Subject Initials | REACH ID | Date (MM-DD-YYYY)

GLOBAL UNIQUE IDENTIFIER

Instructions: Please enter the following information exactly as they appear on your birth certificate.

Complete legal given FIRST name of the subject at birth

FIRST NAME

RE-ENTER FIRST NAME

Complete legal give MIDDLE name of the subject at birth (if applicable)

☐ Select if the subject has no legal given MIDDLE name

MIDDLE NAME

RE-ENTER MIDDLE NAME

Complete legal give LAST name of the subject at birth

LAST NAME

RE-ENTER LAST NAME

Subject's BIRTHDATE

YEAR MONTH DAY

RE-ENTER BIRTHDATE

YEAR MONTH DAY

Subject Initials | | | |

REACH ID | | | | |

Date M M - D D - Y Y Y Y

Physical SEX OF THE SUBJECT AT BIRTH

☐ Female
☐ Male

RE-ENTER SEX OF THE SUBJECT AT BIRTH

☐ Female
☐ Male

Name of CITY/MUNICIPALITY in which the subject was born

BIRTHPLACE

RE-ENTER BIRTHPLACE

STOP: FOR SITE PERSONNEL ONLY

GUID GENERATED

GUID GENERATED

GUID Generated by:

Date GUID generated: M M - D D - Y Y Y Y

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DEMOGRAPHICS

Instructions: Please complete each question below with the answer that best represents you.

Age	
Ethnicity	☐ Hispanic or Latino ☐ Not Hispanic or Latino ☐ Unknown
Race	☐ American Indian or Alaskan Native ☐ Asian ☐ Black or African American ☐ Native Hawaiian or other Pacific Islander ☐ White ☐ Multiple races ☐ Unknown
Employment status	☐ Working now ☐ Temporarily off work (sick leave or maternity leave) ☐ Looking for work, unemployed ☐ Retired ☐ Disabled due to myotonic dystrophy ☐ Disabled due to an injury or disease other than myotonic dystrophy ☐ Other
If other employment status, please describe	
Do you currently collect disability benefits?	☐ Yes ☐ No

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Relationship status	☐ Never married ☐ Domestic Partner ☐ Separated ☐ Married ☐ Divorced ☐ Widowed ☐ Single ☐ Prefer not to answer
Who is in your household with you?	☐ Live alone ☐ Live with children, single parent ☐ Live with partner/spouse ☐ Live with partner/spouse/children ☐ Live with parents ☐ Live with other family ☐ Live with roommate ☐ Other
If other, please describe	
Highest level of education?	☐ Never attended/Kindergarten only ☐ Some school, no degree ☐ High School graduate ☐ GED or equivalent ☐ Some college, no degree ☐ Associate degree ☐ Bachelor's degree (e.g. BA, AB, BS, BBA) ☐ Master's degree (e.g. MA, MS, Meng, Med, MBA) ☐ Professional school degree (e.g. MD, DDS, DVM, JD) ☐ Doctoral degree (e.g. PhD, EdD) ☐ Prefer not to answer

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DM ONSET AND SYMPTOMS

Instructions: Please complete each question below with the answer that best represents you.

What is your diagnosis?	☐ Myotonic Dystrophy Type 1 ☐ Myotonic Dystrophy Type 2 ☐ Congenital Myotonic Dystrophy ☐ Not sure
Do you have any symptoms of myotonic dystrophy?	☐ Yes ☐ No, I have a diagnosis but don't believe I have any symptoms related to Myotonic Dystrophy
What do you consider your first symptom of Myotonic Dystrophy?	
At what age did you experience your first symptom of Myotonic Dystrophy?	
At what age where you diagnosed?	
Was your diagnosis of DM confirmed with a genetic blood test?	☐ Yes ☐ No
If you have DM1 and you have had a genetic test, please enter the number of repeats (if known)	
Do you experience stiffness/locking up (myotonia) in your hands?	☐ Yes ☐ No
At what age did you start to experience stiffness (myotonia) in your hands?	
Do you experience stiffness/locking up (myotonia) in your mouth, tongue or jaw?	☐ Yes ☐ No
At what age did you start to experience stiffness (myotonia) in your mouth, tongue or jaw?	
Do you experience weakness in your hands?	☐ Yes ☐ No

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At what age did you start to experience weakness in your hands?	
Do you experience weakness in any areas besides your hands? (For example, your neck or ankles)	☐ Yes ☐ No
At what age did you start to experience weakness in other areas?	
Do you experience weakness in your hip muscles? (climbing stairs, getting up from a chair, getting up from the ground)	☐ Yes ☐ No
At what age did you start to experience weakness in your hip muscles? (climbing stairs, getting up from a chair, getting up from the ground)	
Do you use a walking aid or bracing? (For example, a cane, walker, or ankle braces)	☐ Yes ☐ No
At what age did you start to use a walking aid or bracing? (For example, a cane, walker, or ankle braces)	
Do you use a wheelchair occasionally?	☐ Yes ☐ No
At what age did you start to use a wheelchair occasionally?	
Do you use a wheelchair full-time?	☐ Yes ☐ No
At what age did you start to use a wheelchair full-time?	
Have you been prescribed non-invasive ventilation (e.g. CPAP/BiPAP)?	☐ Yes ☐ No
At what age did you start using non-invasive ventilation?	

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Were you prescribed non-invasive ventilation but you are not using it?	
Why are you not using it?	
Do you experience daytime sleepiness, e.g. do you take naps on most days of the week?	☐ Yes ☐ No
At what age did you start to experience daytime sleepiness?	
Do you experience muscle pain?	☐ Yes ☐ No
At what age did you start to experience muscle pain?	
Do you experience difficulty with your memory, thinking or learning?	☐ Yes ☐ No
At what age did you start to experience difficulty with your memory, thinking or learning?	

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MENSTRUAL HISTORY

Instructions: Please complete each question below with the answer that best represents you.

Are you in:	☐ Menstruating ☐ Peri-menopause ☐ Menopause ☐ Not menstruating due to hormones (IUD, birth control pill, etc.) ☐ Not menstruating due to hysterectomy ☐ Pregnant ☐ Postpartum
At what age did you have your first period?	
How heavy is/was your menstrual flow usually?	☐ Light ☐ Moderate ☐ Heavy (clots/flooding) ☐ Can't remember
How many days are/were there typically between the start of one period and the start of the next on average?	☐ Less than 21 days ☐ 22-24 days ☐ 25-28 days ☐ 29-32 days ☐ 33 - 35 days ☐ More than 36 days ☐ Too irregular to say

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Do/did you have any of the following symptoms when you have a period? Select all that apply	☐ Pelvic pain (pain in the lower party of your belly) ☐ Pain with having a bowel movement ☐ Bleeding from your back passage when opening your bowels ☐ Pain on passing urine ☐ Passing blood in your urine ☐ Lower back pain ☐ Pain in upper leg or thighs ☐ Nausea ☐ Tiredness ☐ Other
If other, please describe	
Do/did you use pads during your cycle? (not counting pantyliners)	☐ No ☐ Occasionally ☐ Often ☐ Always ☐ Can't remember
Do/did you use tampons during your cycle?	☐ No ☐ Occasionally ☐ Often ☐ Always ☐ Can't remember
How often do/did you sleep with a tampon in place at night?	☐ Never ☐ 1 or 2 nights each period ☐ 3 or 4 nights each period ☐ 5 or more nights each period ☐ Can't remember
In the 5 days leading up to your first day of your period, do/did you experience premenstrual symptoms such as, but not limited to, feeling sad, tearful, irritable, food cravings, bloating, breast tenderness, or hot flashes?	☐ Yes ☐ No

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Would you consider your premenstrual symptoms?	☐ Mild (noticeable, but do not affect your day) ☐ Moderate (affect your day, but you are still able to do activities) ☐ Severe (you miss work or activities due to the symptoms) ☐ You have been diagnosed with PMDD (premenstrual dysphoric disorder

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GSWH: CONTRACEPTION

Instructions: Please complete each question below with the answer that best represents you.

