



## Follow-Up Questionnaire: PLSND Specification

<b>Event:</b>	Pregnancy Visit 1, Pregnancy Visit 2, Birth Event
<b>Participant:</b>	Non-Pregnant Woman
<b>Respondent:</b>	Non-Pregnant Woman
<b>Domain:</b>	Questionnaire
<b>Type of Document:</b>	Specification
<b>Allowable Mode:</b>	In-Person (PAPI), Mail (PAPI)
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Thank you for agreeing to participate in the study. This self-administered questionnaire will take about 10 minutes to complete.

The first section of the questionnaire asks questions about your most recent pregnancy (prior to your current pregnancy if you are now pregnant), including how the pregnancy ended.

1. How many babies did you carry during your most recent pregnancy, including any that were not born alive? MULT\_NUM\_CARRIED

Number of babies carried

1  Not sure

The next questions ask about what happened with each baby you carried during your most recent pregnancy.

If you were pregnant with one baby (or are unsure), please answer Question 2 and then go to Question 7.

If you were pregnant with more than one baby, please go to Question 3.

2. How did your most recent pregnancy end? ONE\_PREG\_END

1  A stillbirth at or after 20 weeks of pregnancy

2  A miscarriage, that is, an involuntary, unplanned pregnancy loss before 20 weeks of pregnancy

3  An induced abortion or voluntary termination

4  The delivery of a live born baby

5  None of the above

*Please go to Question 7*

3. How many of your babies were stillborn, that is, lost at or after 20 weeks of pregnancy?

Number of babies

MULT\_NUM\_STILLBORN

4. How many of your babies were lost due to a miscarriage, that is, an involuntary, unplanned pregnancy loss before 20 weeks of pregnancy?

Number of babies

MULT\_NUM\_MISCARRIAGE

5. If your pregnancy involved an induced abortion or elective reduction, how many fetuses were aborted or reduced? MULT\_NUM\_ABORT

Number of babies

6. How many of your babies were born alive? MULT\_NUM\_BORN\_ALIVE

Number of babies

7. Did your most recent pregnancy involve an ectopic pregnancy, in which the embryo implanted outside of the uterus? (These are sometimes called tubal pregnancies because these pregnancies most often occur in the Fallopian tubes). ECTOPIC\_PREG

1  Yes

2  No

If you had a live birth in your most recent pregnancy and were pregnant with one baby (or are unsure), please answer Questions 8, 9, and 10. Then go to the instructions following Question 13.

If you had a live birth in your most recent pregnancy and were pregnant with more than one baby, please answer Questions 11, 12, and 13.

If you did not have a live birth in your most recent pregnancy, please go to the instructions following Question 13.

8. Did you have a preterm delivery, that is, a delivery occurring before 37 weeks of pregnancy?

1  Yes

2  No

ONE\_PRETERM\_DELIVER

9. Did your baby die after it was born alive? ONE\_DIE

1  Yes

2  No

10. Did your baby die before 28 days after birth? (This refers to the death of your baby up to but not including 28 days from the moment of birth.) ONE\_BEFORE\_28

1  Yes

2  No

*Please go to instructions after Question 13*

11. Did you have a preterm delivery, that is, a delivery occurring before 37 weeks of pregnancy?

1  Yes

2  No

MULT\_PRETERM

12. How many of your babies died after being born alive? MULT\_NUM\_DIED

Number of babies

MULT\_NUM\_DIED

13. How many of your babies died before 28 days after birth? (This refers to the death of your baby up to but not including 28 days from the moment of birth.) MULT\_NUM\_BEFORE\_28

Number of babies

MULT\_NUM\_BEFORE\_28

Please answer the following questions about your most recent pregnancy (prior to your current pregnancy if you are now pregnant,) to help us understand the type of care you received, any problems you may have experienced, and any support you received after your loss.

