

Appendix 1. Written survey.

**NAFC prolapse survey for women**

Please fill out the following survey about POP.

**As a thank you, we are offering 50% off a one-year subscription for renewal or first-time members with NAFC. (\$12.50 value!)**

Please return the survey in the enclosed envelope and, if you choose, payment for \$12.50 for a discounted subscription, no later than **Tuesday 30 August 2006**.

**Thank you for your time and reply. We appreciate your support of NAFC.**

**Basic information**

Tell us something about yourself so we might categorise responses for analysis:

**1. In general, would you say your health is:**

- Excellent
- Very good
- Good
- Fair
- Poor

**2. Please indicate below if you have ever been told by a doctor or another healthcare provider that you have any of the following medical conditions. Check all that apply.**

- |   |   |
|---|---|
| <input type="checkbox"/> Allergies  | <input type="checkbox"/> Hypertension/high blood pressure             |
| <input type="checkbox"/> Anxiety disorder   | <input type="checkbox"/> Kidney disease                               |
| <input type="checkbox"/> Arthritis  | <input type="checkbox"/> Neurological disorder or disease             |
| <input type="checkbox"/> Chronic and recurring urinary tract infections                       | <input type="checkbox"/> Obesity                                      |
| <input type="checkbox"/> Depression   | <input type="checkbox"/> Overactive bladder without incontinence      |
| <input type="checkbox"/> Diabetes   | <input type="checkbox"/> Sleep disorders                              |
| <input type="checkbox"/> Gastrointestinal disease/condition that affects the digestive system | <input type="checkbox"/> Urinary incontinence/lack of bladder control |
| <input type="checkbox"/> Heart disease  | <input type="checkbox"/> None of these                                |

**3. For which of the following conditions are you taking prescription drugs? Check all that apply.**

- |   |   |
|---|---|
| <input type="checkbox"/> Allergies  | <input type="checkbox"/> Hypertension/high blood pressure             |
| <input type="checkbox"/> Anxiety disorder   | <input type="checkbox"/> Kidney disease                               |
| <input type="checkbox"/> Arthritis  | <input type="checkbox"/> Neurological disorder or disease             |
| <input type="checkbox"/> Chronic and recurring urinary tract infections                       | <input type="checkbox"/> Obesity                                      |
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| <input type="checkbox"/> Gastrointestinal disease/condition that affects the digestive system | <input type="checkbox"/> Urinary incontinence/lack of bladder control |
| <input type="checkbox"/> Heart disease  | <input type="checkbox"/> None of these                                |

*Appendix 1 (cont.). Written survey.*

**4. Please indicate your age bracket.**

- 18–24
- 25–34
- 35–44
- 45–54
- 55–64
- 65–74
- 75 or older

**5. Are you Spanish, Hispanic or Latina?**

- Yes
- No

**6. Which of the following best describes your race?**

- White or Caucasian
- Black or African-American
- Asian
- Native Hawaiian or Pacific Islander
- American Indian or Alaskan native
- Other (please specify \_\_\_\_\_ )

**7. What is the highest grade you completed in school?**

- Some high school
- High school diploma or GED
- Some college
- Undergraduate college degree
- Some graduate courses
- One or more graduate degrees

**8. What is your current marital status?**

- Married
- Separated, widowed or divorced
- Single/never married

**9. So that we might classify your responses by region of the country, please indicate the state in which you consider yourself to live permanently:**

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Appendix 1 (cont.). Written survey.

**Health status (related to prolapse)**

**10. Have you ever experienced symptoms associated with POP (i.e. pressure in the perineum/vagina, lower back pain, leg pain, bulging in the vaginal area, etc.)?**

Please check *one* that applies.

Past	Present	Both (past & present)	Neither (past nor present)	I don't know

**11. Have you ever been diagnosed with prolapse by a healthcare provider?**

Past	Present	Both (past & present)	Neither (past nor present)	I don't know

If so, what kind of prolapse has been diagnosed? (Check all that apply.)

- Cystocele (bladder)
- Rectocele (rectum)
- Enterocele (small bowel)
- Other (e.g. vaginal vault prolapse, etc.)
- Don't know

**12. Are you or have you ever pursued treatment for your prolapse?**

Please check *one* that applies.

Past	Present	Both (past & present)	Neither (past nor present)	I don't know

If you have pursued treatment **at any time**, please specify what type. (Check all that apply.)

Pelvic floor muscle exercises to improve support/tone	Pessary	Surgery	None	I don't know

If you have **never** pursued treatment for prolapse, please indicate your reason. (Check all that apply.)

- Don't have prolapse (not applicable)
- Don't understand or know what treatment options are available
- Don't like any of the treatment options currently available
- Don't have health insurance or the financial resources to afford treatment
- Don't have a specialist that I trust
- Don't have confidence that the outcome will be good
- Don't have faith that the treatment will be lasting
- Other

Appendix 1 (cont.). Written survey.