Do you use contraception?

☐ Yes
☐ No

Do you use contraception to:

☐ To prevent pregnancy
☐ To control menstrual symptoms
☐ Both

Contraception	Have used for contraception	Have used for symptoms	Using Now
IUD			
Pill			
Ring			
Depo/shot			
Diaphragm			
Condon			
Other			

If other, please list

Have you ever used the Morning-after Pill?

☐ Yes
☐ No

In the last 3 months, have you had pelvic pain with your periods?

☐ Yes
☐ No

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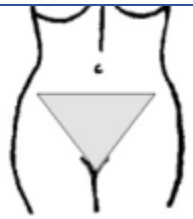
PELVIC PAIN AND PERIODS

By 'pelvic pain' we mean any type of pain in the lower part of your belly (the area from your navel down) as shown by the shaded area in this picture:



How often have you had pelvic pain with your periods in the last 3 months?	☐ Occasionally (with 1 in 3 of my periods) ☐ Often (with 2 in 3 of my periods) ☐ Always (with every period)
In the last 3 months, have you taken pain-killers for the pain that are prescribed for you by a doctor?	☐ Yes ☐ No
In the last 3 months, have you taken pain-killers for the pain, bought over the counter without prescription?	☐ Yes ☐ No
In the last 3 months, has your period pain prevented you from going to work or carrying out your daily activities (even if taking pain-killers)?	☐ Never ☐ Occasionally (with 1 in 3 of my periods) ☐ Often (with 2 in 3 of my periods) ☐ Always (with every period)
In the last 3 months, have you had to lie down for any part of the day or longer because of your period pain?	☐ Never ☐ Occasionally (with 1 in 3 of my periods) ☐ Often (with 2 in 3 of my periods) ☐ Always (with every period)
Please circle on the following scale, going from no pain (0) to worst possible pain (10), the number that indicates how severe your period pain has been ON AVERAGE in the last 3 months:	0 1 2 3 4 5 6 7 8 9 10 (no pain) (worst pain)
Please circle on the following scale, going from no pain (0) to worst possible pain (10), the number that indicates how severe your period pain has been AT ITS WORST in the last 3 months:	0 1 2 3 4 5 6 7 8 9 10 (no pain) (worst pain)

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The following questions are about your bowel movements at the time you had menstrual pain IN THE LAST 3 MONTHS	
When you had menstrual pain in the last 3 months how often did this pain get better or stop after you had a bowel movement?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always
When you had menstrual pain in the last 3 months how often did you have more frequent bowel movements?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always
When you had menstrual pain in the last 3 months how often did you have less frequent bowel movements?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always
When you had menstrual pain in the last 3 months were your stools (bowel movements) looser?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always
When you had menstrual pain in the last 3 months were your stools (bowel movements) harder?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always

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FEMALE SEXUAL FUNCTION INDEX (FSFI)

These questions ask about your sexual feelings and responses during the past 4 weeks. Please answer the following questions as honestly and clearly as possible. Check only one box per question. Your responses will be kept completely confidential. In answering these questions, the following definitions apply:

Sexual activity can include caressing, foreplay, masturbation and vaginal intercourse.
Sexual intercourse is defined as penile penetration (entry) of the vagina.
Sexual stimulation includes situations like foreplay with a partner, self-stimulation, or sexual fantasy.

Sexual desire or interest is a feeling that includes wanting to have a sexual experience, feeling receptive to s partner's sexual initiation, and thinking or fantasizing about having sex.

Sexual arousal is a feeling that includes both physical and mental aspects of sexual excitement. It may include feelings of warmth or tingling in the genitals, lubrication (wetness), or muscle contractions.

What is your current sexual partner preference?	☐ Male ☐ Female ☐ Male and female ☐ Other ☐ None
If other, please explain	
Over the *past 4 weeks*, how often did you feel sexual desire or interest?	☐ Almost always or always ☐ Most times (more than half the time) ☐ Sometimes (about half the time) ☐ A few times (less than half the time) ☐ Almost never or never
Over the *past 4 weeks*, how would you rate your level (degree) of sexual desire or interest?	☐ Very high ☐ High ☐ Moderate ☐ Low ☐ Very low or none at all

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Over the *past 4 weeks*, how confident were you about becoming sexually aroused during sexual activity or intercourse?	☐ No sexual activity ☐ Very high confidence ☐ High confidence ☐ Moderate confidence ☐ Low confidence ☐ Very low or no confidence
Over the *past 4 weeks*, how often have you been satisfied with your arousal (excitement) during sexual activity or intercourse?	☐ No sexual activity ☐ Almost always or always ☐ Most times (more than half the time) ☐ Sometimes (about half the time) ☐ A few times (less than half the time) ☐ Almost never or never
Over the *past 4 weeks*, how often did you become lubricated ("wet") during sexual activity or intercourse?	☐ No sexual activity ☐ Almost always or always ☐ Most times (more than half the time) ☐ Sometimes (about half the time) ☐ A few times (less than half the time) ☐ Almost never or never
Over the *past 4 weeks*, how often did you maintain your lubrication ("wetness") until completion of sexual activity or intercourse?	☐ No sexual activity ☐ Almost always or always ☐ Most times (more than half the time) ☐ Sometimes (about half the time) ☐ A few times (less than half the time) ☐ Almost never or never

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Over the *past 4 weeks*, how difficult was it to maintain your lubrication ("wetness") until completion of sexual activity or intercourse?	☐ No sexual activity ☐ Extremely difficult or impossible ☐ Very difficult ☐ Difficult ☐ Slightly difficult ☐ Not difficult
Over the *past 4 weeks*, when you had sexual stimulation or intercourse, how often did you reach orgasm (climax)?	☐ No sexual activity ☐ Almost always or always ☐ Most times (more than half the time) ☐ Sometimes (about half the time) ☐ A few times (less than half the time) ☐ Almost never or never
Over the *past 4 weeks*, when you had sexual stimulation or intercourse, how difficult was it for you to reach orgasm (climax)?	☐ No sexual activity ☐ Extremely difficult or impossible ☐ Very difficult ☐ Difficult ☐ Slightly difficult ☐ Not difficult
Over the *past 4 weeks*, how satisfied were you with your ability to reach orgasm (climax) during sexual activity or intercourse?	☐ No sexual activity ☐ Very satisfied ☐ Moderately satisfied ☐ About equally satisfied and dissatisfied ☐ Moderately dissatisfied ☐ Very dissatisfied
Over the *past 4 weeks*, how satisfied have you been with the amount of emotional closeness during sexual activity between you and your partner?	☐ No sexual activity ☐ Very satisfied ☐ Moderately satisfied ☐ About equally satisfied and dissatisfied ☐ Moderately dissatisfied ☐ Very dissatisfied
Over the *past 4 weeks*, how satisfied have you been with your sexual relationship with your partner?	☐ Very satisfied ☐ Moderately satisfied ☐ About equally satisfied and dissatisfied ☐ Moderately dissatisfied ☐ Very dissatisfied