14. Did you get any prenatal care from a doctor, nurse, or midwife during your most recent pregnancy?

1  Yes

2  No

PRENATAL\_PROV

During your most recent pregnancy, did you experience any of the complications or conditions listed in the questions below? Please review each item and check "yes" or "no" to tell us if you experienced it during your most recent pregnancy.

15. Hypertension RECENT\_COMPLIC\_HTN  
(High blood pressure)  
1  Yes  
2  No
16. Pre-eclampsia RECENT\_COMPLIC\_PRE\_ECLAMP  
(High blood pressure and excess protein in the urine after 20 weeks of pregnancy in a woman who previously had normal blood pressure)  
1  Yes  
2  No
17. HELLP Syndrome RECENT\_COMPLIC\_HELHP  
(HELLP is “Hemolysis, Elevated Liver enzymes, Low Platelets”. Syndrome includes the breakdown of red blood cells, elevated liver enzymes, and low platelet count. It often follows a diagnosis of high blood pressure or pre-eclampsia).  
1  Yes  
2  No
18. Cervical Incompetence RECENT\_COMPLIC\_CERV\_INCOMP  
(Condition where the cervix is too weak to stay closed during a pregnancy and begins to dilate without contractions before the baby is ready to be born. Often treated with cerclage, that is, stitching the cervix closed.)  
1  Yes  
2  No
19. Placental Abruption RECENT\_COMPLIC\_PLAC\_ABRUP  
(Occurs when the placenta separates from the wall of the uterus prior to the birth of the baby)  
1  Yes  
2  No
20. Trauma RECENT\_COMPLIC\_TRAUMA  
(Such as serious or critical bodily injury, wound, or shock)  
1  Yes  
2  No
21. Infection RECENT\_COMPLIC\_INFECTIO  
(Such as infections from a bacteria or virus)  
1  Yes  
2  No
22. Umbilical Cord Problems RECENT\_COMPLIC\_UMBIL\_CORD  
(Such as a knot in the cord, a leak in the cord, or the cord wraps around the baby’s neck)  
1  Yes  
2  No
23. Premature Rupture of Membranes RECENT\_COMPLIC\_PROM  
(Occurs when the sac containing the developing baby and the amniotic fluid bursts or develops a hole prior to the start of labor, resulting in the leakage of amniotic fluid)  
1  Yes  
2  No

24. Preterm Labor	RECENT_COMPLIC_PRETERM_LABOR
(Occurs when labor begins before 37 completed weeks of pregnancy)	
1 <input type="checkbox"/> Yes	
2 <input type="checkbox"/> No	
25. Rheumatologic problems	RECENT_COMPLIC_RHEUM
(Such as Lupus and other systemic autoimmune diseases)	
1 <input type="checkbox"/> Yes	
2 <input type="checkbox"/> No	
26. Diagnosis of fetal anomalies or chromosomal abnormalities	RECENT_COMPLIC_CHROMOS
(Such as when the fetus or baby's body parts or organs are not formed normally or do not function normally)	
1 <input type="checkbox"/> Yes	
2 <input type="checkbox"/> No	
27. Gestational Diabetes	RECENT_COMPLIC_GEST_DIABETES
(Condition of high blood sugar during pregnancy among women without previously diagnosed diabetes)	
1 <input type="checkbox"/> Yes	
2 <input type="checkbox"/> No	
28. Severe Vomiting	RECENT_COMPLIC_VOMIT
(Such as vomiting three to four times per day. Sometimes called "hyperemesis" or "hyperemesis gravidarum".)	
1 <input type="checkbox"/> Yes	
2 <input type="checkbox"/> No	
29. Uterine blood clots	RECENT_COMPLIC_UTERINE_CLOTS
(Also known as "subchorionic hematoma")	
1 <input type="checkbox"/> Yes	
2 <input type="checkbox"/> No	
30. Did you experience any other complications during your recent pregnancy?	RECENT_OTHER_COMPLIC
1 <input type="checkbox"/> Yes	
2 <input type="checkbox"/> No → Go to Question 32	
31. What other complications did you experience during your recent pregnancy?	RECENT_OTHER_COMPLIC_OTH
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	
32. Do you know the cause of your pregnancy loss or baby's death?	DEATH_CAUSE
1 <input type="checkbox"/> Yes	
2 <input type="checkbox"/> No → Go to Question 34	

