THE NATIONAL CHILDREN'S STUDY

HEALTH   GROWTH   ENVIRONMENT

Pregnancy Loss, Stillbirth, and Neonatal Death (PLSND) Interview

Event:	Pregnancy Visit 1, Pregnancy Visit 2, Birth
Participant:	Non-Pregnant Woman
Respondent:	Non-Pregnant Woman
Domain:	Questionnaire
Type of Document:	Interview
Allowable Mode:	In-person (CAPI), Telephone (CATI)
Allowable Method:	Interviewer-Adminstered
Recruitment Groups:	PBS
Version:	1.0
Release:	MDES 3.3

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TABLE OF CONTENTS

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GENERAL PROGRAMMER INSTRUCTIONS:

WHEN PROGRAMMING INSTRUMENTS, VALIDATE FIELD LENGTHS AND TYPES AGAINST THE MDES TO ENSURE DATA COLLECTION RESPONSES DO NOT EXCEED THOSE OF THE MDES. SOME GENERAL ITEM LIMITS USED ARE AS FOLLOWS:

Data Element Fields	Maximum Characters Permitted	Programmer Instructions
ADDRESS AND EMAIL FIELDS	100	
UNIT AND PHONE FIELDS	10	
_OTH AND COMMENT FIELDS	255	
FIRST NAME AND LAST NAME	30	
ALL ID FIELDS	36	
ZIP CODE	5	
ZIP CODE LAST FOUR	4	
CITY	50	
DOB AND ALL OTHER DATE FIELDS (E.G., DT, DATE, ETC.)	10	• DISPLAY AS MM/DD/YYYY • STORE AS YYYY-MM-DD • HARD EDITS: MM MUST EQUAL 00 TO 12 DD MUST EQUAL 01 TO 31 YYYY MUST BE BETWEEN 1900 AND CURRENT YEAR.
TIME VARIABLES	TWO-DIGIT HOUR AND TWO-DIGIT MINUTE, AM/PM DESIGNATION	• HARD EDITS: HOURS MUST BE BETWEEN 00 AND 12; MINUTES MUST BE BETWEEN 00 AND 59

INSTRUMENT GUIDELINES FOR PARTICIPANT AND RESPONDENT IDS:

PRENATALLY, THE **P_ID** IN THE MDES HEADER IS THAT OF THE PARTICIPANT (E.G. THE NON-PREGNANT WOMAN, PREGNANT WOMAN, OR THE FATHER).

POSTNATALLY, A RESPONDENT ID WILL BE USED IN ADDITION TO THE PARTICIPANT ID BECAUSE SOMEBODY OTHER THAN THE PARTICIPANT MAY BE

COMPLETING THE INTERVIEW. (FOR EXAMPLE, THE PARTICIPANT MAY BE THE CHILD AND THE RESPONDENT MAY BE THE MOTHER, FATHER, OR ANOTHER CAREGIVER). THEREFORE, MDES VERSION 2.2 AND ALL FUTURE VERSIONS CONTAIN A **R_P_ID** (RESPONDENT PARTICIPANT ID) HEADER FIELD FOR EACH POST-BIRTH INSTRUMENT. THIS WILL ALLOW STUDY CENTERS TO INDICATE WHETHER THE RESPONDENT IS SOMEBODY OTHER THAN THE PARTICIPANT ABOUT WHOM THE QUESTIONS ARE BEING ASKED.

A REMINDER:

ALL RESPONDENTS MUST BE CONSENTED AND HAVE RECORDS IN THE PERSON, PARTICIPANT, PARTICIPANT_CONSENT AND LINK_PERSON_PARTICIPANT TABLES, WHICH CAN BE PRELOADED INTO EACH INSTRUMENT. ADDITIONALLY, IN POST-BIRTH QUESTIONNAIRES WHERE THERE IS THE ABILITY TO LOOP THROUGH A SET OF QUESTIONS FOR MULTIPLE CHILDREN, IT IS IMPORTANT TO CAPTURE AND STORE THE CORRECT CHILD **P_ID** ALONG WITH THE LOOP INFORMATION. IN THE MDES VARIABLE LABEL/DEFINITION COLUMN, THIS IS INDICATED AS FOLLOWS: **EXTERNAL IDENTIFIER: PARTICIPANT ID FOR CHILD DETAIL.**

MOST RECENT PREGNANCY

(TIME_STAMP_MRP_ST) PROGRAMMER INSTRUCTION:
- INSERT DATE/TIME STAMP

MRP001. I understand that this topic may be difficult to discuss. If at any time you find the questions too difficult to answer, please let me know. Do you have any questions before we start?

INTERVIEWER INSTRUCTION:
- ANSWER ANY QUESTIONS THE PARTICIPANT HAS.

MRP001A. First, I would like to ask you some questions about your most recent pregnancy [prior to the current pregnancy], including how the pregnancy ended.

PROGRAMMER INSTRUCTIONS:
- IF PARTICIPANT IS PREGNANT, USE "prior to the current pregnancy".

MRP002/(PREG_MULTIPLE). Was your most recent pregnancy a <u>multiple pregnancy</u>, that is, were you pregnant with two or more babies?

```
YES..............................................................................1
NO................................................................................2
(RECENT_LIVE_BORN)
REFUSED ....................................................................-1
(RECENT_LIVE_BORN)
DON'T KNOW...............................................................-2
(RECENT_LIVE_BORN)
```

MRP003/(NUM_CARRIED). How many babies did you carry during your most recent pregnancy, including any that were not born alive?

```
|___|___|
NUMBER OF BABIES

REFUSED .....................................................................-1
DON'T KNOW ..............................................................-2
```

MRP004/(BORN_ALIVE). How many of your babies were <u>born alive</u>?