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Over the *past 4 weeks*, how satisfied have you been with your overall sexual life?	☐ Very satisfied ☐ Moderately satisfied ☐ About equally satisfied and dissatisfied ☐ Moderately dissatisfied ☐ Very dissatisfied
Over the *past 4 weeks*, how often did you experience discomfort or pain during vaginal penetration?	☐ Did not attempt intercourse ☐ Almost always or always ☐ Most times (more than half the time) ☐ Sometimes (about half the time) ☐ A few times (less than half the time) ☐ Almost never or never
Over the *past 4 weeks*, how often did you experience discomfort or pain following vaginal penetration?	☐ Did not attempt intercourse ☐ Almost always or always ☐ Most times (more than half the time) ☐ Sometimes (about half the time) ☐ A few times (less than half the time) ☐ Almost never or never
Over the *past 4 weeks*, how would you rate your level (degree) of discomfort or pain during or following vaginal penetration?	☐ Did not attempt intercourse ☐ Very high ☐ High ☐ Moderate ☐ Low ☐ Very low or none at all
Do you use lubrication during sex?	☐ Yes ☐ No
If yes, why? Select all that apply.	☐ Trouble getting lubricated ☐ Like how it feels ☐ Helps with toys, etc.

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DM AND SEXUAL ACTIVITIES

Instructions: Please complete each question below with the answer that best represents you.

Do any of the following symptoms related to DM impact your ability to engage in sexual activities? Select as many as apply.	☐ Hand weakness ☐ Hand stiffness/locking up (hand myotonia) ☐ Neck weakness (difficulty raising head from bed) ☐ Stiffness in mouth/tongue or jaw (oral myotonia) ☐ Leg weakness (hips) ☐ Shoulder weakness ☐ Core weakness ☐ GI issues ☐ Apathy ☐ Facial weakness (difficulty making a seal with your mouth) ☐ Excessive daytime sleepiness ☐Muscle fatigue ☐ Other
If other, please explain	
Hand Weakness: How much does this affect your ability to engage in sexual activities?	☐ Some ☐ Moderate ☐ Severe
Hand stiffness/locking up: How much does this affect your ability to engage in sexual activities?	☐ Some ☐ Moderate ☐ Severe
Neck weakness: How much does this affect your ability to engage in sexual activities?	☐ Some ☐ Moderate ☐ Severe
Stiffness in mouth/tongue or jaw: How much does this affect your ability to engage in sexual activities?	☐ Some ☐ Moderate ☐ Severe

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Leg weakness: How much does this affect your ability to engage in sexual activities?	☐ Some ☐ Moderate ☐ Severe
Shoulder weakness: How much does this affect your ability to engage in sexual activities?	☐ Some ☐ Moderate ☐ Severe
Core weakness: How much does this affect your ability to engage in sexual activities?	☐ Some ☐ Moderate ☐ Severe
GI Issues: How much does this affect your ability to engage in sexual activities?	☐ Some ☐ Moderate ☐ Severe
Apathy issues: How much does this affect your ability to engage in sexual activities?	☐ Some ☐ Moderate ☐ Severe
Facial Weakness: How much does this affect your ability to engage in sexual activities?	☐ Some ☐ Moderate ☐ Severe
Excessive daytime sleepiness: How much does this affect your ability to engage in sexual activities?	☐ Some ☐ Moderate ☐ Severe
Muscle fatigue: How much does this affect your ability to engage in sexual activities?	☐ Some ☐ Moderate ☐ Severe
If other, how much does this affect your ability to engage in sexual activities?	☐ Some ☐ Moderate ☐ Severe
Are there any other DM symptoms that you experience that affect your sexual health?	

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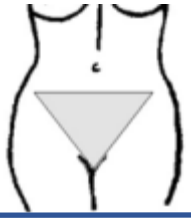
PAIN AND SEXUAL INTERCOURSE

Instructions: This section will ask questions about pain during or after sexual intercourse (intercourse of any type - including penis-vaginal sex, self-pleasure, toys).

By 'pelvic pain' we mean any type of pain in the lower part of your belly (the area from your navel down) as shown by the shaded area in this picture



Check here if you have never had sexual intercourse	☐
In the last 3 months, have you had pelvic pain [pain or discomfort, ranging from a sharp jab to a dull ache, in the lowest part of your abdomen] during or in the 24 hours after sexual intercourse?	☐ Yes ☐ No
Have you been diagnosed with a sexually transmitted disease (STD) or pelvic inflammatory disease (PID)	☐ Yes ☐ No
If yes, please explain	
On average, how often do you have pelvic pain during or in the 24 hours after intercourse?	☐ Never ☐ Occasionally (less than a quarter of the times) ☐ Often (a quarter to half of the times) ☐ Usually (more than half of the times) ☐ Always (every time) ☐ Can't remember
Do you ever interrupt intercourse because of pelvic pain?	☐ Yes ☐ No

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Do you ever avoid intercourse because of pelvic pain?	☐ Yes ☐ No
Is there a time of the month in which intercourse is more painful than at other times? Select all that apply	☐ No ☐ Yes: during a period ☐ Yes: just before or after a period ☐ Yes: at mid-cycle (around ovulation)
Please slide the marker on the following scale, going from no pain (0) to worst possible pain (10), to the number that indicates how severe your pain during sexual intercourse has been ON AVERAGE in the last 3 months:	0 1 2 3 4 5 6 7 8 9 10 (no pain) (worst pain)
Please slide the marker on the following scale, going from no pain (0) to worst possible pain (10), to the number that indicates how severe your pain in the 24 hours after sexual intercourse has been ON AVERAGE in the last 3 months:	0 1 2 3 4 5 6 7 8 9 10 (no pain) (worst pain)
In the last 3 months, have you had pelvic pain at times OTHER than with menstruation or intercourse?	☐ Yes ☐ No
How long ago did this pain first start?	☐ 4-6 months ago ☐ 7-12 months ago ☐ Between 1 and 5 years ago ☐ More than 5 years ago
Do you usually have this pain at about the same time in your cycle? Select all that apply	☐ No ☐ Yes, just before a period ☐ Yes, just after a period ☐ Yes, at mid-cycle (ovulation)
How long did the pain last, approximately, in the last 3 months?	☐ Less than one day a month ☐ One day a month ☐ 2-3 days a month ☐ One day a week ☐ More than one day a week ☐ Every day

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Do you take pain-killers for this pain, prescribed for you by a doctor?	☐ Yes ☐ No
If yes, what do you take?	
Do you take pain-killers for this pain that you can buy over the counter? (e.g. Aspirin, Nurofen, Paracetamol, Aleve, Naproxin, Midol, etc.)	☐ Yes ☐ No
Have you ever been admitted to the hospital for your pain?	☐ Yes ☐ No
Please slide the marker on the following scale, going from no pain (0) to worst possible pain (10), to the number that indicates how severe your pain at times OTHER than with periods or intercourse has been ON AVERAGE in the last 3 months:	0 1 2 3 4 5 6 7 8 9 10 (no pain) (worst pain)
Please slide the marker on the following scale, going from no pain (0) to worst possible pain (10), to the number that indicates how severe your pain at times OTHER than with periods or intercourse has been AT ITS WORST in the last 3 months:	0 1 2 3 4 5 6 7 8 9 10 (no pain) (worst pain)

