

Parent-Caregiver Death Questionnaire

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| --- | --- |
| Event Category: | Trigger-Based |
| Event: | Parent-Caregiver Death |
| Administration: | 3M, 6M, 9M, 12M, 18M, 24M, 30M, 36M, 42M, 48M, 54M, 60M |
| Instrument Target: | Biological Mother; Biological Father; Primary Caregiver; Secondary Caregiver |
| Instrument Respondent: | Proxy |
| Domain: | Questionnaire |
| Document Category: | Questionnaire |
| Method: | Data Collector Administered |
| Mode (for this instrument\*): | Phone, CAI |
| OMB Approved Modes: | In-Person, CAI;Phone, CAI;Web-Based, CAI |
| Estimated Administration Time: | 3 minutes |
| Multiple Child/Sibling Consideration: | Per Event |
| Special Considerations: | N/A |
| Version: | 1.0 |
| MDES Release: | 4.0 |

\*This instrument is OMB-approved for multi-mode administration but this version of the instrument is designed for administration in this/these mode(s) only.

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Parent-Caregiver Death Questionnaire

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Parent-Caregiver Death Questionnaire

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** | **DATA TYPE** | **PROGRAMMER INSTRUCTIONS** |
| ADDRESS AND EMAIL FIELDS | 100 | CHARACTER |  |
| UNIT AND PHONE FIELDS | 10 | CHARACTER |  |
| \_OTH AND COMMENT FIELDS | 255 | CHARACTER | * Limit text to 255 characters
 |
| FIRST NAME AND LAST NAME | 30 | CHARACTER | * Limit text to 30 characters
 |
| ALL ID FIELDS | 36 | CHARACTER |  |
| ZIP CODE | 5 | NUMERIC |  |
| ZIP CODE LAST FOUR | 4 | NUMERIC |  |
| CITY | 50 | CHARACTER |  |
| DOB AND ALL OTHER DATE FIELDS (E.G., DT, DATE, ETC.) | 10 | NUMERICCHARACTER | * DISPLAY AS MM/DD/YYYY
* STORE AS YYYY-MM-DD
* HARD EDITS:

MM MUST EQUAL 01 TO 12DD MUST EQUAL 01 TO 31YYYY MUST BE BETWEEN 1900 AND CURRENT YEAR. |
| TIME VARIABLES | TWO-DIGIT HOUR AND TWO-DIGIT MINUTE, AM/PM DESIGNATION | NUMERIC | * 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 ROCs 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.**

PARENT/CAREGIVER DEATH INTERVIEW

**(TIME\_STAMP\_PDI\_ST).**

|  |
| --- |
| PROGRAMMER INSTRUCTIONS |
| * INSERT DATE/TIME STAMP
* PRELOAD PARTICIPANT ID (**P\_ID**) AND RESPONDENT ID (**R\_P\_ID**) FOR ADULT.
* PRELOAD AND DISPLAY **R\_FNAME** FROM PARTICIPANT VERIFICATION QUESTIONNAIRE AS APPROPRIATE THROUGHOUT THE INSTRUMENT
 |

**PDI01000/(PARENT\_DEATH\_INTRO).** I am sorry to hear that {R\_FNAME} passed away.  {He/She} was an important part of the National Children's Study and we appreciate the contribution that {he/she} made during {his/her} time in the Study.  It is important to the goals of the Study to understand what happened in the time period  between the last time we interviewed {R\_FNAME} and when {he/she} died.  We would like to talk with someone who can provide some information about {R\_FNAME}'s death.  We understand that this is a difficult time for you and {your/R\_FNAME}'s family.  If you are unable or do not wish to talk about {R\_FNAME}'s death right now, I can {call/come} back at a better time.

Would you be able to answer some questions about {R\_FNAME}'s death?