INTERVIEWER INSTRUCTION:
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."

```
|___|___|
NUMBER OF LIVE BIRTHS

REFUSED .....................................................................-1
DON'T KNOW ..............................................................-2
```

PROGRAMMER INSTRUCTIONS:

- IF **NUM_CARRIED** = **BORN_ALIVE,** GO TO **PRETERM_DELIVER.**
- OTHERWISE, GO TO **MRP005.**

MRP005. The next few questions I have will ask about what happened with each baby you carried during your most recent pregnancy. Sometimes in a pregnancy with more than one baby, each baby may have a different outcome. For example, one baby may be lost to a miscarriage, while another may be carried to term. We would like to know what happened to each of your babies in your recent pregnancy.

MRP006/(NUM_STILLBORN). How many of your babies were <u>stillborn</u>, that is, lost at or after 20 weeks of pregnancy?

INTERVIEWER INSTRUCTION:
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."

|___|___|
NUMBER OF BABIES

REFUSED ....-1
DON'T KNOW ....-2

PROGRAMMER INSTRUCTIONS:
- IF **BORN_ALIVE** + **NUM_STILLBORN** = **NUM_CARRIED,** GO TO **ECTOPIC_PREG.**
- OTHERWISE, GO TO **NUM_MISCARRIAGE.**

MRP007/(NUM_MISCARRIAGE). During your most recent pregnancy, how many of your babies were lost due to a <u>miscarriage</u>, that is, an involuntary, unplanned pregnancy loss before 20 weeks of pregnancy?

INTERVIEWER INSTRUCTIONS:
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."
- IF NEEDED, SAY "How many of your babies were lost due to an unplanned spontaneous abortion before 20 weeks of pregnancy?"

|___|___|
NUMBER OF BABIES

REFUSED ....-1
DON'T KNOW ....-2

PROGRAMMER INSTRUCTIONS:
- IF **BORN_ALIVE, NUM_STILLBORN,** AND **NUM_MISCARRIAGE** = **NUM_CARRIED,** GO TO **ECTOPIC_PREG.**
- OTHERWISE, GO TO **INDUCED_ABORTION.**

MRP008/(INDUCED_ABORTION). Did your most recent pregnancy involve an <u>induced abortion or elective reduction</u> in the number of fetuses?

YES...1
NO...2 **(ECTOPIC_PREG)**
REFUSED ....-1 **(ECTOPIC_PREG)**
DON'T KNOW...-2 **(ECTOPIC_PREG)**

MRP009/(NUM_ABORT). How many fetuses were aborted or reduced?

INTERVIEWER INSTRUCTION:
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."

|___|___|
NUMBER OF FETUSES

REFUSED ....-1
DON'T KNOW ....-2

MRP010/(ECTOPIC_PREG). Did your most recent pregnancy involve an <u>ectopic pregnancy</u>, in which an embryo implanted outside of the uterus? (These are sometimes called <u>tubal pregnancies</u> because these pregnancies most often occur in the Fallopian tubes.)

YES...1
NO...2
REFUSED ....-1
DON'T KNOW...-2

PROGRAMMER INSTRUCTIONS:
- IF **BORN_ALIVE** > 0, GO TO **PRETERM_DELIVER.**
- OTHERWISE, GO TO **MRP021.**

MRP011/(PRETERM_DELIVER). At the time of your {baby's/babies'} live birth, did you have a <u>preterm</u> delivery, that is, a delivery occurring <u>before 37 weeks</u> of pregnancy?

YES...1
NO...2
REFUSED ....-1
DON'T KNOW...-2

PROGRAMMER INSTRUCTIONS:
- IF **BORN_ALIVE** = 1, DISPLAY, "baby's."
- IF **BORN_ALIVE** > 1, DISPLAY, "babies'."

MRP012/(NUM_DIED). How many of your babies <u>died</u> after being born alive?

INTERVIEWER INSTRUCTION:
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."

|___|___|

NUMBER OF BABIES

```
REFUSED  ............................................................................-1
DON'T KNOW .....................................................................-2
```

PROGRAMMER INSTRUCTIONS:
- IF **NUM_DIED** = 0, GO TO **MRP021.**
- OTHERWISE, GO TO **MULT_BEFORE_28.**

MRP013/(MULT_BEFORE_28). Did your {baby/babies} die before 28 days <u>after birth</u>?

INTERVIEWER INSTRUCTION:
- IF NEEDED, SAY "That is, the death of your {baby/babies} up to but not including 28 days from the moment of birth."

```
YES..........................................................................................1
NO............................................................................................2  (MRP021)
REFUSED ...............................................................................-1  (MRP021)
DON'T KNOW..........................................................................-2  (MRP021)
```

PROGRAMMER INSTRUCTIONS:
- IF **NUM_DIED** = 1, DISPLAY, "baby."
- IF **NUM_DIED** > 1, DISPLAY, "babies."

MRP013A/(NUM_BEFORE_28). How many of your babies died before 28 days <u>after birth</u>?

