

Consent form and demographic survey

Please read the consent form below.

If you agree to participate, please select 'yes' and answer the following demographic questions (there are less than 20 questions on this survey). If you do not want to participate, please select 'no' and you will be directed out of the survey.

Thank you very much for your participation!

Departments of Medical Genetics and Psychiatry

Subject Information and Consent Form

Longitudinal Study of Depression Symptoms after Prenatal Screening

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Purpose: You are being invited to take part in this study because you have recently received prenatal screening results. Prenatal screening helps to determine whether there is an increased chance that your pregnancy could be affected with a chromosomal problem (such as Down syndrome), or a neural tube defect (like Spina Bifida). We do not know how prenatal screening test results influence women's mood over time. The purpose of this study is to compare the mood of women who have received prenatal screening results that show that there is a higher chance for the baby to have a chromosomal problem, to the mood of women who received test results that show no increased chance. In total we would like 200 women to be involved in the study; 100 that have screening results that indicate there is no increased risk and 100 that have screening results that indicate there is an increased risk for their child to have a chromosome problem. We will monitor mood in these two groups of women throughout pregnancy until 3 months post partum. Understanding how prenatal screening affect women's mood over time will allow us to educate healthcare professionals and expectant mothers and help them cope with the results.

Inclusion criteria: The women that will be invited to participate in the study must be pregnant and must have chosen to undergo prenatal screening in their current pregnancy. Women will be asked to participate regardless of whether their prenatal screening results indicate that there is a higher change for the baby to have a chromosome problem or if the test results show that there is no increased chance of their baby having a chromosome problem. In addition, the women must be:

- 19 years and older
- Less than 26 weeks pregnant
- Able to read and respond to questions in English (due to limitations of the investigator)
- Received prenatal screening test results from the physician or genetic counselor indicating no increased risk for chromosome problems or an increased risk for chromosome problems.

What would I have to do: If you are willing to participate in this study, you will be asked to complete a 10 question, multiple-choice survey about your mood every 4 weeks until 3 months after the baby is born. This means that you will complete this survey 6-7 times total. The study coordinator, Dayna-Lynn Dymianiw (genetic counseling student, UBC), will provide you with email/telephone reminders when it is time to complete the surveys and the survey should take less than 10 minutes to complete. In addition, you will also be asked to complete a short questionnaire asking about your education, age and pregnancy information. Additionally, one week following your estimated due date, we will send you an email and ask you provide the infant's date of birth. Furthermore, when we administer the 4 week and 8 week postpartum questionnaires, there will be one additional question that asks whether you know if your baby has a chromosome problem (yes, no or unsure). As the questionnaires are online, you are not required to travel to participate in the study. If at any time during the study, you do not wish to answer a question or complete a form, you do not have too. It is estimated that the total amount of time that you would need to commit to the study is approximately 1.5 hours over 6 months.

Potential Risks: In some cases, answering questions about your mood and current mental state may cause you to feel distress or sadness. Specifically, one of the questions ask whether you have 'thought of harming yourself.' If you respond 'yes' to this question, we will follow up with you to see how you are feeling and whether you would like further assistance. Furthermore, if you are experiencing difficulty with your mood or stress level during the study, please call your family doctor, the Distress Line #604 872-3311, Healthlink BC #8-1-1 or Vancouver mental health emergency services and 24 hr mental health #604 874-7307.

Potential Benefits: If you decide to participate, you may or may not directly benefit from being a part of the study. We hope that the information that is generated will increase societal knowledge and potentially influence healthcare polices surrounding prenatal screening. All participants will receive email updates regarding the progress of the study and will be provided with any publications derived from this research study.

Confidentiality: Any information that you provide regarding your participation in this research is private and will not be disclosed to anyone outside of the research team. Your records will be kept in locked filing cabinets and your online data will be password protected on a network drive.

Remuneration/ Compensation: All subjects will be entered into a draw for a prize.

Do I have to participate? You have the choice whether or not you would like to participate in the study. You may choose not to answer some of the questions that have been asked and you have the option to withdraw from the study at any time. Please contact Dayna-Lynn Dymianiw at 604 875-2000 ext 2831 if you would like to withdraw.

