

Follow-Up Questionnaire: PLSND Specification

|  |  |
| --- | --- |
| **Event:** | Pregnancy Visit 1, Pregnancy Visit 2,  Birth Event |
| **Participant:**  **Respondent:** | Non-Pregnant Woman  Non-Pregnant Woman |
| **Domain:** | Questionnaire |
| **Type of Document:** | Specification |
| **Allowable Mode:** | In-Person (PAPI), Mail (PAPI) |
| **Allowable Method:** | Self-Administered |
| **Recruitment Groups:** | PBS |
| **Version:** | 1.0 |
| **Release:** | MDES 3.3 |

This page intentionally left blank.

|  |
| --- |
| 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?   **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. |
| 1. 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* |
| 1. How many of your babies were stillborn, that is, lost at or after 20 weeks of pregnancy?   🞎🞎 Number of babies  **MULT\_NUM\_STILLBORN** |
| 1. How many of your babies were lost due to a miscarriage, that is, an involuntary, unplanned pregnancy loss before 20 weeks of pregnancy?   **MULT\_NUM\_MISCARRIAGE**  🞎🞎 Number of babies |
| 1. If your pregnancy involved an induced abortion or elective reduction, how many fetuses were aborted or reduced?   **MULT\_NUM\_ABORT**  🞎🞎 Number of babies |
| 1. How many of your babies were born alive?   **MULT\_NUM\_BORN\_ALIVE**  🞎🞎 Number of babies |
| 1. 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. |
| 1. Did you have a preterm delivery, that is, a delivery occurring before 37 weeks of pregnancy?   1 🞎 Yes  **ONE\_PRETERM\_DELIVER**  2 🞎 No |
| 1. Did your baby die after it was born alive?   **ONE\_DIE**  1 🞎 Yes  2 🞎 No |
| 1. 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* |
| 1. Did you have a preterm delivery, that is, a delivery occurring before 37 weeks of pregnancy?   1 🞎 Yes  **MULT\_PRETERM**  2 🞎 No |
| 1. How many of your babies died after being born alive?   **MULT\_NUM\_DIED**  🞎🞎 Number of babies |
| 1. 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 |
| 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. |
| 1. Did you get any prenatal care from a doctor, nurse, or midwife during your most recent pregnancy?   1 🞎 Yes  **PRENATAL\_PROV**  2 🞎 No |
| 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. |
| 1. Hypertension   **RECENT\_COMPLIC\_HTN**  (High blood pressure)  1 🞎 Yes  2 🞎 No |
| 1. 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 |
| 1. HELLP Syndrome   **RECENT\_COMPLIC\_HELLP**  (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 |
| 1. 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 |
| 1. Placental Abruption   **RECEN\_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 |
| 1. Trauma   **RECENT\_COMPLIC\_TRAUMA**  (Such as serious or critical bodily injury, wound, or shock)  1 🞎 Yes  2 🞎 No |
| 1. Infection   **RECENT\_COMPLIC\_INFECTION**  (Such as infections from a bacteria or virus)  1 🞎 Yes  2 🞎 No |
| 1. 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 |
| 1. 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 |
| 1. Preterm Labor   **RECENT\_COMPLIC\_PRETERM\_LABOR**  (Occurs when labor begins before 37 completed weeks of pregnancy)  1 🞎 Yes  2 🞎 No |
| 1. Rheumatologic problems   **RECENT\_COMPLIC\_RHEUM**  (Such as Lupus and other systemic autoimmune diseases)  1 🞎 Yes  2 🞎 No |
| 1. 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 🞎 Yes  2 🞎 No  **RECENT\_COMPLIC\_GEST\_DIABETES** |
| 1. Gestational Diabetes   (Condition of high blood sugar during pregnancy among women without previously diagnosed diabetes)  1 🞎 Yes  2 🞎 No  **RECENT\_COMPLIC\_VOMIT** |
| 1. Severe Vomiting   (Such as vomiting three to four times per day. Sometimes called “hyperemesis” or “hyperemesis gravidarum”.)  1 🞎 Yes  2 🞎 No |
| 1. Uterine blood clots   **RECENT\_COMPLIC\_UTERINE\_CLOTS**  (Also known as “subchorionic hematoma”)  1 🞎 Yes  2 🞎 No |
| 1. Did you experience any other complications during your recent pregnancy?   **RECENT\_OTHER\_COMPLIC**  1 🞎 Yes  2 🞎 No → *Go to Question 32* |
| 1. What other complications did you experience during your recent pregnancy?   **RECENT\_OTHER\_COMPLIC\_OTH**   |  |  | | --- | --- | |  | | |  | | |  | | |  | | |  |  | |
| 1. Do you know the cause of your pregnancy loss or baby’s death?   **DEATH\_CAUSE**  1 🞎 Yes  2 🞎 No → *Go to Question 34* |
| 1. What was the cause?   **DEATH\_CAUSE\_OTH**   |  |  | | --- | --- | |  | | |  | | |  | | |  | | |  |  | |
| 1. 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. |
| 1. Emotional support from family or friends   **SUPPORT\_FAM\_FRIEND**  1 🞎 Yes  2 🞎 No |
| 1. In-person support group on pregnancy loss and infant death   **SUPPORT\_IN\_PERSON\_GROUP**  1 🞎 Yes  2 🞎 No |
| 1. Web-based support group on pregnancy loss and infant death   **SUPPORT\_WEB\_GROUP**  1 🞎 Yes  2 🞎 No |
| 1. Books and/or magazines on pregnancy loss and infant death   **SUPPORT\_BOOKS**  1 🞎 Yes  2 🞎 No |
| 1. Information from medical care providers on pregnancy loss and infant death   **SUPPORT\_MED\_PROV**  1 🞎 Yes  2 🞎 No |
| 1. Medical treatment   **SUPPORT\_MED\_TRT**  1 🞎 Yes  2 🞎 No |
| 1. Mental health counseling   **SUPPORT\_COUNSELING**  1 🞎 Yes  2 🞎 No |
| 1. Paid or unpaid leave from your job, including maternity leave or family and medical leave   1 🞎 Yes  **SUPPORT\_JOB\_LEAVE**  2 🞎 No |
| 1. 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. |
| 1. 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.* |
| 1. 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.   1. How many of your prior multiple pregnancies involved the delivery of a live born baby?   🞎🞎 Number of multiple pregnancies  **NUM\_MULT\_PRIOR\_LIVE** |
| 1. 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 |
| 1. 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** |
| 1. 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 |
| 1. 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** |
| 1. How many of your prior multiple pregnancies involved an induced abortion or voluntary termination?   🞎🞎 Number of multiple pregnancies  **NUM\_MULT\_PRIOR\_ABORTION** |
| 1. 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).   **NUM\_MULT\_PRIOR\_ECTOPIC**  🞎🞎 Number of multiple pregnancies |
| 1. 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** |
| 1. 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 |
| 1. 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 |
| 1. 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 |
| 1. 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** |
| 1. 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** |
| 1. 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 enclose 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 local Study Center contact information.  **P\_ID**  Click here to insert Participant ID |