INTERVIEWER INSTRUCTION:
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."

```
 |___|___|
NUMBER OF BABIES  (MRP021)

REFUSED  ............................................................................-1  (MRP021)
DON'T KNOW .....................................................................-2  (MRP021)
```

MRP014/(RECENT_LIVE_BORN). Did your most recent pregnancy end with the delivery of a <u>live born baby</u>?

```
YES..........................................................................................1
NO............................................................................................2
(STILLBIRTH_PREG)
REFUSED ...............................................................................-1
(STILLBIRTH_PREG)
DON'T KNOW..........................................................................-2
(STILLBIRTH_PREG)
```

MRP015/(PRETERM_DELIVER_1). At the time of your baby's live birth, did you have a preterm delivery, that is, a delivery occurring <u>before 37 weeks</u> of pregnancy?

      YES...1
      NO..2
      REFUSED ....-1
      DON'T KNOW...-2

MRP015A/(AFTER_BORN). Did your baby die after it was born?

      YES...1
      NO..2 **(MRP021)**
      REFUSED ....-1 **(MRP021)**
      DON'T KNOW...-2 **(MRP021)**

MRP016/(BEFORE_28). Did your baby die before 28 days <u>after birth</u>?

INTERVIEWER INSTRUCTION:
- IF NEEDED SAY, "That is, the death of your baby up to but not including 28 days from the moment of birth."

      YES...1 **(MRP021)**
      NO..2 **(MRP021)**
      REFUSED ....-1 **(MRP021)**
      DON'T KNOW...-2 **(MRP021)**

MRP017/(STILLBIRTH_PREG). Did your most recent pregnancy end with a <u>stillbirth</u>, that is, a loss at or after 20 weeks of pregnancy?

      YES...1
      (ECTOPIC_PREG1)
      NO..2
      REFUSED ....-1
      DON'T KNOW...-2

MRP018/(MISCARRIAGE_PREG). Did your most recent pregnancy end with a <u>miscarriage</u>, that is, an involuntary, unplanned pregnancy <u>loss before 20 weeks</u> of pregnancy?

INTERVIEWER INSTRUCTION:
- IF NEEDED SAY, "Was the loss due to an unplanned spontaneous abortion before 20 weeks of pregnancy?"

      YES...1
      (ECTOPIC_PREG1)
      NO..2
      REFUSED ....-1
      DON'T KNOW...-2

MRP019/(TERMINATION_PREG). Did your most recent pregnancy end with an <u>induced abortion</u> or voluntary termination?

```
YES.......................................................................................1
NO........................................................................................2
REFUSED ............................................................................-1
DON'T KNOW......................................................................-2
```

MRP020/(ECTOPIC_PREG1). Did your most recent pregnancy involve an <u>ectopic pregnancy</u>, in which the embryo implanted outside of the uterus? (These are sometimes called <u>tubal pregnancies</u> because these pregnancies most often occur in the Fallopian tubes.)

```
YES.......................................................................................1
NO........................................................................................2
REFUSED ............................................................................-1
DON'T KNOW......................................................................-2
```

MRP021. Now I would like to ask you some questions about your most recent pregnancy to help us understand the type of care you received, any problems you may have experienced, and any support you received after your loss.

MRP022/(PRENATAL_PROV). Did you get <u>any prenatal care</u> from a doctor, nurse, or midwife during your most recent pregnancy?

```
YES.......................................................................................1
NO........................................................................................2
REFUSED ............................................................................-1
DON'T KNOW......................................................................-2
```

MRP023/(RECENT_COMPLICATIONS). {I am going to read a list of pregnancy complications or conditions. For each complication or condition, please answer "yes" or "no" to let me know if you experienced it during your most recent pregnancy. If you aren't sure what the complication is, please let me know.}

 During your most recent pregnancy, did you experience any of the following complications or conditions? You may select one or more.

