

Research priorities in urinary incontinence: results from citizens' juries

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Objective The objective of this study was to elicit research ideas, priorities and outcome measures from women who suffer from urinary incontinence.

Design Citizens' juries gather participants together for a combination of education and deliberation on a specific topic. The juries were held in November 2007.

Setting Women living in the community with urinary incontinence.

Sample Purposively selected responders to public advertisements in Dunedin, New Zealand, were grouped into two juries dependent on whether stress urinary incontinence or urge urinary incontinence was the predominant problem.

Methods The juries had a day of education in incontinence and research-related issues, with a half day for deliberation and reporting.

Main outcome measures Ideas for areas where research may help the lives of women with incontinence in priority order and how best to measure the outcome of that research.

Results The juries identified five main areas for incontinence research with only minor differences depending on which jury. These are, in priority order, making seeking help easier, making day-to-day life more manageable, finding out total costs, more knowledge about causes and the effects of lifestyle. Quality of life was considered by far the most important outcome.

Conclusions Citizens' juries are able to come up with ideas for research and prioritise these. Research in the areas suggested would be likely to improve the lives of women with urinary incontinence and may lead to a different mix of research projects than is currently the case.

Keywords Citizens' juries, eliciting patient views, female urinary incontinence, priority areas for research.

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Introduction

Most medical research is instigated either by the researcher or by the industry. This includes the topic, the research question, the inclusion/exclusion criteria and the outcomes to be used. It is now realised that including the views of those with the condition in research can be valuable.¹ In research into incontinence, the views of health professionals and patient advocates do differ² as they do in other areas.^{3,4}

The disadvantages of a lack of consumer involvement are that the research questions may well not be those that are the most useful to people with the condition, and the design of studies may lead to information that is not readily applicable to large proportions of women. For example, in research into urinary incontinence, there are many studies comparing

a drug with placebo, but many fewer comparing different drugs or drugs or surgery with conservative therapies. Studies also tend towards the explanatory (testing what happens in ideal circumstances) end of the spectrum rather than the pragmatic (testing what happens in the real world), which may limit their generalisability.^{5,6}

There is clearly a movement for more involvement of consumers in deciding about many aspects of research.^{7,8} Consumer groups exist whose purpose is to improve the design and conduct of randomised trials, and consumer involvement is seen as extremely important by such groups as the Cochrane Collaboration.⁹ There are a range of methods used to elicit patients' views,¹⁰ including ranking, rating or other choice-based approaches, and interviews, participatory action research,¹¹ the Delphi technique, focus groups and citizens'

juries. Citizens' juries are not often used but have found some support.^{12,13} They are often used for policy decisions regarding topics such as about mammographic screening for 40- to 50-year-old women,¹⁴ choices for 'designer babies'¹⁵ or genetic testing for insurance purposes.¹⁶ We could find only one reference (a letter to the editor), referring to the use of juries to suggest research priorities.¹⁷

Although patients' views on many topics differ from those of health professionals, it can be difficult to get informed patients' views on complicated issues, such as incontinence and research. Citizens' juries select a group at random from the population of interest and use a combination of education (presenting evidence) and deliberation^{10,18} to reach a conclusion, in a similar manner to a jury in a criminal court. Citizens' juries differ from other methods of eliciting patients' views in that they have an education component so the views should be more informed. This study used two citizens' juries to inform us about ideas and priorities for research into urinary incontinence.

Methods

Women were recruited by means of advertisements placed in the local community newspaper asking for women with bladder problems, which caused them to leak urine, to contact us by phone. Respondents were screened for eligibility by the research assistant (G.E.) who explained the study. Eligible women were those with self-reported urine leakage and no other important co-morbidities, such as diabetes or neurological conditions. Participants were divided into two groups depending on whether stress urinary incontinence (SUI) or urge urinary incontinence (UUI) was the predominant and most bothersome symptom. Fourteen women from each group were purposively selected to give a range of age and symptom bother and to ensure that potential jurors had conversational English. These women were mailed an information sheet and consent form.

Each jury ran from a Thursday evening to a Saturday morning and started with a 2-hour meeting where the participants had a short introduction explaining the purpose and timetable for the jury, with opportunity for discussion. The second day involved talks on the following subjects:

- How the bladder is supposed to work and what can go wrong.
- The epidemiology of urinary incontinence.
- How urinary incontinence is measured.
- The process of medical research.
- Conservative therapies.
- Drug and surgical treatments.
- Incontinence products (pads etc).
- Local service delivery.