Contact for information about the study: If you have any questions or desire further information with respect to this study, you may contact Dr. Jehannine Austin at 604 875 2000 (ext. 5943) or Dayna-Lynn Dymianiw at 604 875 2000 (ext. 2831).

Contact for concerns about the rights of research subjects: If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at toll-free 1-877-822-8598 or 604-822-8598 or, if long distance, send e-mail to RSIL@ors.ubc.ca.

If you agree to participate in the study, please select yes and it will direct you to the demographic questions. If you do not want to participate, select no.

Thank you!

Yes No

Please complete the demographic questions below. If you feel uncomfortable providing this information you may skip the question (leave it blank) and move onto the next question. However, there are some questions that require an answer and will not let you continue until you provide a response.

Month of Birth

- January
- February
- March
- April
- May
- June
- July
- August
- September
- October
- November
- December

Year of Birth

- 1955
- 1956
- 1957
- 1958
- 1959
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- 1997
- 1998
- 1999
- 2000
- 2001
- 2002

What is the highest level of education that you completed? If currently enrolled in a program that is not yet completed, please check the education that you have completed previously. (please check one box)

- Elementary school/middle school
- High school
- Trade/technical school- diploma or certification program
- Undergraduate degree
- Graduate degree/Professional degree

What is your income before taxes of all household members? (please check one box)

- Less than \$20,000
- Between \$20,000- \$49,999
- Between \$50,000-\$79,999
- Between \$80,000- \$99,999
- Between \$100,000- \$129,999
- Over \$130,000

Are you currently in a relationship with a partner? (please check only one box, e.g. if you have previously had a divorce, but now have a new partner, please select only "Yes, I am currently in a relationship")

- No, I am not currently in a relationship (I am single/widowed/separated/divorced)
 Yes, I am currently in a relationship (I am married/living with/partnered)

How would you best describe your ethnic origin? You may check more than one box.

- Black/African
 Asian
 South Asian
 White/Caucasian
 Arab/West Asian
 First Nation/Aboriginal
 Filipino
 Latin America
 Other

Were you born in Canada?

- Yes No

How long have you lived in Canada?

- Less than a year
 1-5 years
 6-10 years
 Longer than 10 years

Pregnancy Information

In your current pregnancy, did you have non-invasive prenatal testing (NIPT)? This test provides information about the chance for chromosome problems (for example: Down syndrome), but is not covered by MSP (you would have to pay for it yourself).

- Yes
 No
 Unsure

If yes, did it show:

- No increased risk for chromosome problems
 There is an increased risk of chromosome problems

In your current pregnancy, did you have a blood test (for example: Serum Integrated Prenatal Screen (SIPS)) that provides information about the chance for chromosome problems (for example: Down syndrome) that is covered by MSP?

- Yes, and I have my results
 No
 Unsure
 Yes, but I don't have my results yet

In order to be eligible to participate in this study, women need to have had prenatal screening results given to them by a family doctor, midwife or genetic counsellor. The results are usually presented as a CHANCE of having a child with Down Syndrome such as 1:200. If you answered 'no' or 'unsure' and you did receive these results, then please change your answer to 'yes' and continue with the survey.

- Yes No

If yes, did it show:

- No increased risk for chromosome problems or neural tube defects
 There is an increased risk of chromosome problems
 There is an increased risk of neural tube defects.

How many weeks pregnant are you today? You must be less than 26 weeks to participate.

- 8
 9
 10
 11
 12
 13
 14
 15
 16
 17
 18
 19
 20
 21
 22
 23
 24
 25

What is your expected due date?

How many times have you been pregnant, including this pregnancy?

1 2 3 4 5 6 7 8 9 10 More than 10

How many children do you currently have? (including adopted and/or step children)

0
 1
 2
 3
 4
 5
 6
 7
 More than 7

Have you had a previous pregnancy where a chromosome problem was suspected (Example: Down syndrome, Trisomy 18, Trisomy 13)?