33. What was the cause? DEATH\_CAUSE\_OTH


34. After your most recent pregnancy, did you receive any support or draw on any resources that helped you with your pregnancy loss or baby's death, including from family, friends, health care providers, organizations, or other sources? RECEIVE\_RESOURCES

- 1  Yes  
2  No → Go to Instructions following Question 43

We would like to know what types of support or resources helped you after your recent loss. Looking at the questions below, please answer "yes" or "no" to tell us whether any of the types of support or resources listed helped you after your pregnancy loss or baby's death.

35. Emotional support from family or friends SUPPORT\_FAM\_FRIEND

- 1  Yes  
2  No

36. In-person support group on pregnancy loss and infant death SUPPORT\_IN\_PERSON\_GROUP

- 1  Yes  
2  No

37. Web-based support group on pregnancy loss and infant death SUPPORT\_WEB\_GROUP

- 1  Yes  
2  No

38. Books and/or magazines on pregnancy loss and infant death SUPPORT\_BOOKS

- 1  Yes  
2  No

39. Information from medical care providers on pregnancy loss and infant death SUPPORT\_MED\_PROV

- 1  Yes  
2  No

40. Medical treatment SUPPORT\_MED\_TRT

- 1  Yes  
2  No

41. Mental health counseling SUPPORT\_COUNSELING

- 1  Yes  
2  No

42. Paid or unpaid leave from your job, including maternity leave or family and medical leave

- 1  Yes  
2  No SUPPORT\_JOB\_LEAVE

43. What other types of support or resources helped you with your pregnancy loss or baby's death?

SUPPORT_OTH

Please answer the following questions about your pregnancies prior to your most recent pregnancy.

44. How many times have you been pregnant before your most recent pregnancy, including any that may have ended in a live birth, miscarriage, stillbirth, induced abortion, or ectopic pregnancy?

Number of prior pregnancies NUM\_PREG\_PRIOR

-7  Not applicable (I have had no pregnancies before my most recent pregnancy.) → *Go to instructions following Question 59.*

45. How many of your prior pregnancies were multiple pregnancies (that is, you were pregnant with two or more babies)? NUM\_PRIOR\_MULT

Number of prior pregnancies

**The following questions ask about the outcomes of your pregnancies before your recent pregnancy.**

**If all of your prior pregnancies were multiple pregnancies, please answer Questions 46 – 52 and then go to the instructions following Question 59.**

**If all of your prior pregnancies were pregnancies with only one baby, please answer Questions 53 - 59.**

**If your prior pregnancies have included both multiple pregnancies and pregnancies with only one baby, please answer Questions 46 – 59.**

**For the next set of questions, think about the outcomes of prior pregnancies before your most recent pregnancy.**

46. How many of your prior multiple pregnancies involved the delivery of a live born baby?

Number of multiple pregnancies NUM\_MULT\_PRIOR\_LIVE

47. How many of your prior multiple pregnancies involved a preterm delivery, or a delivery occurring before 37 weeks of pregnancy? NUM\_MULT\_PRIOR\_PRETERM

Number of multiple pregnancies

48. How many of your prior multiple pregnancies involved the death of a baby before 28 days after birth? (This refers to the death of your baby up to but not including 28 days from the moment of birth.)