These talks were delivered by a nonspecialist obstetrician/gynaecologist, two physiotherapists, a nurse continence advi-

sor and a medical statistician and emphasised the strengths and weaknesses of current knowledge and focused on knowledge specific to stress or urge incontinence for each group as appropriate. The advantages and disadvantages of current treatments, and the likely outcomes in terms of patient-reported rates of cure, or improvement were highlighted. During these presentations, the jury members were free to ask questions and make comments. Each session was followed by an open discussion: the programme was sufficiently flexible to allow discussion to reach a natural conclusion, and some sessions took longer than originally timetabled, while others took less time.

The final session began with an hour and half of deliberation by the jury, led by a member the juries had selected. None of the professionals was present. Juries were asked to deliberate on the question 'What can researchers study to make your life better?' with the supplementary question of 'What should we measure to see if your life is better?' The deliberation was not recorded: both juries used whiteboards and flip charts to keep track of their discussion and ideas. During the deliberation, two researchers (P.H. and J.H.-S.) were available in another room for the juries to consult if necessary: neither jury asked for any help or further information.

After a short break, the jury reported back to two researchers over an hour. This was led by a jury member, with all jury members able to expand or clarify any point made, and the session was digitally audio recorded, observed by one researcher (P.H.), while the other researcher (J.H.-S.) summarised and recorded the results of the jury deliberation on a flip chart or expanded on the flip charts already filled in by the juries. The pages from the flip charts were displayed around the room. The researchers asked the jury to elaborate where appropriate which led to further discussion. Everyone was encouraged to participate, and no idea was discarded. Towards the end of the session, the ideas recorded on the flip chart were graded for priority by the jury. This was performed simply into three groups: top priority, still important but not top priority and lesser priority.

Women were asked to fill in a questionnaire with brief demographic data and information about their bladder problem. Self-reported severity was measured on a numeric rating scale ranging from 0 (not at all) to 10 (extreme).

The flip chart data were used to derive categories of research ideas. The exact words used were entered into a computer, and related ideas were then grouped by cutting and pasting the statements together. A descriptive title was selected that described each category. The audio recording was then checked to verify that no idea had been missed from categorisation. The process of categorisation was carried out by one researcher (P.H.) and then verified by another (J.H.-S.). The process was completed for each jury independently and then the data combined to form five superordinate categories. These categories were then reported back to the

participants at a further 2-hour meeting of the combined juries to confirm that we had summarised their ideas appropriately. Comments were sought on the ideas within each category and on the wording.

The study was approved by the University of Otago Human Ethics Committee, and all women gave signed informed consent. They were free to leave at any time. Women were paid \$NZ150 to recompense them for the time they contributed to the project.

Results

More than 100 women replied to the advertisements, with slightly more women reporting stress incontinence than urge incontinence as the predominant symptom. The 14 women selected for each jury covered a wide range in terms of age, time with the problem and severity of the problem (Table 1). About half of each group had sought treatment and more than half of each group reported mixed urinary incontinence symptoms (Table 1).

Five main areas of research interest emerged from the reporting: research into interventions that make seeking help easier, research into information giving and interventions designed to make day-to-day life more manageable, research into the true costs of incontinence, research to increase our knowledge about causes and the effects of lifestyle modifica-

tion on incontinence (Table 2). Both juries contributed ideas in each of the five categories, with minor variations depending on the type of incontinence, and feedback from the combined juries resulted in no changes to the categories, with a few minor changes to emphasis or wording suggested.

Recording the final session provided little extra information or insight into the juries' thinking because it was often impossible to follow what was being discussed because it related to an item on the flip charts, which was being pointed to or referred to obliquely. Therefore, illustrative quotes given do not cover all the categories and may unintentionally be concentrated in particular areas. Quotes about the major priority, making it easier to seek and get help included:

Research doctors ability to discuss this issue with the patient;
How to get women to discuss the problem with their GP;
... not taboo to talk about it and get it out into the open;
... finding ways to reach the silent suffering majority;
... getting it out of the water closet;
A lot of sufferers may come out of the woodwork if they know that it is a group of people that have this problem'.

