Appendix. Survey Measure

Ehlers-Danlos Syndrome and Fertility

1. The purpose of this anonymous survey is to determine how often women with Ehlers-Danlos syndrome experience menstrual disorders, reproductive problems, infertility or early miscarriage. Which of the following best describes your diagnosis:
   a. Classical (Type I or II)
   b. Hypermobility (Type III)
   c. Vascular (Type IV)
   d. Kyphoscoliosis (Type VI)
   e. Arthrochalasia (Type VIIA or VIIB)
   f. Dermatosparaxis (Type VIIC)
   g. Unspecified (Type V)
   h. Peridontosis (Type VIII)
   i. Occipital Horn Syndrome (Type IX)
   j. Other (Type X)
   k. I have Ehlers-Danlos syndrome, but I’m not sure what type
   l. I may have Ehlers-Danlos syndrome, but the diagnosis has not been confirmed
   m. I do not have Ehlers-Danlos syndrome
   n. Other (please specify)

2. What is your current age in years?

3. Infertility is often defined as the inability to achieve pregnancy after 12 months or more years of regular unprotected intercourse. A couple is not required to be “actively pursuing” conception to be considered infertile. Considering this definition, have you ever experienced infertility?
   a. Yes
   b. No
   c. Not applicable; I have not has 12 or more consecutive months of unprotected intercourse in my life
   d. Other (please specify)

4. Please estimate the number of months or years that you have had intercourse without contraception until age 40 (do not include time during a pregnancy or breast feeding).
   a. 0
   b. 1-6 months
   c. 7-12 months
   d. 1-2 years


The authors provided this information as a supplement to their article.
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<th>Option</th>
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<td>e.</td>
<td>2-3 years</td>
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<td>3-4 years</td>
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<td>g.</td>
<td>4-5 years</td>
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<td>h.</td>
<td>More than 5 years</td>
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5. How many times have you ever been pregnant? (include total of all births, miscarriages, ectopic pregnancies, and pregnancy terminations).

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<td>j.</td>
<td>9</td>
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<td>k.</td>
<td>10 or more</td>
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<td>l.</td>
<td>Other (please specify)</td>
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6. How many living children do you have?

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7. How many term births have you ever had?

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<td>e.</td>
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<td>f.</td>
<td>5 or more</td>
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<td>g.</td>
<td>Other (please specify)</td>
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8. How many pre-term births have you had (20 to 36 weeks)?

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<td>b.</td>
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</tbody>
</table>


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c. 2  
d. 3  
e. 4  
f. 5 or more  
g. Other (please specify)  
9. How many miscarriages (loss before 20 weeks) have you had?  
a. 0  
b. 1  
c. 2  
d. 3  
e. 4  
f. 5 or more  
g. Other (please specify)  
10. How many ectopic pregnancies have you had?  
a. 0  
b. 1  
c. 2  
d. 3  
e. 4 or more  
f. Other (please specify)  
11. What is your menstrual cycle pattern (check all that apply)  
a. Regular periods  
b. Spotting before periods  
c. Bleeding between periods  
d. Irregular periods  
e. Heavy periods  
f. Light periods  
g. No periods  
h. Other (please specify)  
12. What is your menstrual cycle length, from the start of one period to the start of the next (choose range of days)  
a. 26 to 32 days  
b. Less than 26 days  
c. More than 32 days  
13. How many days of bleeding do you usually have during your period?  
a. 2 or less  
b. 3 to 4  


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c. 5 to 6

d. 7 to 8

e. More than 8

14. In the last year, have you needed to take medication to bring on a period?
   a. No
   b. Yes
   c. Other (please specify)

15. Do you have severe cramping or pelvic pain with your periods?
   a. No
   b. I have mild pain but usually don’t take medications
   c. I have pain but it is controlled with non-prescription medications using the recommended dose or less
   d. Yes – always
   e. Yes – sometimes
   f. Yes – in the past
   g. Other (please specify)