INTERVIEWER INSTRUCTIONS:
- IF USING SHOWCARDS, REFER PARTICIPANT TO APPROPRIATE SHOWCARD.
- OTHERWISE, READ RESPONSE CATEGORIES TO PARTICIPANT.
- PROBE, "Any others?"
- ONLY SELECT "SOME OTHER COMPLICATION" OR "NO COMPLICATIONS/CONDITIONS" IF VOLUNTEERED.
- SELECT ALL THAT APPLY.

```
HYPERTENSION ({THAT IS} HIGH BLOOD PRESSURE).............1
PRE-ECLAMPSIA ({THIS INVOLVES} HIGH BLOOD
PRESSURE AND EXCESS PROTEIN IN THE URINE AFTER 20
WEEKS OF PREGNANCY IN A WOMAN WHO PREVIOUSLY
HAD NORMAL BLOOD PRESSURE)...........................................2
HELLP SYNDROME (HELLP IS "*H*EMOLYSIS, *E*LEVATED
*L*IVER ENZYMES, *LOW P*LATELETS".  {THE} 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) 3
CERVICAL INCOMPETENCE({THIS IS A} 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. {IT IS} OFTEN TREATED WITH CERCLAGE,
THAT IS, STITCHING THE CERVIX CLOSED)............................4
PLACENTAL ABRUPTION ({THIS} OCCURS WHEN THE
PLACENTA SEPARATES FROM THE WALL OF THE UTERUS
PRIOR TO THE BIRTH OF THE BABY) 5
TRAUMA (SUCH AS A SERIOUS OR CRITICAL BODILY
INJURY, WOUND, OR SHOCK)...6
INFECTION (SUCH AS INFECTIONS FROM A BACTERIA
OR VIRUS)...7
UMBILICAL CORD PROBLEMS (SUCH AS A KNOT IN THE
CORD, A LEAK IN THE CORD, OR IF THE CORD WRAPS
AROUND THE BABY'S NECK)...8
PREMATURE RUPTURE OF MEMBRANES ({THIS} 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) 9
PRETERM LABOR ({THIS} OCCURS WHEN LABOR BEGINS
BEFORE 37 COMPLETED WEEKS OF PREGNANCY).................10
RHEUMATOLOGIC PROBLEMS (SUCH AS LUPUS AND
OTHER SYSTEMIC AUTOIMMUNE DISEASES)...........................11
DIAGNOSIS OF FETAL ANOMALIES OR CHROMOSOMAL
ABNORMALITIES (SUCH AS WHEN THE BABY'S BODY
PARTS OR ORGANS ARE NOT FORMED NORMALLY OR DO
NOT FUNCTION)..12
GESTATIONAL DIABETES ({THIS IS A} CONDITION OF HIGH
BLOOD SUGAR DURING PREGNANCY AMONG WOMEN
WITHOUT PREVIOUSLY DIAGNOSED DIABETES)......................13
SEVERE VOMITING (SUCH AS VOMITING THREE TO FOUR
TIMES PER DAY. SOMETIMES CALLED "HYPEREMESIS"
OR "HYPEREMESIS GRAVIDARUM")...14
UTERINE BLOOD CLOTS ({THIS IS} ALSO KNOWN AS
"SUBCHORIONIC HEMATOMA")..15
NO COMPLICATIONS/CONDITIONS...16
SOME OTHER COMPLICATION..-5
REFUSED..-1
DON'T KNOW...-2

PROGRAMMER INSTRUCTIONS:
- IF MODE = CATI, DISPLAY BRACKETED TEXT FOR EACH RESPONSE ITEM.

- IF USING SHOWCARDS, DISPLAY RESPONSE CATEGORIES IN ALL CAPITAL LETTERS.
- OTHERWISE, DISPLAY RESPONSE CATEGORIES AS MIXED UPPER/LOWER CASE.
- IF **RECENT_COMPLICATIONS** = -5, OR ANY COMBINATION OF 1 THROUGH 15 AND -5, GO TO **RECENT_COMPLICATIONS_OTH.**
- IF **RECENT_COMPLICATIONS** = 16, -1 OR -2, DO NOT ALLOW ANY OTHER RESPONSES AND
    o IF **TERMINATION_PREG** = 1, GO TO **RECEIVE_RESOURCES.**
    o IF **TERMINATION_PREG** = 2, -1, OR -2, GO TO **DEATH_CAUSE**
- IF **RECENT_COMPLICATIONS** = ANY COMBINATION OF 1 THROUGH 15, AND
    o IF **TERMINATION_PREG** = 1, GO TO **RECEIVE_RESOURCES.**
    o IF **TERMINATION_PREG** = 2, -1, OR -2, GO TO **DEATH_CAUSE.**

MRP025/(RECENT_COMPLICATIONS_OTH). What other complications did you experience during your recent pregnancy?

SPECIFY: _____

REFUSED ....-1
DON'T KNOW..-2

PROGRAMMER INSTRUCTIONS:
- IF **TERMINATION_PREG** = 1, GO TO **RECEIVE_RESOURCES.**
- OTHERWISE, GO TO **DEATH_CAUSE.**

MRP026/(DEATH_CAUSE). Do you know the cause of your [pregnancy loss/baby's death]?

INTERVIEWER INSTRUCTIONS:
- IF LOSS REPORTED DURING PREGNANCY VISIT 1 OR PREGNANCY VISIT 2 EVENT, USE "pregnancy loss" AS APPROPRIATE.
- IF LOSS REPORTED DURING BIRTH EVENT, USE "baby's death" AS APPROPRIATE.

YES...1
NO...2
(RECEIVE_RESOURCES)
REFUSED ....-1
(RECEIVE_RESOURCES)
DON'T KNOW..-2
(RECEIVE_RESOURCES)

MRP027/(DEATH_CAUSE_OTH). What was the cause?

SPECIFY: _____

REFUSED ....-1
DON'T KNOW..-2
MRP028/(RECEIVE_RESOURCES). After your most recent pregnancy, did you receive any support or draw on any resources that helped you with your [pregnancy loss/baby's

death], including from family, friends, health care providers, organizations, or other sources?

INTERVIEWER INSTRUCTIONS:
- IF LOSS REPORTED DURING PREGNANCY VISIT 1 OR PREGNANCY VISIT 2 EVENT, USE "pregnancy loss" AS APPROPRIATE.
- IF LOSS REPORTED DURING BIRTH EVENT, USE "baby's death" AS APPROPRIATE.

YES..1
NO...2
(TIME_STAMP_OBH_ST)
REFUSED ....-1
(TIME_STAMP_OBH_ST)
DON'T KNOW...-2
(TIME_STAMP_OBH_ST)

MRP029/(SUPPORT_HELPED). We would like to know <u>what types of support or resources</u> helped you after your recent loss. {I am going to read a list of the types of support or resources that may have helped you after your [pregnancy loss/baby's death].} Please tell me if any of the following types of support or resources helped you after your [pregnancy loss/baby's death].

INTERVIEWER INSTRUCTIONS:
- IF LOSS REPORTED DURING PREGNANCY VISIT 1 OR PREGNANCY VISIT 2 EVENT, USE "pregnancy loss" AS APPROPRIATE.
- IF LOSS REPORTED DURING BIRTH EVENT, USE "baby's death" AS APPROPRIATE.
- IF USING SHOWCARDS, REFER PARTICIPANT TO APPROPRIATE SHOWCARD.
- OTHERWISE, READ RESPONSE CATEGORIES TO PARTICIPANT.
- PROBE, "Any others?"
- ONLY SELECT "SOME OTHER TYPE OF SUPPORT OR RESOURCES" OR "NO TYPE OF SUPPORT OR RESOURCES" IF VOLUNTEERED.
- SELECT ALL THAT APPLY.

EMOTIONAL SUPPORT FROM FAMILY OR FRIENDS.................1
IN-PERSON SUPPORT GROUP ON PREGNANCY
LOSS AND INFANT DEATH...2
WEB-BASED SUPPORT GROUP ON PREGNANCY
LOSS AND INFANT DEATH...3
BOOKS AND/OR MAGAZINES ON PREGNANCY LOSS
AND INFANT DEATH...4
INFORMATION FROM MEDICAL CARE PROVIDERS ON
PREGNANCY LOSS AND INFANT DEATH...................................5
MEDICAL TREATMENT...6
MENTAL HEALTH COUNSELING...7
PAID OR UNPAID LEAVE FROM YOUR JOB,
INCLUDING MATERNITY LEAVE OR FAMILY AND MEDICAL
LEAVE..8
NO TYPE OF SUPPORT OR RESOURCES.................................9
SOME OTHER TYPE OF SUPPORT OR RESOURCES................-5