The following questions are about your bowel movements/stool when you had pelvic pain OTHER than with periods IN THE LAST 3 MONTHS

When you had pelvic pain OTHER than with periods in the last 3 months how often did this pain get better or stop after you had a bowel movement?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always

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When you had pelvic pain OTHER than with periods in the last 3 months how often did you have more frequent bowel movements?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always
When you had pelvic pain OTHER than with periods in the last 3 months how often did you have less frequent bowel movements?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always
When you had pelvic pain OTHER than with periods in the last 3 months were your stools (bowel movements) looser?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always
When you had pelvic pain OTHER than with periods in the last 3 months were your stools (bowel movements) harder?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always

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SEXUAL QUALITY OF LIFE QUESTIONNAIRE – FEMALE

Instructions: This questionnaire consists of a set of statements, each asking about thoughts and feelings that you may have about your sex life. The statement may be positive or negative.

You are asked to rate each one according to how much you agree or disagree with the statement by choosing one of six response choices.

In answering these items, the following definitions apply:

Sex life: is both the physical sexual activities and the emotional sexual relationship that you have with your partner.

Sexual activity: Includes any activity with may result in sexual stimulation or sexual pleasure such as intercourse, caressing, foreplay, masturbation (self-masturbation or your partner masturbating you) and oral sex (your partner giving you oral sex).

Usually, the first answer that comes into your head is the best one so please do not spend too long on each question.

When I think about my sex life, it is an enjoyable part of my overall life	☐ Completely agree ☐ Moderately agree ☐ Slightly agree ☐ Slightly disagree ☐ Moderately disagree ☐ Completely disagree
When I think about my sex life, I feel frustrated	☐ Completely agree ☐ Moderately agree ☐ Slightly agree ☐ Slightly disagree ☐ Moderately disagree ☐ Completely disagree
When I think about my sex life, I feel depressed	☐ Completely agree ☐ Moderately agree ☐ Slightly agree ☐ Slightly disagree ☐ Moderately disagree ☐ Completely disagree

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When I think about my sex life, I feel like less of a woman	☐ Completely agree ☐ Moderately agree ☐ Slightly agree ☐ Slightly disagree ☐ Moderately disagree ☐ Completely disagree
When I think about my sex life, I feel good about myself	☐ Completely agree ☐ Moderately agree ☐ Slightly agree ☐ Slightly disagree ☐ Moderately disagree ☐ Completely disagree
I have lost my confidence in myself as a sexual partner	☐ Completely agree ☐ Moderately agree ☐ Slightly agree ☐ Slightly disagree ☐ Moderately disagree ☐ Completely disagree
When I think about my sex life, I feel anxious	☐ Completely agree ☐ Moderately agree ☐ Slightly agree ☐ Slightly disagree ☐ Moderately disagree ☐ Completely disagree
When I think about my sex life, I feel angry	☐ Completely agree ☐ Moderately agree ☐ Slightly agree ☐ Slightly disagree ☐ Moderately disagree ☐ Completely disagree

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When I think about my sex life, I feel close to my partner	☐ Completely agree ☐ Moderately agree ☐ Slightly agree ☐ Slightly disagree ☐ Moderately disagree ☐ Completely disagree
I worry about the future of my sex life	☐ Completely agree ☐ Moderately agree ☐ Slightly agree ☐ Slightly disagree ☐ Moderately disagree ☐ Completely disagree
I have lost pleasure in sexual activity	☐ Completely agree ☐ Moderately agree ☐ Slightly agree ☐ Slightly disagree ☐ Moderately disagree ☐ Completely disagree
When I think about my sex life, I feel embarrassed	☐ Completely agree ☐ Moderately agree ☐ Slightly agree ☐ Slightly disagree ☐ Moderately disagree ☐ Completely disagree
When I think about my sex life, I feel that I can talk to my partner about sexual matters	☐ Completely agree ☐ Moderately agree ☐ Slightly agree ☐ Slightly disagree ☐ Moderately disagree ☐ Completely disagree

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I try to avoid sexual activity	☐ Completely agree ☐ Moderately agree ☐ Slightly agree ☐ Slightly disagree ☐ Moderately disagree ☐ Completely disagree
When I think about my sex life, I feel guilty	☐ Completely agree ☐ Moderately agree ☐ Slightly agree ☐ Slightly disagree ☐ Moderately disagree ☐ Completely disagree
When I think about my sex life, I worry that my partner feels hurt or rejected	☐ Completely agree ☐ Moderately agree ☐ Slightly agree ☐ Slightly disagree ☐ Moderately disagree ☐ Completely disagree
When I think about my sex life, I feel like I have lost something	☐ Completely agree ☐ Moderately agree ☐ Slightly agree ☐ Slightly disagree ☐ Moderately disagree ☐ Completely disagree
When I think about my sex life, I am satisfied with the frequency of sexual activity	☐ completely agree ☐ moderately agree ☐ slightly agree ☐ slightly disagree ☐ moderately disagree ☐ completely disagree

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PELVIC FLOOR DISTRESS INVENTORY (PFDI)

Instructions: Please answer all of the questions in the following survey. These questions will ask you if you have certain bowel, bladder, or pelvic symptoms and, if you do, how much they bother you. Answer these by selecting the appropriate answer. While answering these questions, please consider your symptoms over the last 3 months.

			If yes, how much does it both you?			
	YES	**NO**	**NOT AT ALL**	**SOMEWHAT**	**MODERATELY**	**QUITE A BIT**
Do you usually experience pressure in the lower abdomen?						
Do you usually experience heaviness or dullness in the lower abdomen?						
Do you usually have a bulge or something falling out that you can see or fell in the vaginal area?						
Do you usually have to push on the vagina or around the rectum to have a complete bowel movement?						
Do you usually experience a feeling of incomplete bladder emptying?						
Do you ever have to push up in the vaginal area with your fingers to start or complete urination?						
Do you feel you need to strain too hard to have a bowel movement?						
Do you feel you have not completely emptied your bowels at the end of a bowel movement?						
Do you usually lose stool beyond your control if your stool is well formed?						
Do you usually lose stool beyond your control if your stool is loose or liquid?						
Do you usually lose gas from the rectum beyond your control?						
Do you usually have pain when you pass your stool?						
Do you experience a strong sense of urgency and have to rush to the bathroom to have a bowel movement?						
Does part of your stool ever pass through the rectum and bulge outside during or after a bowel movement?						
Do you usually experience frequent urination?						

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			If yes, how much does it both you?			
	YES	**NO**	**NOT AT ALL**	**SOMEWHAT**	**MODERATELY**	**QUITE A BIT**
Do you usually experience urine leakage associated with a feeling of urgency; that is, a strong sensation of needing to go to the bathroom?						
Do you usually experience urine leakage related to laughing, coughing, or sneezing?						
Do you usually experience small amounts of urine leakage (that is, drops)?						
Do you usually experience difficulty emptying your bladder?						
Do you usually experience pain or discomfort in the lower abdomen or genital region?						

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GSWH BOWEL AND BLADDER FUNCTION

Instructions: Please complete each question below with the answer that best represents you.

