



## Parent-Caregiver Death Questionnaire

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

Public reporting burden for this collection of information is estimated to average 3 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0593\*). Do not return the completed form to this address.

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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	<ul style="list-style-type: none"> <li>Limit text to 255 characters</li> </ul>
FIRST NAME AND LAST NAME	30	CHARACTER	<ul style="list-style-type: none"> <li>Limit text to 30 characters</li> </ul>
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	NUMERIC CHARACTER	<ul style="list-style-type: none"> <li>DISPLAY AS MM/DD/YYYY</li> <li>STORE AS YYYY-MM-DD</li> <li>HARD EDITS: MM MUST EQUAL 01 TO 12 DD MUST EQUAL 01 TO 31 YYYY MUST BE BETWEEN 1900 AND CURRENT YEAR.</li> </ul>
TIME VARIABLES	TWO-DIGIT HOUR AND TWO-DIGIT MINUTE, AM/PM DESIGNATION	NUMERIC	<ul style="list-style-type: none"> <li>HARD EDITS: HOURS MUST BE BETWEEN 00 AND 12; MINUTES MUST BE BETWEEN 00 AND 59</li> </ul>

### **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)

### 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

Label	Code	Go To
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

**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	

<b>SOURCE</b>
New

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

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

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

<b>SOURCE</b>
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	

<b>SOURCE</b>
New

PROGRAMMER INSTRUCTIONS
<ul style="list-style-type: none"> <li>• IF MODE = CAPI, DISPLAY "this"</li> <li>• IF MODE = CATI, DISPLAY "the" "we sent you" AND ", and sending it back"</li> <li>• IF <b>CONSENT</b> = 1 AND <ul style="list-style-type: none"> <li>◦ IF MODE = CAPI, GO TO <b>CONSENT_FORM</b>.</li> <li>◦ IF MODE = CATI, GO TO <b>PDI28000</b>.</li> </ul> </li> <li>• OTHERWISE, IF <b>CONSENT</b> = 2, -1 OR -2, GO TO <b>NO_CONSENT</b></li> </ul>

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

Label	Code	Go To
YES	1	PDI28000
NO	2	

<b>SOURCE</b>
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
<ul style="list-style-type: none"> <li>SELECT ALL THAT APPLY</li> </ul>

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
<ul style="list-style-type: none"> <li>IF WHY_NO_CONSENT = -5, OR ANY COMBINATION OF 1 THROUGH 4 AND -5, GO TO WHY_NO_CONSENT_OTH.</li> <li>OTHERWISE, GO TO PDI28000.</li> </ul>

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

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

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