Both juries thought that quality of life (QoL) was by far the most important research outcome to measure, and this had to include sex life, the QoL of partners and emotional stress:

Quality of life—what it stops them doing with their problem

Sleep disruption was considered very important, and self-empowerment was also mentioned. It is unlikely that a generic QoL measure would capture all these aspects of QoL that the women deemed important, although sleep disturbance does feature in some QoL instruments. The women were dismissive of the common research outcome measures, such as pad tests and bladder diaries: based on awareness of their own behaviour they considered these tests were likely to lack validity or reproducibility given the circumstances in which many women would complete them:

Frequency and amount are really a subsidiary outcome and a little bit to one person is a lot to another.

Discussion

Citizens' juries are a method of eliciting patients' views. We used them to obtain views about topics for research into female urinary incontinence and about what outcomes should be used to measure the results of the research. The two juries came up with five main areas that they thought needed to be given priority in research. These were research into interventions designed to make seeking and getting help easier, research into information giving and interventions designed to make day-to-day life more manageable, research into the true costs of incontinence, research to increase our knowledge about causes and the effects of lifestyle modification on incontinence. These areas seem quite different

Table 1. Characteristics of participants

	Stress incontinence predominant jury (n = 14)	Urge incontinence predominant jury (n = 14)
Age (years)		
<40	2	3
40–60	7	4
>60	5	7
Duration of problem (years)		
<5	8	3
≥5	6	11
Mixed incontinence	8	10
Sought help	6	7
Had treatment	3	6
Severity (0 = not at all severe and 10 = extreme)		
0–3	4	2
4–6	8	5
7–10	2	7
Ethnicity		
New Zealand European	9	10
Other European	2	3
Māori	1	1
Chinese	2	

Table 2. Research areas, in priority order, arising from the two juries' deliberations**Making it easier to seek and get help: investigate ways to**

Help to remove the stigma associated with incontinence
 Educate doctors (particularly general practitioners) and other health professionals to know what to do
 Educate midwives to inform women about risks with pregnancy and childbirth (SUI group)
 Educate women to approach health professionals
 Set up, run and evaluate walk in one stop nurse led clinics
 Educate the public to make leakage less of an embarrassment
 Similar to campaigns to remove the stigma associated with mental illness

Making life more manageable

Information on how to minimise effects on QoL—what information helps and how much?
 Studies about simple and self-managed things like which pads offer the best value for money
 Include subgroups such as active women
 What is the place of self-help/support, and how much does it help?
 Are support groups a possibility and would these help?
 Would support for families help as well?
 How can we get more public toilets and disseminate knowledge about where they are?
 What is the impact of waiting for condition to get bad enough for surgery (SUI group)
 More information about the effects or social impact
 For example, inhibitions in starting new relationships

Find out the true costs of incontinence

What is the total cost to society—not just direct costs to the health system or patient?
 Include things like lost opportunities (e.g. early retirement, not seeking promotion, cease volunteering etc.)
 How can the health system be made more aware of incontinence and make incontinence more of a priority?
 How does treatment affect the total cost to society?

More information on causes: what more can be learned about the roles of

Obesity/weight loss
 Obstetric and gynaecological history
 Ethnic/cultural factors
 The role of the nervous system (UUI group)
 Chemicals/hormones
 Other things such as potty training, toileting at school

Lifestyle factors: what are the roles of these in the development and treatment of incontinence in women?

Complementary and alternative medicines
 Food and drink
 Helpful as well as harmful
 Exercise (other than pelvic floor muscle training)

Women were asked to give ideas for research that would make their lives better so it is not surprising that issues about access to care were important to them. One aspect of access is the availability of suitable care, which can be seen as a financial matter for the health system rather than a research project. However, it is quite clear that even if there was a surplus of excellent facilities for care, many women with incontinence would not access them or find the results less than satisfactory. There are opportunities for research into improving the quality of the available care, and in making women more aware that seeking care may improve their lives.

Many of the questions derived from these areas would lead to research that is different to the current emphasis on comparing treatments, requiring the inclusion of other types of health research, such as health economics, health promotion, social science and health services research. These methods are already used in incontinence research, but this study indicates that they should perhaps have a more prominent role.