```
REFUSED.............................................................................-1
DON'T KNOW....................................................................-2
```

PROGRAMMER INSTRUCTIONS:
- IF MODE = CATI, DISPLAY BRACKETED TEXT.
- IF USING SHOWCARDS, DISPLAY RESPONSE CATEGORIES IN ALL CAPITAL LETTERS.
- OTHERWISE, DISPLAY RESPONSE CATEGORIES AS MIXED UPPER/LOWER CASE.
- IF **SUPPORT_HELPED** = -5, OR ANY COMBINATION OF 1 THROUGH 8 AND -5, GO TO **SUPPORT_OTH.**
- IF **SUPPORT_HELPED** = 9, -1 OR -2, DO NOT ALLOW ANY OTHER RESPONSES AND GO TO **TIME_STAMP_MRP_ET.**
- IF **SUPPORT_HELPED** = ANY COMBINATION OF 1 THROUGH 8, GO TO **TIME_STAMP_MRP_ET.**

MRP030/(SUPPORT_OTH). What other types of support or resources helped you with your [pregnancy loss/baby's death]?

INTERVIEWER INSTRUCTIONS:
- IF LOSS REPORTED DURING PREGNANCY VISIT 1 OR PREGNANCY VISIT 2 EVENT, USE "pregnancy loss" AS APPROPRIATE.
- IF LOSS REPORTED DURING BIRTH EVENT, USE "baby's death" AS APPROPRIATE.