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| YES | 1 |  |
| NO | 2 | PDI28000 |
| REFUSED | -1 | PDI28000 |
| DON'T KNOW | -2 | PDI28000 |

|  |
| --- |
| SOURCE |
| National Social Health and Aging Project (NSHAP) Wave 2 Proxy Questionnaire (modified) |

|  |
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| DATA COLLECTOR INSTRUCTIONS |
| * IF MODE = CATI, DISPLAY "call"
* OTHERWISE, DISPLAY "come"
 |

 **PDI03000.** This questionnaire will take approximately 4 minutes of your time.  As a reminder, your participation is completely voluntary.  You may refuse to answer any question and you may stop the interview at any time.  The information you provide will be kept strictly confidential.  First . . .

|  |
| --- |
| SOURCE |
| National Social Health and Aging Project (NSHAP) Wave 2 Proxy Questionnaire (modified) |

**PDI04000/(RELATION\_TYPE).** What was your relationship to {R\_FNAME}?  Were you {his/her}

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| Spouse | 1 | PDI06000 |
| Unmarried partner | 2 | PDI06000 |
| Ex-spouse | 3 | PDI06000 |
| Parent or parent-in-law | 4 | PDI06000 |
| Child or step-child | 5 | PDI06000 |
| Brother or sister | 6 | PDI06000 |
| Other relative or other in-law | 7 |  |
| Friend | 8 | PDI06000 |
| Related in some other way | -5 |  |
| REFUSED | -1 | PDI06000 |
| DON'T KNOW | -2 | PDI06000 |

|  |
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| SOURCE |
| National Children's Study, Vanguard Phase (Participant Verification) (modified) |

**PDI05000/(RELATION\_TYPE\_OTH).** SPECIFY:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| REFUSED | -1 |  |
| DON'T KNOW | -2 |  |

|  |
| --- |
| SOURCE |
| New |

**PDI06000.** When did {R\_FNAME} die?

|  |
| --- |
| INTERVIEWER INSTRUCTIONS |
| * IF INCOMPLETE DATE IS GIVEN, PROBE FOR COMPLETE DATE.
 |

|  |
| --- |
| SOURCE |
| National Social Health and Aging Project (NSHAP) Wave 2 Proxy Questionnaire (modified) |

**(DATE\_OF\_DEATH\_MM)** MONTH:

|\_\_\_\_|\_\_\_\_|

    M      M

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| REFUSED | -1 |  |
| DON'T KNOW | -2 |  |

**(DATE\_OF\_DEATH\_DD)** DATE:

|\_\_\_\_|\_\_\_\_|

    D      D

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| REFUSED | -1 |  |
| DON'T KNOW | -2 |  |

**(DATE\_OF\_DEATH\_YYYY)** YEAR:

|\_\_\_\_|\_\_\_\_|\_\_\_\_|\_\_\_\_|

    Y       Y       Y       Y

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| REFUSED | -1 |  |
| DON'T KNOW | -2 |  |

**PDI07000/(STATE\_OF\_DEATH).** In what state did {R\_FNAME}'s death occur?

|\_\_\_\_|\_\_\_\_|

    STATE

|  |
| --- |
| INTERVIEWER INSTRUCTIONS |
| * ENTER 2-LETTER POSTAL STATE ABBREVIATION
 |

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| REFUSED | -1 | MAIN\_CAUSE |
| DON'T KNOW | -2 | MAIN\_CAUSE |

|  |
| --- |
| SOURCE |
| New |

**PDI08000/(CITY\_OF\_DEATH).** In what city did {R\_FNAME}'s death occur?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

                                  CITY

|  |
| --- |
| INTERVIEWER INSTRUCTIONS |
| * CONFIRM SPELLING OF CITY
 |

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| REFUSED | -1 |  |
| DON'T KNOW | -2 |  |

|  |
| --- |
| SOURCE |
| New |

**PDI09000/(COUNTY\_OF\_DEATH).** In what county did {R\_FNAME}'s death occur?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