The following questions are about your bowel movements IN GENERAL in the last 3 months.	
In the last 3 months did you have loose, mushy, or watery stools?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always
In the last 3 months did you have hard or lumpy stools?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always
How many days per week, on average, do you have a bowel movement in the last 3 months?	
How much time do you spend in the bathroom, on average, per day?	
The following questions are about bladder function in the last 3 months	
In the last 3 months how often have you had a sensation of *not emptying your bladder completely* after you finished urinating?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always
In the last 3 months how often have you had to urinate again *less than two hours* after you finished urinating?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always

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In the last 3 months how often have you found it *difficult* to postpone urination?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always
In the last 3 months have you felt '*stinging*' on passing urine?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always
In the last 3 months how often have you had pelvic pain during urination?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always
In the last 3 months how often have you had pelvic pain after you finished urination?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always
How often did pelvic pain with urination *increase just before a period*?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always
In the last 3 months, how many times did you typically *get up to urinate* from the time you went to bed at night until the time you got up in the morning?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always

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In the last 3 months, how often have you had Urinary Tract Infection?	☐ Never/Rarely ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always

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GSWH: PREGNANCY

Instructions: This section will ask you about your pregnancy history.
There are questions in this section for up to 10 pregnancies.

Have you ever been pregnant (including miscarriages, ectopic pregnancies or terminations)?	☐ Yes ☐ No
How many times have you been pregnant (including miscarriages, ectopics or terminations?	☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐ More than 10

1st Pregnancy

How old were you when you were first pregnant?	
What was the outcome of this pregnancy?	☐ Live birth ☐ Still birth ☐ Ectopic pregnancy ☐ Miscarriage ☐ Termination (abortion)
How many weeks were you pregnant for? (Full term = 40 wks)	☐ Less than 37 ☐ 37 or more
If this pregnancy resulted in a birth, was the delivery vaginal or via Caesarean section?	☐ Vaginal birth ☐ Caesarean ☐ Not applicable

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If this pregnancy resulted in a birth, what was your baby's sex?	☐ Male ☐ Female ☐ Not applicable
If this pregnancy resulted in a birth, what was your baby's birthweight?	☐ Not applicable ☐ Can't remember ☐ Enter weight below
Enter the weight in:	☐.... lbs & .... Oz ☐.... grams
Weight:	
If this pregnancy resulted in a live birth, did you breastfeed your child? If so, for how long?	☐ No ☐ Yes (enter time below) ☐ Not applicable
Breastfed (pumped or chest fed) for how many months?	
If you did not breastfeed, was this due to:	☐ DM related reasons ☐ Other reasons
If due to DM, please select all that apply	☐ Weakness ☐ Myotonia ☐ Sleepiness ☐ Other
Other, please specify	

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2nd Pregnancy

How old were you when you were first pregnant?	
What was the outcome of this pregnancy?	☐ Live birth ☐ Still birth ☐ Ectopic pregnancy ☐ Miscarriage ☐ Termination (abortion)
How many weeks were you pregnant for? (Full term = 40 wks)	☐ Less than 37 ☐ 37 or more
If this pregnancy resulted in a birth, was the delivery vaginal or via Caesarean section?	☐ Vaginal birth ☐ Caesarean ☐ Not applicable
If this pregnancy resulted in a birth, what was your baby's sex?	☐ Male ☐ Female ☐ Not applicable
If this pregnancy resulted in a birth, what was your baby's birthweight?	☐ Not applicable ☐ Can't remember ☐ Enter weight below
Enter the weight in:	☐.... lbs & .... Oz ☐.... grams
Weight:	
If this pregnancy resulted in a live birth, did you breastfeed your child? If so, for how long?	☐ No ☐ Yes (enter time below) ☐ Not applicable
Breastfed (pumped or chest fed) for how many months?	
If you did not breastfeed, was this due to:	☐ DM related reasons ☐ Other reasons
If due to DM reasons, please select all that apply	☐ Weakness ☐ Myotonia ☐ Sleepiness ☐ Other

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Other, please specify	

3rd Pregnancy

How old were you when you were first pregnant?	
What was the outcome of this pregnancy?	☐ Live birth ☐ Still birth ☐ Ectopic pregnancy ☐ Miscarriage ☐ Termination (abortion)
How many weeks were you pregnant for? (Full term = 40 wks)	☐ Less than 37 ☐ 37 or more
If this pregnancy resulted in a birth, was the delivery vaginal or via Caesarean section?	☐ Vaginal birth ☐ Caesarean ☐ Not applicable
If this pregnancy resulted in a birth, what was your baby's sex?	☐ Male ☐ Female ☐ Not applicable
If this pregnancy resulted in a birth, what was your baby's birthweight?	☐ Not applicable ☐ Can't remember ☐ Enter weight below
Enter the weight in:	☐.... lbs & .... Oz ☐.... grams
Weight:	
If this pregnancy resulted in a live birth, did you breastfeed your child? If so, for how long?	☐ No ☐ Yes (enter time below) ☐ Not applicable
Breastfed (pumped or chest fed) for how many months?	
If you did not breastfeed, was this due to:	☐ DM related reasons ☐ Other reasons

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If due to DM reasons, please select all that apply	☐ Weakness ☐ Myotonia ☐ Sleepiness ☐ Other
Other, please specify	

4th Pregnancy

How old were you when you were first pregnant?	
What was the outcome of this pregnancy?	☐ Live birth ☐ Still birth ☐ Ectopic pregnancy ☐ Miscarriage ☐ Termination (abortion)
How many weeks were you pregnant for? (Full term = 40 wks)	☐ Less than 37 ☐ 37 or more
If this pregnancy resulted in a birth, was the delivery vaginal or via Caesarean section?	☐ Vaginal birth ☐ Caesarean ☐ Not applicable
If this pregnancy resulted in a birth, what was your baby's sex?	☐ Male ☐ Female ☐ Not applicable
If this pregnancy resulted in a birth, what was your baby's birthweight?	☐ Not applicable ☐ Can't remember ☐ Enter weight below
Enter the weight in:	☐.... lbs & .... Oz ☐.... grams
Weight:	
If this pregnancy resulted in a live birth, did you breastfeed your child? If so, for how long?	☐ No ☐ Yes (enter time below) ☐ Not applicable

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Breastfed (pumped or chest fed) for how many months?	
If you did not breastfeed, was this due to:	☐ DM related reasons ☐ Other reasons
If due to DM reasons, please select all that apply	☐ Weakness ☐ Myotonia ☐ Sleepiness ☐ Other
Other, please specify	

5th Pregnancy

How old were you when you were first pregnant?	
What was the outcome of this pregnancy?	☐ Live birth ☐ Still birth ☐ Ectopic pregnancy ☐ Miscarriage ☐ Termination (abortion)
How many weeks were you pregnant for? (Full term = 40 wks)	☐ Less than 37 ☐ 37 or more
If this pregnancy resulted in a birth, was the delivery vaginal or via Caesarean section?	☐ Vaginal birth ☐ Caesarean ☐ Not applicable
If this pregnancy resulted in a birth, what was your baby's sex?	☐ Male ☐ Female ☐ Not applicable
If this pregnancy resulted in a birth, what was your baby's birthweight?	☐ Not applicable ☐ Can't remember ☐ Enter weight below
Enter the weight in:	☐.... lbs & .... Oz ☐.... grams