16. How many times have you had intercourse in the past month?
   a. None
   b. Once
   c. 2 to 3 times (less than once a week)
   d. 4 to 7 times (approximately 1-2 times a week)
   e. 8 to 12 times (approximately 2-3 times a week)
   f. 13 or more times (more than 3 times a week)

17. Do you have pain during intercourse
   a. No
   b. Some mild discomfort occasionally
   c. Yes, moderate or severe pain occasionally
   d. Yes, I usually have pain during intercourse, but not always
   e. Yes, I avoid intercourse because it is so painful

18. Have you ever had surgery for any of these conditions? Check all that apply.
   a. No
   b. Endometriosis
   c. Infertility
   d. Pelvic pain
   e. Ectopic pregnancy
   f. Ovarian cyst
   g. Pelvic adhesions


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h. Uterine fibroids
i. Heavy periods
j. Damaged fallopian tubes
k. Uterine polyps
l. Other (please specify)

19. If you have experienced infertility, what cause has been suspected?
   a. I have not experienced infertility
   b. I have been infertile, but never sought medical care
   c. I have been infertile, but no explanation was ever found
   d. Male infertility
   e. Polycystic ovarian syndrome
   f. Endometriosis
   g. Diminished ovarian reserve
   h. Fibroids
   i. Other uterine abnormality
   j. Adhesions
   k. Damaged fallopian tube(s)
   l. Abnormal cervix
   m. Other (please specify)

20. If you have been treated for infertility, what treatments have you had? (check all that apply)
   a. Fertility medications (clomid, letrozole, fertility injections)
   b. Intrauterine insemination (IUI)
   c. In vitro fertilization (IVF)
   d. IVF with preimplantation genetic diagnosis
   e. Surgery
   f. No treatment
   g. Other (please specify)

21. If you were treated for infertility, what was the outcome?
   a. I was never treated for infertility
   b. I have not been able to conceive
   c. I became pregnant only once, but had a miscarriage
   d. I became pregnant only once, and lost the pregnancy after the first trimester
   e. I became pregnant only once, and had a live birth
   f. I became pregnant more than once, but never had a live births
   g. I became pregnant more than once, and had a live birth
   h. Other (please specify)
22. Did a medical professional ever tell you that you should not become pregnant?
   a. No
   b. Yes – because of Ehlers-Danlos
   c. Yes – because of condition unrelated to Ehlers-Danlos
   d. Other (please specify)

23. If your physician (or other medical professional) talked to you about options for a family, what options did you discuss?
   a. Risks and benefits of carrying my own child
   b. Adoption
   c. Gestational carrier (another woman carries your pregnancy)
   d. Egg donation (using eggs from a donor)
   e. Sperm donation
   f. Embryo donation
   g. In vitro fertilization with preimplantation genetic diagnosis
   h. I never wanted to (or needed to) discuss this with a medical providers
   i. I wanted to discuss this with my provider, but I never did
   j. Other (please specify)

24. If you wanted information about family building options with Ehlers-Danlos syndrome, which do you believe were NOT adequately discussed by your provider? (check all that apply)
   a. Not applicable
   b. Risks and benefits of carrying my own child
   c. Adoption
   d. Gestational carrier (another woman carries your pregnancy to avoid pregnancy complications of Ehlers-Danlos syndrome)
   e. Egg donation (using eggs from a donor to avoid passing on Ehlers-Danlos syndrome to your child)
   f. Sperm donation (using donor sperm to avoid passing Ehlers-Danlos syndrome from your partner to your child)
   g. Embryo donation (using donated embryos to avoid passing Ehlers-Danlos syndrome to your child)
   h. In vitro fertilization with preimplantation genetic diagnosis to screen embryos for Ehlers-Danlos syndrome

25. How well informed do you feel you are about the risks and benefits of…

<table>
<thead>
<tr>
<th></th>
<th>Not informed at all</th>
<th>Very limited information</th>
<th>Fairly well informed</th>
<th>Well informed</th>
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<tbody>
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<tr>
<td>own child</td>
<td>Adoption</td>
<td>Gestational Carrier</td>
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<td>Egg donation</td>
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26. Thank you for taking the time to complete this survey. If you have any additional information you would like to provide, you may do so here.