```
SPECIFY: _____

REFUSED ...........................................................................-1
DON'T KNOW....................................................................-2
```

(TIME_STAMP_MRP_ET) PROGRAMMER INSTRUCTION:
- INSERT DATE/TIME STAMP

OBSTETRIC HISTORY

(TIME_STAMP_OBH_ST) PROGRAMMER INSTRUCTION:
- INSERT DATE/TIME STAMP

OBH001. I have just a few more questions I would like to ask you. These questions are about your pregnancies <u>prior</u> to your most recent pregnancy.

OBH002/(NUM_PREG_PRIOR). How many times have you been pregnant <u>before your most recent pregnancy</u>, including any that may have ended in a live birth, miscarriage, stillbirth, induced abortion, or ectopic pregnancy?

INTERVIEWER INSTRUCTION:
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."

|___|___|
NUMBER OF PRIOR PREGNANCIES

REFUSED ....-1
DON'T KNOW ....-2

PROGRAMMER INSTRUCTIONS:
- IF **NUM_PREG_PRIOR** = 0, GO TO **TIME_STAMP_RQ_ST.**
- OTHERWISE, GO TO **NUM_PRIOR_MULT.**

OBH003/(NUM_PRIOR_MULT). How many of your prior pregnancies were <u>multiple pregnancies</u> (that is, you were pregnant with two or more babies)?

INTERVIEWER INSTRUCTION:
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."

|___|___|
NUMBER OF PRIOR MULTIPLE PREGNANCIES

REFUSED ....-1
DON'T KNOW ....-2

PROGRAMMER INSTRUCTIONS:
- IF **NUM_PRIOR_MULT** = 0, GO TO **OBH005.**
- OTHERWISE, GO TO **OBH004.**

OBH004. How many of these prior <u>multiple pregnancies</u> involved…

OBH004A/(NUM_MULT_PRIOR_LIVE). The delivery of a <u>live born baby</u>?

INTERVIEWER INSTRUCTION:
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."

|___|___|
NUMBER OF PRIOR LIVE BIRTH PREGNANCIES

REFUSED ....-1
                DON'T KNOW ....-2

PROGRAMMER INSTRUCTIONS:
   • IF **NUM_MULT_PRIOR_LIVE** = 0 AND **NUM_PRIOR_MULT** = **NUM_PREG_PRIOR**,
     THEN GO TO **TIME_STAMP_RQ_ST.**
   • OTHERWISE, GO TO **NUM_MULT_PRIOR_PRETERM**.

INTERVIEWER INSTRUCTION:
   • FOR **NUM_MULT_PRIOR_PRETERM, NUM_MULT_PRIOR_DEATH**,
     NUM_MULT_PRIOR_MISCARRIAGE, NUM_MULT_PRIOR_STILLBIRTH,
     NUM_MULT_PRIOR_ABORTION, AND **NUM_MULT_PRIOR_ECTOPIC,** RE-READ
     INTRODUCTORY STATEMENT (How many involved…) AS NEEDED.

OBH004B/(NUM_MULT_PRIOR_PRETERM). A <u>preterm delivery</u>, or a delivery occurring <u>before
      37 weeks</u> of pregnancy?

INTERVIEWER INSTRUCTION:
   • IF THE PARTICIPANT REPORTS NONE, RECORD "00."

      |___|___|
      NUMBER OF TIMES

                REFUSED ....-1
                DON'T KNOW ....-2

OBH004C/(NUM_MULT_PRIOR_DEATH). The <u>death of a baby</u> before 28 days <u>after birth</u>?

INTERVIEWER INSTRUCTIONS:
   • IF NEEDED, SAY: "That is, the death of your baby up to but not including 28 days from
     the moment of birth."
   • IF THE PARTICIPANT REPORTS NONE, RECORD "00."

      |___|___|
      NUMBER OF TIMES

                REFUSED ....-1
                DON'T KNOW ....-2

OBH004D/(NUM_MULT_PRIOR_MISCARRIAGE). A <u>miscarriage</u>, that is, an involuntary,
      unplanned pregnancy loss <u>before 20 weeks</u> of pregnancy?

INTERVIEWER INSTRUCTION:
   • IF THE PARTICIPANT REPORTS NONE, RECORD "00."

      |___|___|
      NUMBER OF PRIOR MISCARRIAGE PREGNANCIES

                REFUSED ....-1
                DON'T KNOW ....-2

OBH004E/(NUM_MULT_PRIOR_STILLBIRTH). A <u>stillbirth</u> at or after 20 weeks of pregnancy?

INTERVIEWER INSTRUCTION:
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."

    |___|___|
    NUMBER OF PREGNANCIES

    REFUSED ....-1
    DON'T KNOW ....-2

OBH004F/(NUM_MULT_PRIOR_ABORTION). An <u>induced abortion</u> or voluntary termination?

INTERVIEWER INSTRUCTION:
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."

    |___|___|
    NUMBER OF PRIOR ABORTED PREGNANCIES

    REFUSED ....-1
    DON'T KNOW ....-2

OBH004G/(NUM_MULT_PRIOR_ECTOPIC). An <u>ectopic pregnancy</u>, in which the embryo implanted outside of the uterus? (These are sometimes called <u>tubal pregnancies</u> because these pregnancies most often occur in the Fallopian tubes.)

    |___|___|
    NUMBER OF PRIOR ECTOPIC PREGNANCIES

    REFUSED ....-1
    DON'T KNOW ....-2

PROGRAMMER INSTRUCTIONS:
- CREATE DERIVED VARIABLE, **NUM_PRIOR_MULT_CALC**, WHERE **NUM_PRIOR_MULT_CALC** = SUM OF **NUM_MULT_PRIOR_LIVE** + **NUM_MULT_PRIOR_MISCARRIAGE** + **NUM_MULT_PRIOR_STILLBIRTH** + **NUM_MULT_PRIOR_ABORTION** + **NUM_MULT_PRIOR_ECTOPIC**; THEN SET **NUM_PRIOR_MULT** = **NUM_PRIOR_MULT_CALC**.
- IF **NUM_PRIOR_MULT** = **NUM_PREG_PRIOR**, GO TO **TIME_STAMP_RQ_ST**.
- OTHERWISE, GO TO **OBH005.**

OBH005. Now I would like to ask you about your pregnancies prior to your most recent pregnancy in which you were pregnant with just one baby.

OBH006. How many of these prior pregnancies {with one baby} ended with:

PROGRAMMER INSTRUCTION:
- DISPLAY "with one baby" IF **NUM_PRIOR_MULT** ≠ 0.

OBH006A/(NUM_ONE_PRIOR_LIVE). The delivery of a <u>live born baby</u>?

INTERVIEWER INSTRUCTION:
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."

|___|___|
NUMBER OF TIMES

REFUSED ....-1
DON'T KNOW ....-2

PROGRAMMER INSTRUCTIONS:
- IF **NUM_ONE_PRIOR_LIVE** = 0, GO TO **NUM_ONE_PRIOR_MISCARRIAGE**.
- OTHERWISE, GO TO **NUM_ONE_PRIOR_PRETERM**.

INTERVIEWER INSTRUCTION:
- FOR **NUM_ONE_PRIOR_PRETERM, NUM_ONE_BEFORE_28, NUM_ONE_PRIOR_MISCARRIAGE, NUM_ONE_PRIOR_STILLBIRTH, NUM_ONE_PRIOR_ECTOPIC,** AND **NUM_ONE_PRIOR_ABORTION**, RE-READ INTRODUCTORY STATEMENT (How many ended in…) AS NEEDED.

OBH006B/(NUM_ONE_PRIOR_PRETERM). A <u>preterm delivery</u>, or a delivery occurring <u>before 37 weeks</u> of pregnancy?

INTERVIEWER INSTRUCTION:
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."

|___|___|
NUMBER OF TMES

REFUSED ....-1
DON'T KNOW ....-2

OBH006C/(NUM_ONE_PRIOR_BEFORE_28). The <u>death of your baby</u> before 28 days <u>after birth</u>?

INTERVIEWER INSTRUCTIONS:
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."