                           COUNTY

|  |
| --- |
| INTERVIEWER INSTRUCTIONS |
| * CONFIRM SPELLING OF COUNTY
 |

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| REFUSED | -1 |  |
| DON'T KNOW | -2 |  |

|  |
| --- |
| SOURCE |
| New |

**PDI11000/(MAIN\_CAUSE).** What was the cause of death?

SPECIFY:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| REFUSED | -1 | CONSENT |
| DON'T KNOW | -2 | CONSENT |

|  |
| --- |
| SOURCE |
| New |

**PDI22000/(CONSENT).** Researchers for the National Children's Study are interested in obtaining death certificates for participants who pass away during their time in the Study.  For the Study's research purposes, we would like your permission to obtain {R\_FNAME}'s death certificate.  Would you authorize us to obtain {R\_FNAME}'s death certificate by filling out {this/the} form {we sent you}, signing and dating it at the bottom{, and sending it back}?

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| YES | 1 |  |
| NO | 2 |  |
| REFUSED | -1 |  |
| DON'T KNOW | -2 |  |

|  |
| --- |
| SOURCE |
| New |

|  |
| --- |
| PROGRAMMER INSTRUCTIONS |
| * IF MODE = CAPI, DISPLAY "this"
* IF MODE = CATI, DISPLAY "the" "we sent you" AND ", and sending it back"
* IF **CONSENT**= 1 AND
	+ IF MODE = CAPI, GO TO **CONSENT\_FORM.**
	+ IF MODE = CATI, GO TO **PDI28000.**
* OTHERWISE, IF **CONSENT**= 2, -1 OR -2, GO TO **NO\_CONSENT**
 |

**PDI23000/(CONSENT\_FORM).** WAS THE FORM FILLED OUT CORRECTLY AND COMPLETELY?

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| YES | 1 | PDI28000 |
| NO | 2 |  |

|  |
| --- |
| SOURCE |
| New |

**PDI24000/(NOT\_FILLED\_OUT).** WHY WAS THE FORM NOT FILLED OUT CORRECTLY AND COMPLETELY?

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| RESPONDENT REFUSED AFTER SEEING FORM | 1 |  |
| SOME OTHER REASON | 2 | PDI28000 |

|  |
| --- |
| SOURCE |
| New |

**PDI25000/(NO\_CONSENT).** DID THE RESPONDENT INDICATE WHY THEY WOULD NOT ALLOW CONSENT?

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| YES | 1 |  |
| NO | 2 | PDI28000 |

|  |
| --- |
| SOURCE |
| New |

**PDI26000/(WHY\_NO\_CONSENT).** WHY DID THE RESPONDENT NOT ALLOW CONSENT?

|  |
| --- |
| INTERVIEWER INSTRUCTIONS |
| * SELECT ALL THAT APPLY
 |

|  |  |  |
| --- | --- | --- |
| Label | Code | Go To |
| PRIVACY CONCERNS | 1 |  |
| CONFIDENTIALITY CONCERNS | 2 |  |
| TOO PERSONAL | 3 |  |
| GENERAL OBJECTION TO CONSENT | 4 |  |
| SOME OTHER REASON | -5 |  |

|  |
| --- |
| SOURCE |
| New |

|  |
| --- |
| PROGRAMMER INSTRUCTIONS |
| * IF **WHY\_NO\_CONSENT**  = -5, OR ANY COMBINATION OF 1 THROUGH 4 AND -5, GO TO **WHY\_NO\_CONSENT\_OTH**.
* OTHERWISE, GO TO **PDI28000**.
 |

**PDI27000/(WHY\_NO\_CONSENT\_OTH).** WHAT OTHER REASON(S)?

SPECIFY:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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| --- |
| SOURCE |
| New |

**PDI28000.** Those are all of the questions I have for you.  On behalf of myself and the National Children's Study, please accept our sincerest condolences.  Thank you for your time.

|  |
| --- |
| SOURCE |
| New |

**(TIME\_STAMP\_PDI\_ET).**

|  |
| --- |
| PROGRAMMER INSTRUCTIONS |
| INSERT DATE/TIME STAMP |