QoL was clearly the preferred outcome to measure the results of research into incontinence. It was considered much more important and more valid than such things as incontinence episodes and amount of leakage that are much more commonly used. This is being increasingly used, but overwhelmingly as a secondary outcome rather than as a primary outcome, which may be a reflection of the preference of researchers and funders for objective outcomes rather than subjective ones.

It is desirable to fill citizens' juries with a random sample from the desired population, but this is extremely difficult to do for people with a particular health condition. We recruited our juries from public advertisements and then purposely sampled from predominant stress and urgency incontinent groups to obtain women with a range of severity and age and broad ethnic representation. It is possible that some bias may have existed, such as respondents being women most upset by their condition or most wanting to have their views heard. Participants might also have found the recompense overly attractive.

Bias may also have been introduced by the researchers also leading some of the teaching sessions without a moderator, which may have inhibited discussion, and our personal points of view may have been over emphasised. We have not replicated the study in either group but were encouraged to believe that we had reasonable answers because of the concordance between the two groups. This may have been because we, as organisers and educators, led the groups to the same conclusions. We did consciously try not to do this, but the results may reflect our biases.

The educational background of the participants may have affected their ability to grasp the messages from the teaching sessions, their responses and their self-selection in volunteering for the study. We did wonder whether we had set too large a task—to get up to date with the state of knowledge about

from the current research priorities, which are industry and investigator driven. They are not yet defined research questions but are ideas that could easily be translated into research projects.

incontinence in one day is very difficult, and the understanding may not be that deep. The knowledge and understanding of incontinence among the jury members certainly increased during the study: both juries expressed a desire to keep meeting with the researchers after the study was over to keep up to date with new knowledge as it becomes available.

There may be some issues that are particularly relevant to New Zealand that may have a bearing on the results of this research. For example, surgery for SUI is not as readily available in the publicly funded health system as in some countries, and there is only a limited range of anticholinergic drugs available with different levels of government subsidy.

The use of citizens' juries has been criticised for using non-rational persuasion in reaching their decisions (allowing them to do things such as deny treatment to sick people).¹⁹ It is also possible that something like a strong personality on the jury could sway people and inhibit discussion. We think this was less likely in the present study because the juries were asked for a comprehensive list of ideas. In fact, one participant in the urge group said 'I like the way we all went around (to get everyone's ideas)'.

We found recording the feedback session of limited use and would not use it again. It may have provided more information about the juries' thinking if the deliberation session had been recorded, but we were loath to do this for fear of inhibiting discussion, and in traditional juries the deliberation is private.

There are examples of focus groups being used for determining research priorities, sometimes supplemented by questionnaires.^{3,4,20-22} These lack the education component present in citizens' juries so may miss some things through lack of knowledge. We think the education component is essential to allow people to make a more informed deliberation about their ideas and priorities.

The views of the patient advocate in another study agree with our findings.² The study identified research into removing the stigma associated with incontinence as important for women.

We found that the process appeared to work well. It provided a forum where all the women felt free to contribute ideas and ask questions. The participants were pleased to find they were not alone in dealing with their condition and enjoyed finding out more about how their bladders worked and could go wrong.

This was our first attempt at using citizens' juries. There are some changes that we would make if we did it again. We would be more formal in the conduct of the juries and incorporate things like a steering committee to determine the wording of the question and supervise the selection of independent presenters. This would ensure that the jury heard a balanced presentation of the evidence. Other improvements such as having an independent chair/moderator to ensure fairness may also enhance the proceedings.

Conclusions

Despite the large amount of research that has been carried out on female urinary incontinence, it still remains a large problem, with most studies reporting between 25 and 45% of adult women suffering from incontinence and with the majority not seeking help.²³ More research, similar to this study, needs to be carried out to confirm that these research areas are important to women. Research into the ideas brought out in the juries' deliberation should be performed and would result in a quite different research agenda to what exists at the moment. We believe that research derived from these ideas is likely to benefit women with incontinence and is likely to make their lives more manageable.

Disclosure of interest

The authors declare that they have no conflicts of interest.

Contribution to authorship

P.H. devised the study and applied for funding with help from J.H.-S. and D.W. The education day was planned by P.H., J.H.-S. and H.P. G.E. recruited the women and helped with the education day. P.H. wrote the first draft of the paper, which was then commented on by the other authors.

Details of ethics approval

The study was approved by the University of Otago Human Ethics Committee.

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