- IF NEEDED SAY, "That is, the death of your baby up to but not including 28 days from the moment of birth."
|___|___|
NUMBER OF TIMES

REFUSED ....-1
DON'T KNOW ....-2

OBH006D/(NUM_ONE_PRIOR_MISCARRIAGE). A <u>miscarriage</u>, that is, an involuntary, unplanned pregnancy loss <u>before 20 weeks</u> of pregnancy?

INTERVIEWER INSTRUCTION:

- IF THE PARTICIPANT REPORTS NONE, RECORD "00."

|___|___|
NUMBER OF TIMES

REFUSED ....-1
DON'T KNOW ....-2

OBH006E/(NUM_ONE_PRIOR_STILLBIRTH). A <u>stillbirth</u> at or after 20 weeks of pregnancy?

INTERVIEWER INSTRUCTION:
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."

|___|___|
NUMBER OF TIMES

REFUSED ....-1
DON'T KNOW ....-2

OBH006F/(NUM_ONE_PRIOR_ABORTION). An <u>induced abortion</u> or voluntary termination?

INTERVIEWER INSTRUCTION:
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."

|___|___|
NUMBER OF TIMES

REFUSED ....-1
DON'T KNOW ....-2

OBH006G/(NUM_ONE_PRIOR_ECTOPIC). An <u>ectopic pregnancy</u>, in which the embryo implanted outside of the uterus? (These are sometimes called <u>tubal pregnancies</u> because these pregnancies most often occur in the Fallopian tubes.)

INTERVIEWER INSTRUCTION:
- IF THE PARTICIPANT REPORTS NONE, RECORD "00."

|___|___|
NUMBER OF TIMES

REFUSED ....-1
DON'T KNOW ....-2

PROGRAMMER INSTRUCTIONS:
CREATE DERIVED VARIABLE, **NUM_PRIOR_ONE_CALC**, WHERE
NUM_PRIOR_ONE_CALC = SUM OF **NUM_ONE_PRIOR_LIVE +
NUM_ONE_PRIOR_MISCARRIAGE + NUM_ONE_PRIOR_STILLBIRTH +
NUM_ONE_PRIOR_ABORTION + NUM_ONE_PRIOR_ECTOPIC**; THEN SET
NUM_PRIOR_MULT = **NUM_PRIOR_MULT_CALC**.

(TIME_STAMP_OBH_ET) PROGRAMMER INSTRUCTION:

- INSERT DATE/TIME STAMP

RECORDS RELEASE REQUESTS

(TIME_STAMP_RQ_ST) PROGRAMMER INSTRUCTION:
- INSERT DATE/TIME STAMP

RQ001. 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.

{We would like to send you two copies of a Medical Record Release form in the mail. If you have questions after reading the form, please contact us at the number we will include on the form. If you agree to let us access the medical records, you will complete and sign the form, and mail it back to us. We will provide a pre-addressed stamped envelope for this purpose. The second copy of the form will be yours to keep.}

PROGRAMMER INSTRUCTION:
- IF MODE = CATI, DISPLAY BRACKETED TEXT AND THEN GO TO **MAILING_ADDRESS_VARIABLES**.
- OTHERWISE, IF MODE = CAPI, GO TO **MED_RECORD_LOSS**.

RQ001A (MAILING_ADDRESS_VARIABLES). What is your mailing address?

INTERVIEWER INSTRUCTION:
- PROBE AND ENTER AS MUCH INFORMATION AS PARTICIPANT KNOWS.

_____
(MAIL_ADDRESS_1) ADDRESS 1 - STREET/PO BOX

_____
(MAIL_ADDRESS_2) ADDRESS 2

_____
(MAIL_UNIT) UNIT

_____
(MAIL_CITY) CITY

|___|___| |___|___|___|___|___| |___|___|___|___
  STATE   ZIP CODE   ZIP+4
(MAIL_STATE) (MAIL_ZIP) (MAIL_ZIP4)

REFUSED...-1 **(RQ009)**
DON'T KNOW..-2 **(RQ009)**

RQ002/(MED_RECORD_LOSS). May we {have your permission to access your medical records to learn more about the loss/send you the Medical Record Release form to review}?

YES {ALLOWS MAILING}...1
NO {SAID DOES NOT WANT RELEASE MAILED TO HER}..........2
REFUSED ....-1
DON'T KNOW..-2

PROGRAMMER INSTRUCTIONS:
- IF MODE = CAPI, DISPLAY "have your permission to access your medical records to learn more about the loss."
- IF MODE = CATI, DISPLAY "send you the Medical Record Release form to review" AND BRACKETED TEXT FOR RESPONSE CODES.
- IF MODE = CAPI AND **MED_RECORD_LOSS** = 1, GO TO **RQ003.**
- IF MODE = CATI AND **MED_RECORD_LOSS** = 1, GO TO **REVIEW_RELEASE.**
- OTHERWISE, GO TO PROGRAMMER INSTRUCTIONS FOLLOWING **SIGN_RELEASE.**

RQ003. Please read and complete the Medical Record Release Form and let me know if you have any questions. All of the information we obtain will be kept strictly confidential.

INTERVIEWER INSTRUCTIONS:
- PROVIDE PARTICIPANT WITH TWO COPIES OF THE MEDICAL RECORD RELEASE FORM.
- ANSWER ANY QUESTIONS THE PARTICIPANT HAS.
- THE PARTICIPANT SHOULD SIGN ONE COPY FOR THE INTERVIEWER, AND SHE SHOULD BE GIVEN THE OTHER COPY TO KEEP.

RQ004/(SIGN_RELEASE). DID PARTICIPANT SIGN THE MEDICAL RECORD RELEASE?

YES...1
NO...2

PROGRAMMER INSTRUCTIONS:
- IF **NUM_STILLBORN** > 0 AND/OR **NUM_DIED** > 0, AND **STILLBIRTH_PREG** = 1, OR **AFTER_BORN** = 1, GO TO **RQ005.**
- OTHERWISE, GO TO **RQ009.**

RQ004A/(REVIEW_RELEASE). DID PARTICIPANT AGREE TO REVIEW THE MEDICAL RECORD RELEASE?

YES...1
NO...2

PROGRAMMER INSTRUCTIONS:
- IF **NUM_STILLBORN** > 0 AND/OR **NUM_DIED** > 0, AND **STILLBIRTH_PREG** = 1, OR **AFTER_BORN** = 1, GO TO **RQ005.**
- OTHERWISE, GO TO **RQ009.**

RQ005. Your {baby's/babies'} death certificate{s} can give us important information about the {cause of/circumstances of your {baby's/babies'}} death. All of the information we obtain will be kept strictly confidential and will only be seen by members of the NCS study team. {We will send you 2 copies of a Death Certificate Release form in the mail {per child}. Please review and complete the form{s}. If you have questions after you read the Death Certificate Release form, please contact us at the number we will include on the form. Once you have completed and signedthe release form, please mail it back to us, using the same envelope as you will use for sending us the Medical Records Release form. The second copy of the form will be yours to keep.}

PROGRAMMER INSTRUCTIONS:
- IF MODE = CAPI, DISPLAY "cause of."
- IF MODE = CATI, DISPLAY "circumstances of your {baby's/babies'}" AND BRACKETED PARAGRAPH THAT BEGINS "We will send you 2 copies…".
- IF **PREG_MULTIPLE** = 1, DISPLAY "per child".
- IF **PREG_MULTIPLE** = 1 AND SUM OF **NUM_STILLBORN** + **NUM_DIED** = 1, DISPLAY "baby's", "certificate" AND "form".
- OTHERWISE, IF **PREG_MULTIPLE** = 1 AND SUM OF **NUM_STILLBORN** + **NUM_DIED** > 1, DISPLAY "babies", "certificates" AND "forms".

RQ006/(DEATH_CERT). May we {also} {have your permission to access your {baby's/babies'} death certificate{s}/send you the Death Certificate Release form to review}?

