Source: The Australian - 2 November 2006
An update on the continence research project

Nick Marosszeky and Jan Sansoni
The Research Trinity - Kline (2009)
“No constant system of measurement existed in Europe during the Napoleonic wars, the local variations probably being responsible for the miscalculation of certain noted events.”

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Haythornthwaite (1990) *The Napoleonic Source Book*
Kirshner & Guyatt (1985)

- The use of measures in clinical practice and research has three main purposes:
  - To **discriminate** between individuals along a continuum of health
  - To **predict** outcome or prognosis
  - To **evaluate** within-person change over time
Continence Outcomes Measurement

◆ To develop a set of recommended measures / instruments for the assessment, screening and outcomes monitoring of incontinence conditions, which are suitable for routine use in the Australian Health Care context.

◆ By developing a set of recommended measures it is hoped to standardise the assessment and evaluation procedures used in the field to enhance comparability of findings across research and practice settings.
The AHOC Approach

- Create a tool-kit of measures for clinicians and researchers in order to assist with communication

- Is to try and not “re-invent the wheel”

- But to adapt recognised and/or promising instruments for Australian conditions

Overall

- We need to identify whether our treatments work and which do so most effectively

- For this you need reliable and valid measures for assessment and outcome evaluation
The AHOC Process

- Review the scientific literature, as well as psychometric texts and resources
- Develop an expert panel to advise on measurement issues and to consider relevant applications
- Consult widely with the field, getting feedback from user groups

Producing transparent and systematic evaluation criteria for assessing instruments - combining psychometric research and clinical practice perspectives

Using a standard form for instrument reviews - AHOC review sheet
Research Products

◆ Revised Urinary Incontinence Scale
◆ Revised Faecal Incontinence Scale
◆ Short Assessment of Patient Satisfaction (SAPS) scale
Revised Urinary Incontinence Scale

Do you experience and if so how much are you bothered by:

◆ Urine leakage related to the feeling of urgency
◆ Urine leakage related to physical activity, coughing or sneezing
◆ Small amounts of urine leakage (drops)

The response scale for each item is

– Not at all
– Slightly
– Moderately
– Greatly
Revised Urinary Incontinence Scale (Cont.)

◆ How often do you experience urine leakage?
  – Never
  – Less than once a month
  – A few times a month
  – A few times a week
  – Every day and/or night

◆ How much urine do you lose each time?
  – None
  – Drops
  – Small splashes
  – More
Revised Faecal Incontinence Scale

Do you leak, have accidents or lose control with solid stool?

Do you leak, have accidents or lose control with liquid stool?

Do you leak stool if you don’t get to the toilet in time?

Does stool leak so that you have to change your underwear?

Does bowel or stool leakage cause you to alter your lifestyle?

(Note: Does not include flatus)

The response scale for each item is

- Never
- Rarely, i.e. less than once in the past four weeks
- Sometimes, i.e. less than once a week, but more than once in the past four weeks
- Often or usually, i.e. less than once a day but more than once a week
- Always, i.e. more than once a day or whenever you have a bowel movement
### Final model of a unidimensional Short Assessment of Patient Satisfaction scale (SAPS)

<table>
<thead>
<tr>
<th>Dimension</th>
<th>N</th>
<th>Item stem (abbreviated)</th>
<th>Item source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effectiveness</td>
<td>1</td>
<td>Happy with the effect of your treatment</td>
<td>GUTSS</td>
</tr>
<tr>
<td>Information</td>
<td>2</td>
<td>Satisfaction with explanations of treatment results</td>
<td>GUTSS</td>
</tr>
<tr>
<td>Technical skill</td>
<td>3</td>
<td>The clinician was careful to check everything</td>
<td>Consult SQ</td>
</tr>
<tr>
<td>Participation</td>
<td>4</td>
<td>Satisfaction with health care choices</td>
<td>PSI</td>
</tr>
<tr>
<td>Relationship</td>
<td>5</td>
<td>How much were you respected</td>
<td>PSI</td>
</tr>
<tr>
<td>Access &amp; facilities</td>
<td>6</td>
<td>The time with the clinician was not long enough</td>
<td>Consult SQ</td>
</tr>
<tr>
<td>Satisfaction general</td>
<td>7</td>
<td>Happy with the care received</td>
<td>GUTSS</td>
</tr>
</tbody>
</table>
Continence Projects

- Continence Outcomes Measurement Suite (COMS) project (2004 - 2005)
- Continence Outcomes Measures Dissemination Strategy (2007)
- Validation and Clinical Translation of the Revised Continence and Patient Satisfaction Tools (2008 - current)

* National Continence Management Strategy *
Development 1

Continence Outcomes Measurement Suite (COMS) project

Reviewed the scientific literature and recommended measures for field testing (UDI-6, ISI, Wexner)

Refining Continence Measurement Tools

Field testing (n = 3015) SAHOS 2004 community survey. Examined psychometric properties - CTT and IRT approaches. Revised instruments
Development 2

The Measurement of Patient Satisfaction in Incontinence

Post treatment testing of satisfaction and revised continence measures. Need more males

Continence Outcomes Measures Dissemination Strategy

Knowledge transfer of results
Development 3

Validation and Clinical Translation of the Revised Continence and Patient Satisfaction Tools

Further validity – in clinical settings and sensitivity to change, plus test-retest reliability

TODAY
Project Outputs 1

◆ CHSD reports
  - Thomas et al. (2006) Continence Outcomes Measurement Suite Project
  - Sansoni et al. (2006) Refining Continence Measurement Tools
  - Hawthorne et al. (2006) Measuring Patient Satisfaction with Incontinence Treatment

◆ Related reports

* Reports on the Health Department’s continence web-site: Bladder and Bowel *
Project Outputs 2

◆ Academic Publications


Research Questions

- Are the revised instruments sensitive to patient experience and clinical improvement?
- Do we need to include additional items in our revised instruments?
- Do the revised instruments have adequate comparative validity?
- Do the revised instruments have adequate test-retest reliability?
- What is the relationship between the revised instruments and clinical outcome and quality of life?
- Faecal Cost of Illness Study
Research Instruments

- Pre-treatment Survey – demographics, revised instruments, alternative items, quality of life instruments
- Clinic Diary
- Post-treatment Survey – revised instruments, quality of life instruments, treatment satisfaction items
- Clinician’s Form (pre-treatment) – clinical descriptors and treatment history, clinical global impression of severity
- Clinician’s Form (post-treatment) – treatment descriptors, clinical global impression of severity and improvement
Inclusion / Exclusion criteria

◆ Inclusion criteria:
Primary complaint of urinary or faecal incontinence (Concomitant urinary and faecal incontinence symptoms may be included)

◆ Exclusion criteria:
Existing stoma
Behavioural element or disorder associated with the patient’s condition
Medically unfit for surgery / or unsuitable for treatment
Under 18 years of age
Over 80 years of age
A poor understanding of English
Cognitive impairment