13. How much time passed from the time you first experienced symptoms to the point you pursued treatment?

\_\_\_ Less than 1 year      \_\_\_ 1–3 years      \_\_\_ 4–6 years      \_\_\_ More than 6 years      \_\_\_ N/A

14. Based on all of your outcomes and experiences, how would you rate each of the treatments you pursued in the past?

Check **one** response for each experience.

	Extremely pleased	Somewhat pleased	Indifferent	Somewhat displeased	Very displeased	Not applicable/ did not pursue
Pelvic floor muscle exercises						
Pessary						
Surgery						

15. Throughout your experiences, what aspect(s) of your life has been negatively affected by your symptoms? Please rank the following by using ‘1’ as affecting you the most to ‘7’ affecting you the least.

- \_\_\_\_\_ Intimacy with my spouse or partner
- \_\_\_\_\_ Ability to enjoy sports and other physical activities
- \_\_\_\_\_ Ability to exercise for good cardiovascular health and weight management
- \_\_\_\_\_ Compromises with respect to bladder and/or bowel control
- \_\_\_\_\_ Freedom from pain and discomfort
- \_\_\_\_\_ Compromises in the workplace
- \_\_\_\_\_ Other

If ‘Other’, explain:

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Reflection based on prolapse experiences

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16. What do you feel is most lacking in public health information regarding POP?

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17. What do you feel is most lacking with respect to the patient–doctor relationship regarding POP?

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18. What is needed most with respect to research and innovation regarding POP?

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*Appendix 2. Outline of scripted questions for in-depth telephone interviews.*

**What do you feel is most lacking in public health information regarding POP?**

1. Is commonality of the condition important to know? How does this affect you and your behaviour with respect to motivation for diagnosis and treatment?
2. What is missing with respect to information about prevention? What would be believable? Not believable?
3. What do you generally feel to be the responsibility of the government with respect to public health information versus your own private doctor?
4. Where should these public health messages appear in order to be credible? TV, print, radio? Examples of where it's acceptable? Examples of where it is not acceptable or credible?
5. Should doctors be trying to educate their patients about POP when they are young and having babies or when they are older and more likely to begin experiencing symptoms of POP? What is the answer?
6. How can the doctors (and nurse practitioners, physician's assistants and their nurses) be helped to do a better job of opening the dialogue with their patients about POP? Whose responsibility is that? The teaching institutions? The residency programmes? The government? Private industry? Not-for-profits like NAFC?
7. Specifically, what details are lacking in this communication?
8. What about the taboo factor? Is there a taboo factor or stigma with respect to POP? How do we help media, doctors and patients overcome this?
9. Other thoughts on the question of what is most lacking in public health information regarding POP?

**What is most lacking with respect to the patient–doctor relationship regarding POP?**

1. How can older women be better educated to talk to their primary care provider/OBGYN about POP? What needs to happen to help them overcome their embarrassment about talking to their doctor, particularly if he's male, about POP symptoms?
2. What is it about surgery that you don't like? Is this more difficult to discuss than other interventions?
3. Many women complain about their doctors "not listening" to them when they describe symptoms of POP. What is the gap about? How could NAFC make a difference?
4. Some women talk about a lack of a sense of urgency once doctors even diagnose the condition. Have you experienced this? Why don't doctors feel a sense of urgency to take action? What is missing in their understanding? Or is there something more, like a fear of losing you as their patient to a sub-specialist who will do the surgery that they are not trained themselves to do?
5. Why don't doctors ask about POP symptoms as a part of the routine annual visit? What is missing?
6. How important is it to you that your doctor initiate questions about your symptoms of POP versus being willing to listen to and take action upon hearing you initiate your own complaint?
7. How difficult has it been for you to find a doctor to address and treat your symptoms of POP? Did it turn out to be your regular OBGYN? Or someone to whom you were referred? Was that an urologist? Or an urogynaecologist?
8. Do you know the difference between a urologist and an urogynaecologist? What is that and is it valuable to you to have access to either/or? What is the best way for you to obtain information about the training of each and the difference between them and your family physician and OBGYN?
9. If you didn't live in a major metropolitan area in which an easy referral network to specialists and sub-specialists existed, how would you go about finding someone beyond your primary care provider (if he or she wasn't prepared to help you?) for

*Appendix 2 (cont.). Outline of scripted questions for in-depth telephone interviews.*

diagnosis/treatment?

**What is needed most with respect to research and innovation regarding POP?**

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1. Respondents have indicated that some of their highest research priorities are learning ways to reduce the risks of prolapse, lowering the incidence of prolapse and finding better, lasting treatments for prolapse. Which of these is your highest priority and why?
2. What are other priorities that should be undertaken?
3. What are NAFC's responsibilities? What are the responsibilities of physician societies? Of the government? Of private insurance carriers? Of others, such as consumer advocacy organisations?