```
YES{, ALLOWS MAILING}...............................................................1
NO{, SAID DOES NOT WANT RELEASE MAILED TO HER}.........2
REFUSED ................................................................................-1
DON'T KNOW...........................................................................-2
```

PROGRAMMER INSTRUCTIONS:
- IF **MED_RECORD_LOSS** = 1, DISPLAY, "also."
- IF MODE = CAPI, DISPLAY "have your permission to access your {baby's/babies'} death certificate{s}."
- IF MODE = CATI, DISPLAY "send you the Death Certificate Release form to review" AND BRACKETED TEXT FOR RESPONSE CODES.
- IF SUM OF **NUM_STILLBORN** + **NUM_DIED** = 1, DISPLAY "baby's and "certificate".
- OTHERWISE, IF SUM OF **NUM_STILLBORN** + **NUM_DIED** > 1, DISPLAY "babies" and "certificates".
- IF MODE = CAPI AND **MED_RECORD_LOSS** = 1, GO TO **RQ007.**
- IF MODE = CATI AND **MED_RECORD_LOSS** = 1, GO TO **REVIEW_DEATH_CERT.**
- OTHERWISE, GO TO **RQ009.**

RQ007. Please read and complete the Death Certificate Record Release Form and let me know if you have any questions.

INTERVIEWER INSTRUCTIONS:
- PROVIDE PARTICIPANT WITH TWO COPIES OF THE DEATH CERTIFICATE RELEASE FORM FOR EACH CHILD.
- OBTAIN RELEASE FORM WHERE NUMBER OF RELEASE FORMS = SUM OF **NUM_STILLBORN** + **NUM_DIED**.
- ANSWER ANY QUESTIONS THE PARTICIPANT HAS.
- HAVE THE PARTICIPANT SIGN ONE COPY OF THE FORM, AND GIVE HER THE OTHER COPY TO KEEP.

RQ008/(SIGN_DEATH_CERT). DID PARTICIPANT SIGN THE DEATH CERTIFICATE RELEASE{S}?

      YES...1
      NO...2

PROGRAMMER INSTRUCTIONS:
- IF SUM OF **NUM_STILLBORN** + **NUM_DIED** = 1, DISPLAY "release".
- OTHERWISE, IF SUM OF **NUM_STILLBORN** + **NUM_DIED** > 1, DISPLAY "releases".

RQ008A/(REVIEW_DEATH_CERT). DID PARTICIPANT AGREE TO REVIEW THE DEATH CERTIFICATE RELEASE{S}?

      YES...1
      NO...2

PROGRAMMER INSTRUCTIONS:
- IF SUM OF **NUM_STILLBORN** + **NUM_DIED** = 1, DISPLAY "release".
- OTHERWISE, IF SUM OF **NUM_STILLBORN** + **NUM_DIED** > 1, DISPLAY "releases".

RQ009. Those are all the questions I have. I'd like to thank you for your help in answering our questions. Your participation is very important to the National Children's Study.

(TIME_STAMP_RQ_ET) PROGRAMMER INSTRUCTION:
- INSERT DATE/TIME STAMP