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Weight:	
If this pregnancy resulted in a live birth, did you breastfeed your child? If so, for how long?	☐ No ☐ Yes (enter time below) ☐ Not applicable
Breastfed (pumped or chest fed) for how many months?	
If you did not breastfeed, was this due to:	☐ DM related reasons ☐ Other reasons
If due to DM reasons, please select all that apply	☐ Weakness ☐ Myotonia ☐ Sleepiness ☐ Other
Other, please specify	

6th Pregnancy

How old were you when you were first pregnant?	
What was the outcome of this pregnancy?	☐ Live birth ☐ Still birth ☐ Ectopic pregnancy ☐ Miscarriage ☐ Termination (abortion)
How many weeks were you pregnant for? (Full term = 40 wks)	☐ Less than 37 ☐ 37 or more
If this pregnancy resulted in a birth, was the delivery vaginal or via Caesarean section?	☐ Vaginal birth ☐ Caesarean ☐ Not applicable
If this pregnancy resulted in a birth, what was your baby's sex?	☐ Male ☐ Female ☐ Not applicable

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If this pregnancy resulted in a birth, what was your baby's birthweight?	☐ Not applicable ☐ Can't remember ☐ Enter weight below
Enter the weight in:	☐.... lbs & .... Oz ☐.... grams
Weight:	
If this pregnancy resulted in a live birth, did you breastfeed your child? If so, for how long?	☐ No ☐ Yes (enter time below) ☐ Not applicable
Breastfed (pumped or chest fed) for how many months?	
If you did not breastfeed, was this due to:	☐ DM related reasons ☐ Other reasons
If due to DM reasons, please select all that apply	☐ Weakness ☐ Myotonia ☐ Sleepiness ☐ Other
Other, please specify	

7th Pregnancy

How old were you when you were first pregnant?	
What was the outcome of this pregnancy?	☐ Live birth ☐ Still birth ☐ Ectopic pregnancy ☐ Miscarriage ☐ Termination (abortion)
How many weeks were you pregnant for? (Full term = 40 wks)	☐ Less than 37 ☐ 37 or more

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If this pregnancy resulted in a birth, was the delivery vaginal or via Caesarean section?	☐ Vaginal birth ☐ Caesarean ☐ Not applicable
If this pregnancy resulted in a birth, what was your baby's sex?	☐ Male ☐ Female ☐ Not applicable
If this pregnancy resulted in a birth, what was your baby's birthweight?	☐ Not applicable ☐ Can't remember ☐ Enter weight below
Enter the weight in:	☐.... lbs & .... Oz ☐.... grams
Weight:	
If this pregnancy resulted in a live birth, did you breastfeed your child? If so, for how long?	☐ No ☐ Yes (enter time below) ☐ Not applicable
Breastfed (pumped or chest fed) for how many months?	
If you did not breastfeed, was this due to:	☐ DM related reasons ☐ Other reasons
If due to DM reasons, please select all that apply	☐ Weakness ☐ Myotonia ☐ Sleepiness ☐ Other
Other, please specify	

8th Pregnancy

How old were you when you were first pregnant?	
What was the outcome of this pregnancy?	☐ Live birth ☐ Still birth ☐ Ectopic pregnancy ☐ Miscarriage ☐ Termination (abortion)

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How many weeks were you pregnant for? (Full term = 40 wks)	☐ Less than 37 ☐ 37 or more
If this pregnancy resulted in a birth, was the delivery vaginal or via Caesarean section?	☐ Vaginal birth ☐ Caesarean ☐ Not applicable
If this pregnancy resulted in a birth, what was your baby's sex?	☐ Male ☐ Female ☐ Not applicable
If this pregnancy resulted in a birth, what was your baby's birthweight?	☐ Not applicable ☐ Can't remember ☐ Enter weight below
Enter the weight in:	☐.... lbs & .... Oz ☐.... grams
Weight:	
If this pregnancy resulted in a live birth, did you breastfeed your child? If so, for how long?	☐ No ☐ Yes (enter time below) ☐ Not applicable
Breastfed (pumped or chest fed) for how many months?	
If you did not breastfeed, was this due to:	☐ DM related reasons ☐ Other reasons
If due to DM reasons, please select all that apply	☐ Weakness ☐ Myotonia ☐ Sleepiness ☐ Other
Other, please specify	

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9th Pregnancy

How old were you when you were first pregnant?	
What was the outcome of this pregnancy?	☐ Live birth ☐ Still birth ☐ Ectopic pregnancy ☐ Miscarriage ☐ Termination (abortion)
How many weeks were you pregnant for? (Full term = 40 wks)	☐ Less than 37 ☐ 37 or more
If this pregnancy resulted in a birth, was the delivery vaginal or via Caesarean section?	☐ Vaginal birth ☐ Caesarean ☐ Not applicable
If this pregnancy resulted in a birth, what was your baby's sex?	☐ Male ☐ Female ☐ Not applicable
If this pregnancy resulted in a birth, what was your baby's birthweight?	☐ Not applicable ☐ Can't remember ☐ Enter weight below
Enter the weight in:	☐.... lbs & .... Oz ☐.... grams
Weight:	
If this pregnancy resulted in a live birth, did you breastfeed your child? If so, for how long?	☐ No ☐ Yes (enter time below) ☐ Not applicable
Breastfed (pumped or chest fed) for how many months?	
If you did not breastfeed, was this due to:	☐ DM related reasons ☐ Other reasons

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If due to DM reasons, please select all that apply	☐ Weakness ☐ Myotonia ☐ Sleepiness ☐ Other
Other, please specify	

10th Pregnancy

How old were you when you were first pregnant?	
What was the outcome of this pregnancy?	☐ Live birth ☐ Still birth ☐ Ectopic pregnancy ☐ Miscarriage ☐ Termination (abortion)
How many weeks were you pregnant for? (Full term = 40 wks)	☐ Less than 37 ☐ 37 or more
If this pregnancy resulted in a birth, was the delivery vaginal or via Caesarean section?	☐ Vaginal birth ☐ Caesarean ☐ Not applicable
If this pregnancy resulted in a birth, what was your baby's sex?	☐ Male ☐ Female ☐ Not applicable
If this pregnancy resulted in a birth, what was your baby's birthweight?	☐ Not applicable ☐ Can't remember ☐ Enter weight below
Enter the weight in:	☐.... lbs & .... Oz ☐.... grams
Weight:	
If this pregnancy resulted in a live birth, did you breastfeed your child? If so, for how long?	☐ No ☐ Yes (enter time below) ☐ Not applicable

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Breastfed (pumped or chest fed) for how many months?	
If you did not breastfeed, was this due to:	☐ DM related reasons ☐ Other reasons
If due to DM reasons, please select all that apply	☐ Weakness ☐ Myotonia ☐ Sleepiness ☐ Other
Other, please specify	

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FERTILITY HISTORY

Instructions: This section will ask you about your fertility history.

