

## RESEARCH PRIORITIES FOR ELDERLY WOMEN WITH URINARY INCONTINENCE: RESULTS OF A CITIZENS JURY

### Hypothesis / aims of study

Most studies on urinary incontinence (UI) are initiated by clinicians, researchers or the pharmaceutical industry. Women with UI are rarely involved in developing the research questions or methodology. However, recent studies show that the needs of women with UI may in fact differ from those perceived by both health and industry professionals.(1) The failure to include beneficiaries in research discussions could limit research or, worse, result in poorly-designed research questions and poor prioritization of research (interventions & diagnostic tools); the ultimate consequence being minimally applicable research results, hence less transferable, to targeted populations. We hypothesized that elderly women with UI would prioritize research on less invasive UI interventions, e.g., lifestyle changes and pelvic floor exercises, and outcome measures that focused on quality of life. Further, these priorities would not differ significantly between women, irrespective of UI type (stress, urge or mixed).

### Study design, materials and methods

The study design employed a qualitative study utilising a Citizens Jury approach and the Nominal Group Technique (NGT). A "Citizens Jury" is a mechanism for "participatory action research" drawing on the symbolism and some practices of a jury trial. A representative group (the jury) is selected, randomly, from a targeted population; the evidence and opinions of experts are presented and then deliberated by the "jury" to reach a specific or multiple outcomes (e.g., a consensus, priority lists). In May 2011, we organised a Citizens Jury for elderly women with UI to identify 1) their priorities for future research on intervention types and 2) which (relevant) measures of outcome are most significant to them. The participants were recruited through ads in newspapers, a continence foundation, UI clinics, and from a research centre's pre-established bank of potential participants. To be included in the study, women had to be 60 or older, ambulatory, present symptoms of stress, urge or mixed UI for a consecutive 3-month period during the past year, give informed consent, and agree to complete the ICIQ-UI short form and a 3-day bladder diary. Women were excluded if they had medical problems, functional impairments or co-morbidities likely to interfere with the jury process. Participants completed the questionnaire and bladder diary. On the day of the workshop, bladder diaries had to be returned to the research team to confirm the presence, type and severity of UI. Women then participated in a 7-hour workshop: the Citizens Jury. Following a brief introduction, experts in UI (1 urogynaecologist, 1 physiotherapist, 1 radiologist and 2 urologists) presented the latest evidence-based literature on UI outcome measures and interventions: 1) UI measurement tools, 2) UI lifestyle interventions and physical therapies, 3) incontinence pessaries, 4) UI medications, and 5) UI surgeries. The level of evidence, in relation to each UI outcome and treatment option, was presented to the participants. All oral presentations were reviewed and standardized (i.e., same outline style, number of slides, slide background) and based on the latest Cochrane reviews and the 2009 International Consultation on Incontinence book. Each session was followed by a 15-minute discussion period in which the jury was invited to ask questions. After the presentations and lunch, the women were divided into three groups by UI type (SUI, UUI & MUI). Group participants, guided by a trained facilitator, were invited to discuss their views. The clinicians (presenters) were excluded from these discussions. Each group was asked to answer two questions: 1) What intervention should be highest priority for UI researchers? 2) What measurement tools should be used in research on UI and prioritised how? The methodology aligns with that recommended in both NGT and Citizen Jury literature. NGT was used to address each question; that is, after listing the interventions and measurement tools on a flip chart, each group discussed, voted on and ranked 5 from each list. These were discussed again, and a final three were voted on and ranked in priority.(2) The moderator concluded the wrap-up session with a summary of each group's recommendations.

### Results

Overall, 43 women with UI and a mean age of 70.7 years (61 to 84) participated in the jury. Table I summarises the participants' characteristics. Table II lists the three priority areas for intervention research and Table III the three priority outcome measures to be used in future research; the results are aggregated by group, which was pre-determined by UI type.

