not at all	Slightly	Moderately	A lot
a. Does your bladder problem affect your relationship with your partner?					
b. Does your bladder problem affect your sex life?					
c. Does your bladder problem affect your family life?					

7. Emotions (Tick the box that applies to you)

	Not at all	Slightly	Moderately	A lot
a. Does your bladder problem make you feel depressed?				
b. Does your bladder problem make you feel anxious or nervous?				
c. Does your bladder problem make you feel bad about yourself?				

8. Sleep/ Energy (Tick the box that applies to you)

	Not at all	Slightly	Moderately	A lot
a. Does your bladder problem affect your sleep?				
b. Do you feel worn out/tired?				

9. Do you do any of the following? If so how much? (Tick the box that applies to you)

	Never	Sometimes	Often	All the time
a. Wear pads to keep dry?				
b. Be careful how much fluid you drink?				
c. Change you underclothes when they get wet?				
d. Worry in case you smell?				
e. Get embarrassed because of your bladder problem?				

UDI Short form

Name: _____

Score: **/24**

1. Do you experience frequent urination?

Yes No (Skip to 2)

If yes, how much does it bother you?

Not at all Slightly Moderately Greatly

2. Do you experience urine leakage related to the feeling of urgency?

Yes No (Skip to 3)

If yes, how much does it bother you?

Not at all Slightly Moderately Greatly

3. Do you experience urine leakage related to physical activity?

Yes No (Skip to 4)

If yes, how much does it bother you?

Not at all Slightly Moderately Greatly

4. Do you experience small amounts of urine leakage (drops)?

Yes No (Skip to 5)

If yes, how much does it bother you?

Not at all Slightly Moderately Greatly

5. Do you experience difficulty emptying your bladder?

Yes No (Skip to 6)

If yes, how much does it bother you?

Not at all Slightly Moderately Greatly

6. Do you experience pain or discomfort in the lower abdominal or genital area?

Yes No

If yes, how much does it bother you?

Not at all Slightly Moderately Greatly

Scoring:

Not at all = 0
Slightly = 1
Moderately = 2
Greatly = 3

Yes = 1
No = 0

Maximum Score: 24

Minimum Score: 0

The Modified Caregiver Strain Index

Directions: Here is a list of things that other caregivers have found to be difficult. Please put a check mark in the columns that apply to you. We have included some examples that are common caregiver experiences to help you think about each item. Your situation may be slightly different, but the item could still apply.

	Yes, on a regular basis	Yes, Sometimes	No
My sleep is disturbed (For example: the person I care for is in and out of bed or wanders around at night)			
Care giving is inconvenient. (For example: helping takes so much time, or it's a long drive over to help)			
Care giving is a physical strain. (For example: lifting in and out of a chair; effort or concentration is required)			
Care giving is confining. (For example: helping restricts free time or I cannot go visiting)			
There have been family adjustments. (For example: helping has disrupted my routine; there has been no privacy)			
There have been changes in personal plans. (For example: I had to turn down a job; I could not go on vacation)			
There have been other demands on my time. (For example: other family members need me)			
There have been emotional adjustments. (For example: severe arguments about care giving)			
Some behaviour is upsetting. (For example: incontinence; the person cared for has trouble remembering things; or the person I care for accuses people of taking things)			
It is upsetting to find the person I care for has changed so much from his/ her former self. (For example: he/ she is a different person than he/ she used to be)			
There have been work adjustments. (For example: I have to take time off for care giving duties)			
Care giving is a financial strain.			
I feel completely overwhelmed. (For example: I worry about the person I care for; I have concerns about how I will manage)			

Office use only: Sum responses for "yes on a regular basis" (2 points each) and "yes sometimes" (1 point each)

Total Score: /26

Bladder Diary

Instructions for using the bladder diary

This diary helps you and us to understand why you get trouble with your bladder. The diary is a very important part of the tests we do, so that we can try to improve your symptoms. On the chart you need to record:-

1. When you get out of bed in the morning, show this on the diary by writing 'Got out of bed'.
2. During the day please enter at the correct time the drinks you have during the day (e.g. 8.30am – two cups of coffee, total 250 ml).
3. The time you pass your urine (e.g. 7:00am). Do this every time you pass urine throughout the day and night.
4. Each time you pass your urine, collect the urine in a measuring jug and record the amount (in mls or fluid ozs) next to the time you passed the urine (e.g. 1.30pm/320ml).
5. Each time you pass your urine, please write down how urgent was the need to pass urine:

“O” means it was not urgent.

+ means I had to go within 10 minutes

++ means I had to stop what I was going and go to the toilet

6. If you leak urine, show this by writing a “W” on the diary at the time you leaked.
7. If you have a leak, please add 'P' if you have to change a pad and 'C' if you have to change your underclothes or even outer clothes. So if you leak and need to change a pad, please write 'WP' at the time you leaked.
8. If you have a leakage please write in the column called 'Comments' whether you leaked a small amount or a large amount and what you were doing when you leaked, (e.g. 'leaked small amount when I sneezed three times.')
9. Each time you change a pad or change clothes, please write in the 'Comments' column.
10. When you go to bed at the end of the day show it on the diary – write 'Went to Bed.'"

Example diary:

Date: 1st January 2003

<i>Time</i>	<i>Fluids taken in (mls/ounces)</i>	<i>Amount of urine passed (mls/ounces) and urgency (0, +, ++)</i>	<i>Degree of incontinence</i>	<i>Comments (what you were doing if/when you leaked etc.).</i>
2am	-	150 mls +	-	-
7am – Got up	-	250 mls ++	WP	Coughing, then ran to the toilet Leaked a small amount
8:30am	Coffee – 250 mls	-	-	-
8:45am	-	160mls +	-	-
10:00am	Glass juice – 300mls	-	-	-
11:30am	-	200mls 0	-	-
And so on...				

Appendix Four: Focus Group Questions

Continence Clinic Project

Outcome Measures Focus Group with Clinical Staff participants

Introduction:

- 60 – 90 minute session
- All responses will be de-identified for purposes of report writing and verbal feedback
- A summary of the themes discussed in the focus group will be sent to services for verification within one week
- Clinicians not able to attend the focus group will be offered an opportunity to provide individual feedback. Clinicians wanting to take this opportunity should contact Fiona at NARI on 8 387 2377. Individual data may be analysed separately to their service's focus group data depending on the information obtained.
- All contributions in the focus group are voluntary. There is an expectation that matters discussed within the focus group will remain confidential by focus group participants.

1. Clarify what outcome measures are currently used? (with survey information)

Are they used routinely or as needed?

Are they used at both admission and discharge? Issues?

Advantages/ disadvantages/ issues:

2. What features do outcome measures need to have to be practical within your service?

3. Is there anything particular about your service that you think needs to be considered with respect to implementing outcome measures?

4. Considering outcome measurement, what is your feedback on the outcome measures used within the trial?

Do they address the broad domains and items within each domain identified in Q2 as needing to be measured? Level of comprehensiveness?

Advantages/ Disadvantages/ Method of administration-scoring/ Appropriateness for service population etc.

7. Would you continue to use the tools – routinely/ as needed?

Additional information needed?

8. Are there any outcome measurement domains that you consider have not been reviewed in this process that you would like to measure either routinely or on an 'as needed basis'?

9. Other