Yes
 No
 Unsure

Have you had a previous pregnancy where a neural tube defect was suspected (Example: Spina Bifida)?

Yes
 No
 Unsure

Mental Health Information

During this pregnancy, have you experienced any symptoms of depression (low mood, loss of interest in things you enjoy) or anxiety that lasted for longer than 2 weeks?

Yes No

Are you currently receiving any mental health treatment (e.g. counselling, antidepressant medications, cognitive behavioural therapy)?

Yes No

If yes, please specify:

Medication Cognitive behavioural therapy Counselling Other

Please Specify:

Have you ever received a diagnosis of a psychiatric condition (e.g. depression, schizophrenia, schizoaffective disorder, bipolar disorder)?

Yes No

If yes, please specify:

Depression
 Schizophrenia
 Schizoaffective disorder
 Bipolar disorder
 Anxiety
 Other

Please Specify:

Maternal Mood Survey

As you are currently pregnant/have just had a baby, we would like to know how you are feeling. Please CHECK the answer which comes closest to how you have felt IN THE PAST 7 DAYS, not just how you feel today. Please complete all ten items. Please complete the scale yourself, unless you have difficulty with reading.

I have been able to laugh and see the funny side of things.

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

I have looked forward with enjoyment to things.

- As much as I ever did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

I have blamed myself unnecessarily when things went wrong.

- Yes, most of the time
- Yes, some of the time
- Not very often
- No, never.

I have been anxious or worried for no good reason.

- No, not at all
- Hardly ever
- Yes, sometimes
- Yes, very often

I have felt scared or panicky for no very good reason.

- Yes, quite a lot
- Yes, sometimes
- No, not much
- No, not at all

Things have been getting on top of me.

- Yes, most of the time I haven't been able to cope at all
- Yes, sometimes I haven't been coping as well as usual
- No, most of the time I have coped quite well
- No, I have been coping as well as ever

I have been so unhappy that I have had difficulty sleeping.

- Yes, most of the time
- Yes, sometimes
- Not very often
- No, not at all

I have felt sad or miserable.

- Yes, most of the time
- Yes, quite often
- Not very often
- No, not at all

I have been so unhappy that I have been crying.

- Yes, most of the time
- Yes, quite often
- Only occasionally
- No, never

The thought of harming myself has occurred to me.

- Yes, quite often
- Yes, sometimes
- Hardly ever
- No, never

We will be following up with you to see how you are doing and to see if we can provide any assistance. In the meantime, if you are struggling with thoughts of harming yourself please call your family doctor, the Distress Line #604 872-3311, Healthlink BC #8-1-1 or Vancouver mental health emergency services and 24 hr mental health #604 874-7307.

Select 'yes' if you have had your detailed ultrasound yet. This usually happens between 18-22 weeks.

- Yes, I have had my detailed ultrasound
- No, I have not had my detailed ultrasound

Were you told that "soft marker(s)" were identified? (Examples of "soft markers" include the following: nuchal translucency/thickness, echogenic intracardiac focus, choroid plexus cysts, mild pyelectasis). Soft markers can indicate increased risk for chromosome problems.

- Yes
- No
- Unsure

Select 'yes' if you had an amniocentesis (where a sample is taken of the fluid that surrounds the baby) during this pregnancy.

- Yes, I had an amniocentesis during this pregnancy
- No, I have not had an amniocentesis during this pregnancy

Do you have the results of the amniocentesis?

- Yes
- No

What were the results of the amniocentesis?

- My baby has a chromosome problem
- My baby does not have a chromosome problem

Have you decided to continue the pregnancy?

- Yes
- No
- Unsure

Have you delivered your baby/ies?

- Yes, I have delivered my baby/ies
- No, I have not delivered my baby/ies

Has he/she been diagnosed with a chromosome problem?

- Yes
- No
- Unsure

Answering questions about your mood and mental health may raise feelings of sadness or distress. If at any point during the study you feel that you need help or to talk to someone please call your family doctor, the Distress Line #604 872-3311, Healthlink BC #8-1-1 or Vancouver mental health emergency services and 24 hr mental health #604 874-7307.