**Table I: Participants' characteristics grouped by UI type**

Demographics	SUI (n=13)	UUI (n=14)	MUI (n=16)
Age (mean and SD)	71.86 (5.30)	69.50 (5.02)	70.92 (7.04)
BMI (mean and SD)	25.68 (3.04)	24.99 (4.04)	24.93 (4.00)
# of medications (mean & SD)	3.43 (3.15)	3.44 (2.92)	2.92 (2.99)
<b>Education (%)</b>			
• High school	21.4	28.0	15.4
• College	14.3	18.8	30.8
• University	64.3	43.8	46.2
Sought previous help/treatment (%)	57.2	62.5	69.2
<b>Symptom severity</b>			
ICIQ total (mean and SD)	8.86 (2.28)	10.87 (4.32)	10.31 (4.73)
Mean number of micturition/day	7.79 (3.02)	9.08 (3.89)	9.13 (3.19)
Mean number of UI episodes/day	2.10 (3.51)	2.54 (2.57)	1.41 (1.58)
Mean protection/day	0.64 (0.85)	2.08 (2.49)	0.92 (1.45)

**Table II: Priority intervention research areas, grouped by UI type**

Priority	SUI Group (n=13)	UUI Group (n=14)	MUI Group (n=16)
1 <sup>st</sup>	Physiotherapy (n=9, 69%)	Surgery (n=6, 43%)	Physiotherapy (n=8, 50%)
2 <sup>nd</sup>	Lifestyle interventions (n=9, 69%)	Bladder training (n=5, 36%)	Lifestyle interventions (n=6, 38%)/ Bladder training (n =6, 38%)
3 <sup>rd</sup>	Bladder training (n=11, 85%)	Physiotherapy (n=8, 57%)	Pads and protections (n=9, 56%)

**Table III: Priority outcome measures, grouped by UI type**

Priority	SUI Group (n=13)	UUI Group (n=14)	MUI Group (n=16)
1 <sup>st</sup>	Symptoms questionnaire (n=6, 46%)	Urodynamics (n=6, 43%)	PFM evaluation (n=8, 50%)
2 <sup>nd</sup>	Bladder diary (n=7, 54%)	Cystoscopy (n=6, 43%)	Bladder diary (n=7, 44%)
3 <sup>rd</sup>	QoL questionnaire (n=8, 62%)	Symptom questionnaire (n=4, 29%)	Symptom questionnaire (n=6, 38%)

#### Interpretation of results

In line with previous results from other Citizens Juries comprised of women with UI (3) conservative management treatments (bladder training, life style interventions and physiotherapy) were identified as the priority areas for intervention research with only minor differences between UI group types. Surprisingly, women with UUI identified surgery as their 1<sup>st</sup> priority research intervention, even though the evidence clearly did not support a surgery option for their specific UI condition. Compared to other UI types, UUI sufferers, in general and within this group, experience more severe symptoms. Thus, UUI group discussions were intense (echoing pent-up frustration over ineffective treatments) and dominated by the urgent need for more efficient and definitive interventions. In terms of outcome measures that best reflected their needs, hence should be standard measures in UI research design, all 3 groups identified symptom questionnaires as a priority. Noteworthy again, women with UUI identified more invasive outcome measure such as urodynamics and cystoscopy as important outcome measures.

#### Concluding message

The Citizens Jury identify priority research intervention areas and outcome measures most significant to elderly women with UI. Self-management through conservative management interventions was given the highest priority by women with SUI and MUI but not those with UUI, in whom such treatments are less effective. In selecting treatment options and developing new research avenues, clinicians and researchers need to take note of these views and priorities as, in all likelihood, they also reflect elderly women's receptiveness and adherence to preferred treatments.

#### References

1. Whitehead WE. Gastroenterology. 2004;126:S180-5.
2. Gallagher M. Family Practice. 1993;10:76-81.
3. Herbison P, Hay-Smith J, Paterson H, Ellis G, Wilson D. BJOG. 2009 Apr;116(5):713-8.

#### Disclosures

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