Number of multiple pregnancies NUM\_MULT\_PRIOR\_BEFORE\_28



49. How many of your prior multiple pregnancies involved a miscarriage, that is, an involuntary, unplanned pregnancy loss before 20 weeks of pregnancy? NUM\_MULT\_PRIOR\_MISCARRIAGE

Number of multiple pregnancies

50. How many of your prior multiple pregnancies involved a stillbirth at or after 20 weeks of pregnancy?

Number of multiple pregnancies

NUM\_MULT\_PRIOR\_STILLBIRTH

51. How many of your prior multiple pregnancies involved an induced abortion or voluntary termination?

Number of multiple pregnancies

NUM\_MULT\_PRIOR\_ABORTION

52. How many of your prior multiple pregnancies involved an ectopic pregnancy, in which the embryo implanted outside of the uterus? (These are sometimes called tubal pregnancies because these pregnancies most often occur in the Fallopian tubes).

Number of multiple pregnancies

NUM\_MULT\_PRIOR\_ECTOPIC

53. For the next set of questions, think about the outcomes of all of your pregnancies with one baby only before your most recent pregnancy. How many of your prior pregnancies with one baby ended with the delivery of a live born baby?

Number of pregnancies with one baby

NUM\_ONE\_PRIOR\_LIVE

54. How many of your prior pregnancies with one baby ended with a preterm delivery, or a delivery occurring before 37 weeks of pregnancy?

Number of pregnancies with one baby

55. How many of your prior pregnancies with one baby ended with the death of a baby before 28 days after birth? (This refers to the death of your baby up to but not including 28 days from the moment of birth.)

Number of pregnancies with one baby

56. How many of your prior pregnancies with one baby ended with a miscarriage, that is, an involuntary, unplanned pregnancy loss before 20 weeks of pregnancy? NUM\_ONE\_PRIOR\_MISCARRIAGE

Number of pregnancies with one baby

57. How many of your prior pregnancies with one baby ended with a stillbirth at or after 20 weeks of pregnancy?

Number of pregnancies with one baby

NUM\_ONE\_PRIOR\_STILLBIRTH

58. How many of your prior pregnancies with one baby involved an induced abortion or voluntary termination?

Number of pregnancies with one baby

NUM\_ONE\_PRIOR\_ABORTION

59. How many of your prior pregnancies with one baby involved an ectopic pregnancy, in which the embryo implanted outside of the uterus? (These are sometimes called tubal pregnancies because these pregnancies most often occur in the Fallopian tubes). NUM\_ONE\_PRIOR\_ECTOPIC

Number of pregnancies with one baby

#### Request for Your Medical Record:

Thank you for answering our questions about this difficult topic. We appreciate your participation. To better understand your loss, we would like to review your medical record related to your most recent pregnancy. Information from your medical record will only be seen by members of the NCS study team. Your doctors, hospitals, and other medical care providers can tell us more about your pregnancy and the care you and your baby received. What your medical care providers can tell us is also very important to understanding your loss.

- Please review the enclosed form titled, "AUTHORIZATION TO OBTAIN INFORMATION FROM MEDICAL RECORDS FOR THE NATIONAL CHILDREN'S STUDY".
- If you agree to give us permission to access your medical record related to your recent pregnancy, please complete and sign the form, and mail it to the NCS Study Office in the pre-addressed, stamped envelope marked "Release". The second copy of the form is for your records. Before sealing the envelope please read the next set of instructions on this page.

#### Request for Your Baby's Death Certificate:

In addition, if your recent pregnancy ended in a stillbirth or your infant died after being born alive, your baby's death certificate can give us important details about the cause of death. If your baby was stillborn or died after birth, we would like to request permission to access your baby's death certificate. All of the information we obtain will be kept strictly confidential and will only be seen by members of the NCS study team.

- Please review the enclosed form that is titled, "PARENT OR GUARDIAN AUTHORIZATION TO OBTAIN DEATH CERTIFICATE".
- If you agree to give us permission to access your baby's death certificate, please place the completed and signed form into the pre-addressed, stamped envelope marked "Release" (with the medical record release) and mail it to the NCS Study Office. The second copy of the form is for your records.

Thank you very much for your participation and answering our questions. We appreciate your participation in the National Children's Study.

**For Office Use Only:**

Click here to insert Participant ID

**P\_ID**

Click here to insert local Study Center contact information.