After the birth of your child and <u>after you stopped breastfeeding</u>, were your menstrual cycles different in any way compared to before you became pregnant with your first child? Please check all that apply	☐ No change ☐ Periods more regular ☐ Periods less regular ☐ Periods more painful ☐ Periods less painful ☐ Duration of flow shorter ☐ Duration of flow longer ☐ Flow heavier ☐ Flow lighter ☐ Can't remember
Have you ever tried to get pregnant for more than 12 consecutive months without success?	☐ Yes ☐ No
Did you or your partner have any test(s) to discover the cause of the fertility problem?	☐ Yes ☐ No
If yes, what were you diagnosed with? (Please mark all that apply)	☐ Endometriosis ☐ Polycystic ovaries ☐ Pelvic inflammatory disease / Pelvic infection ☐ Uterine fibroids ☐ Blocked tubes ☐ No or irregular ovulation ☐ Male factor/sperm ☐ Other problem (please explain):
If other, please explain the diagnosis	

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Have you ever had any treatment to help you to become pregnant (e.g. ovulation stimulants, donor insemination, in vitro fertilization [IVF])?	☐ Yes ☐ No
If yes, this was due to	☐ Fertility issues ☐ Female partner/partner without sperm ☐ To select for healthy egg/sperm (no Myotonic Dystrophy) ☐ Other
If other, please describe	
If you had IVF, was the embryo genetically checked whether they carried the DM mutation?	☐ Yes ☐ No ☐ Unsure
What is the current status of your fertility therapy?	☐ Still trying ☐ No longer trying ☐ I became pregnant

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DM AND FAMILY HISTORY

Instructions: Please complete each question below with the answer that best represents you.

Do any family members besides you have a positive myotonic dystrophy diagnosis?	☐ Yes ☐ No
If yes, select all that apply	☐ Grandfather ☐ Grandmother ☐ Father ☐ Mother ☐ Sibling(s) ☐ Aunt(s) ☐ Uncle(s) ☐ Cousin(s)
Do you have biological children (not adopted)?	☐ Yes ☐ No
Number of biological children you have?	☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

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Biological child #1	☐ Never had a genetic test (blood test) for DM1 and doesn't show any symptoms of myotonic dystrophy ☐ Never had a genetic test (blood test) for DM1 but shows symptoms of myotonic dystrophy ☐ Had a negative genetic test (blood test) and does not have myotonic dystrophy ☐ Had a genetic test (blood test) that shows the child has myotonic dystrophy
Biological child #2	☐ Never had a genetic test (blood test) for DM1 and doesn't show any symptoms of myotonic dystrophy ☐ Never had a genetic test (blood test) for DM1 but shows symptoms of myotonic dystrophy ☐ Had a negative genetic test (blood test) and does not have myotonic dystrophy ☐ Had a genetic test (blood test) that shows the child has myotonic dystrophy
Biological child #3	☐ Never had a genetic test (blood test) for DM1 and doesn't show any symptoms of myotonic dystrophy ☐ Never had a genetic test (blood test) for DM1 but shows symptoms of myotonic dystrophy ☐ Had a negative genetic test (blood test) and does not have myotonic dystrophy ☐ Had a genetic test (blood test) that shows the child has myotonic dystrophy
Biological child #4	☐ Never had a genetic test (blood test) for DM1 and doesn't show any symptoms of myotonic dystrophy ☐ Never had a genetic test (blood test) for DM1 but shows symptoms of myotonic dystrophy ☐ Had a negative genetic test (blood test) and does not have myotonic dystrophy ☐ Had a genetic test (blood test) that shows the child has myotonic dystrophy

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Biological child #5	☐ Never had a genetic test (blood test) for DM1 and doesn't show any symptoms of myotonic dystrophy ☐ Never had a genetic test (blood test) for DM1 but shows symptoms of myotonic dystrophy ☐ Had a negative genetic test (blood test) and does not have myotonic dystrophy ☐ Had a genetic test (blood test) that shows the child has myotonic dystrophy
Biological child #6	☐ Never had a genetic test (blood test) for DM1 and doesn't show any symptoms of myotonic dystrophy ☐ Never had a genetic test (blood test) for DM1 but shows symptoms of myotonic dystrophy ☐ Had a negative genetic test (blood test) and does not have myotonic dystrophy ☐ Had a genetic test (blood test) that shows the child has myotonic dystrophy
Biological child #7	☐ Never had a genetic test (blood test) for DM1 and doesn't show any symptoms of myotonic dystrophy ☐ Never had a genetic test (blood test) for DM1 but shows symptoms of myotonic dystrophy ☐ Had a negative genetic test (blood test) and does not have myotonic dystrophy ☐ Had a genetic test (blood test) that shows the child has myotonic dystrophy
Biological child #8	☐ Never had a genetic test (blood test) for DM1 and doesn't show any symptoms of myotonic dystrophy ☐ Never had a genetic test (blood test) for DM1 but shows symptoms of myotonic dystrophy ☐ Had a negative genetic test (blood test) and does not have myotonic dystrophy ☐ Had a genetic test (blood test) that shows the child has myotonic dystrophy

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Biological child #9	☐ Never had a genetic test (blood test) for DM1 and doesn't show any symptoms of myotonic dystrophy ☐ Never had a genetic test (blood test) for DM1 but shows symptoms of myotonic dystrophy ☐ Had a negative genetic test (blood test) and does not have myotonic dystrophy ☐ Had a genetic test (blood test) that shows the child has myotonic dystrophy
Biological child #10	☐ Never had a genetic test (blood test) for DM1 and doesn't show any symptoms of myotonic dystrophy ☐ Never had a genetic test (blood test) for DM1 but shows symptoms of myotonic dystrophy ☐ Had a negative genetic test (blood test) and does not have myotonic dystrophy ☐ Had a genetic test (blood test) that shows the child has myotonic dystrophy

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FACIAL DISABILITY INDEX (FDI)

Instructions: Please select the most appropriate response to the following questions related to problems associated with the function of your facial muscles. For each question, consider your function during the past month:

How much difficulty did you have keeping food in your mouth, moving food around your mouth, or getting food stuck in your cheek?	☐ No difficulty ☐ A little difficulty ☐ Some difficulty ☐ Much difficulty ☐ Usually did not eat because of health ☐ Usually did not eat because of other reasons
How much difficulty did you have drinking from a cup?	☐ No difficulty ☐ A little difficulty ☐ Some difficulty ☐ Much difficulty ☐ Usually did not eat because of health ☐ Usually did not eat because of other reasons
How much difficulty did you have saying specific sounds while speaking?	☐ No difficulty ☐ A little difficulty ☐ Some difficulty ☐ Much difficulty ☐ Usually did not eat because of health ☐ Usually did not eat because of other reasons
How much difficulty did you have with your eye tearing excessively or becoming dry?	☐ No difficulty ☐ A little difficulty ☐ Some difficulty ☐ Much difficulty ☐ Usually did not eat because of health ☐ Usually did not eat because of other reasons
How much difficulty did you have with brushing your teeth or rinsing your mouth?	☐ No difficulty ☐ A little difficulty ☐ Some difficulty ☐ Much difficulty ☐ Usually did not eat because of health ☐ Usually did not eat because of other reasons

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Apathy Evaluation Scale (AES)

Instructions: For each statement, circle the answer that best describes your thoughts, feelings, and activity in the past 4 weeks.

I am interested in things.	☐ Not at all ☐ Slightly ☐ Somewhat ☐ A lot
I get things done during the day.	☐ Not at all ☐ Slightly ☐ Somewhat ☐ A lot
Getting things started on my own is important to me.	☐ Not at all ☐ Slightly ☐ Somewhat ☐ A lot
I am interested in having new experiences.	☐ Not at all ☐ Slightly ☐ Somewhat ☐ A lot
I am interested in learning new things.	☐ Not at all ☐ Slightly ☐ Somewhat ☐ A lot
I put little effort into anything	☐ Not at all ☐ Slightly ☐ Somewhat ☐ A lot
I approach life with intensity.	☐ Not at all ☐ Slightly ☐ Somewhat ☐ A lot

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Seeing a job through to the end is important to me.	☐ Not at all ☐ Slightly ☐ Somewhat ☐ A lot
I spend time doing things that interest me.	☐ Not at all ☐ Slightly ☐ Somewhat ☐ A lot
Someone has to tell me what to do each day.	☐ Not at all ☐ Slightly ☐ Somewhat ☐ A lot
I am less concerned about my problems than I should be.	☐ Not at all ☐ Slightly ☐ Somewhat ☐ A lot
I have friends.	☐ Not at all ☐ Slightly ☐ Somewhat ☐ A lot
Getting together with friends is important to me.	☐ Not at all ☐ Slightly ☐ Somewhat ☐ A lot
When something good happens, I get excited.	☐ Not at all ☐ Slightly ☐ Somewhat ☐ A lot
I have an accurate understanding of my problems.	☐ Not at all ☐ Slightly ☐ Somewhat ☐ A lot

Subject Initials	REACH ID	Date
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Getting things done during the day is important to me.	☐ Not at all ☐ Slightly ☐ Somewhat ☐ A lot
I have initiative.	☐ Not at all ☐ Slightly ☐ Somewhat ☐ A lot
I have motivation.	☐ Not at all ☐ Slightly ☐ Somewhat ☐ A lot

Subject Initials	REACH ID	Date
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MEDICAL HISTORY

Instructions: This section will ask you about your medical history. From the list below please mark whether you have had any of the following medical conditions, and at what age you were first diagnosed.

Have you had breast cancer?	☐ Yes ☐ No
If Yes, first diagnosed at age	
Deafness or difficulty hearing	☐ Yes ☐ No
If Yes, first diagnosed at age	
Depression requiring medication or medical consultation	☐ Yes ☐ No
If Yes, first diagnosed at age	
Do you have chronic pain syndrome? Chronic pain - have pain most days of the week and it impacts your well-being	☐ Yes ☐ No
If Yes, first diagnosed at age	
Diabetes requiring insulin or tablets	☐ Yes ☐ No
If Yes, first diagnosed at age	
Fibroid uterus	☐ Yes ☐ No
If Yes, first diagnosed at age	

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Endometriosis	☐ Yes ☐ No
If Yes, first diagnosed at age	
Rectal prolapse?	☐ Yes ☐ No
If Yes, first diagnosed at age	
Vaginal prolapse?	☐ Yes ☐ No
If Yes, first diagnosed at age	
Uterine prolapse?	☐ Yes ☐ No
If Yes, first diagnosed at age	
Thyroid disease	☐ Yes ☐ No
If Yes, first diagnosed at age	
Incomplete opening of the vagina (imperforate hymen)	☐ Yes ☐ No
If Yes, first diagnosed at age	
Ovarian Cancer	☐ Yes ☐ No
If Yes, first diagnosed at age	

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Polycystic Ovary Syndrome	☐ Yes ☐ No
If Yes, first diagnosed at age	
Scoliosis (curvature of the spine)	☐ Yes ☐ No
If Yes, first diagnosed at age	
Do you have another symptom or diagnosis to report that you feel may have an impact on menstruation or sexual health?	☐ Yes ☐ No, I have no other symptoms or diagnosis to report
Specify the additional symptom or diagnosis	
First diagnosed at age	
Do you have another symptom or diagnosis to report that you feel may have an impact on menstruation or sexual health?	☐ Yes ☐ No, I have no other symptoms or diagnosis to report
Specify the additional symptom or diagnosis	
First diagnosed at age	
Do you have another symptom or diagnosis to report that you feel may have an impact on menstruation or sexual health?	☐ Yes ☐ No, I have no other symptoms or diagnosis to report
Specify the additional symptom or diagnosis	
First diagnosed at age	

Subject Initials	REACH ID	Date
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Do you have another symptom or diagnosis to report that you feel may have an impact on menstruation or sexual health?	☐ Yes ☐ No, I have no other symptoms or diagnosis to report
Specify the additional symptom or diagnosis	
First diagnosed at age	
Do you have another symptom or diagnosis to report that you feel may have an impact on menstruation or sexual health?	☐ Yes ☐ No, I have no other symptoms or diagnosis to report
Specify the additional symptom or diagnosis	
First diagnosed at age	
Do you have another symptom or diagnosis to report that you feel may have an impact on menstruation or sexual health?	☐ Yes ☐ No, I have no other symptoms or diagnosis to report
Specify the additional symptom or diagnosis	
First diagnosed at age	

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SURGICAL HISTORY

Instructions: This section will ask you about a couple specific surgeries.

Have you had a hysterectomy?	☐ Yes ☐ No
Have you had an oophorectomy (removal of ovaries)?	☐ Yes ☐ No
Have you had any other surgeries to your uterus, tubes, or ovaries? Check all that apply:	☐ Myomectomy/fibroid removal ☐ Tubal surgery for ectopic pregnancy ☐ Tubal surgery for fertility ☐ Endometriosis surgery ☐ Polyps removal/surgery ☐ Ovarian cyst rupture/removal ☐ Ovarian torsion/twist ☐ D&C (dilation and curettage for failed pregnancy or to terminate pregnancy ☐ Termination of pregnancy ☐ Ectopic pregnancy ☐ Cervical procedure for cancer or abnormal cells of cervix (LEEP or colposcopy) ☐ Repair rectal prolapse ☐ Repair vaginal prolapse ☐ Repair uterine prolapse ☐ Bladder sling placed ☐ Other
If other, please describe	
Have you had breast surgery to remove breast cancer?	☐ Yes ☐ No
Have you had a small bowel obstruction?	☐ Yes ☐ No

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SMOKING/ALCOHOL/DRUGS

Instructions: This section will ask about your smoking, alcohol, and drug habits.

Have you smoked more than 100 cigarettes during your lifetime?	☐ Yes ☐ No
How old were you when you first started smoking?	
Do you smoke currently?	☐ No, I stopped ☐ Yes, I smoke
If no, please specify how long ago you quit	
If yes, please specify number of cigarettes per week	
Do you currently drink alcohol?	☐ Yes ☐ No
If yes, please specify how many drinks per week	
Do you use medicinal marijuana?	☐ Yes ☐ No
If yes, please specify how many times per week	
Do you use recreational drugs?	☐ Yes ☐ No
If yes, please specify how many times per week	

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EXERCISE

Instructions: This section will ask you questions about your exercise habits.

On how many days per week do you exercise? This can entail walking, cycling, weights, dancing or other.	☐ None ☐ One day a week ☐ 2-3 days a week ☐ 4 or more days a week
In the last 3 months, how often did you do vigorous exercise or sports? By vigorous we mean exercise in which you can't even utter a few words without taking a breath.	☐ Never ☐ Occasionally (2-3 times a month) ☐ Regularly (about once a week) ☐ Often (a few times a week) ☐ Every day ☐ Can't remember
In the last 3 months, did you avoid vigorous exercise at certain times, because of pelvic pain?	☐ Yes ☐ No
In the last 3 months, did you avoid vigorous exercise at certain times, because you had your period?	☐ Yes ☐ No