

CODING MANUAL

**QODD: SIGNIFICANT OTHER AFTER-DEATH INTERVIEW
CODING MANUAL
NON-UNIVERSITY OF WASHINGTON SITES**

General Coding Conventions, Rules

1. The following three-digit numbers are used for missing values:

666 = 'not asked' either by the interviewer or not included in the questionnaire

777 = 'refused'

888 = 'skipped, not applicable'

999 = 'don't know'

NOTE: 888 is always used when a question is skipped as directed in the questionnaire. For example, part B will be coded "888" if the respondent answers "don't know" or refuses to answer part A of a question.

2. Dates:

Years are entered as 4 digit numbers

Months, days are entered as 2 digit numbers

3. Seven day vs. last month versions

7 = seven day recall

30 = 30 day recall

The same variable names are used, regardless of which version has been administered. Versions are identified by the variable, **VERSION**

PART I, "CIRCUMSTANCES"

Page 1 - Cover Page

Patient ID (PID)

No missing values

Significant other ID (SID)

No missing values

Interview date (INTMO, INTDY, INTYR)

Month, day are 2 digit numbers.

Year is a 4 digit number (ex: 2000).

No missing values.

Start and stop time (STRTIME, STPTIME)

Time, with AM or PM.

For patients interviewed over a number of sessions, field is left blank.

Time (MINUTE)

Minutes required to complete the questionnaire.

If multiple sessions were used, calculate the total time.

Version (VERSION)

7 day recall = 7

30 day recall = 30

Pages 2-4 Circumstances of Death

Question 1-7

Q.1 Date of death (DTHM, DTHMDY, DTHYR)

Month, day are 2 digit numbers.

Year is a 4 digit number (ex. 1999).

No missing values.

Is date correct (DTHDTOK)?

1 = yes, 2 = no

Corrected date (ADTHM, ADTHDY, ADTHYR)

If date is incorrect, enter corrected date from significant other.

If date is correct, enter 888/888/888.

Q. 2. Days seeing patient over past week? (DAY1, DAY2, DAY3, DAY4, DAY5, DAY6, DAY7)

0 = not seen, 1 = seen.

Q. 3 Where was patient on each of these days? (PLDAY1, PLDAY2, PLDAY3, PLDAY4, PLDAY5, PLDAY6, PLDAY7)

1 = patient's own home

2 = significant other's home

3 = other's home

4 = hospital

5 = in-patient hospice

6 = nursing home

7 = other

Q. 4 What was most time spent with patient? (MSTIME).

- 1 = < 1hour
- 2 = 1-4 hours
- 3 = 4-8 hours
- 4 = >=8 hours

Q. 5 Least number of hours spent with patient? (LSTIME).

- 1 = < 1hour
- 2 = 1-4 hours
- 3 = 4-8 hours
- 4 = >=8 hours

Q. 6 During the last year, how frequently see patient? (FRQYR).

- 1 = daily
- 2 = at least once a week
- 3 = at least once a month
- 4 = less than once a month

Q. 7 How long before death was patient aware they were dying? (AWARE)

- 1 = never aware
- 2 = one week before death
- 3 = 2-4 weeks before death
- 4 = 2-6 months before death
- 5 = 6-12 months before death

Screening Question (SEVDAY)

Did patient talk with you in a way you could understand during the last seven days of life?

- 1 = yes-→ use 7 day version, 2 = no-→ use 30 day version

PART 2, "QODD"

Page 5-Cover Page

No data entry required for this page; this cover page allows a link between Part 1 and Part 2 with Part 2 selected from either the 7-day or 30-day version.

Pages 6-12 Quality of Dying and Death, Section A (QODD)

Question QODD Example, 1-16

Example: Frequency of listening to music (QODEXA)
 Values 0-5.
 Quality of experience, if listened to music (QODEXB)
 Values 0-10.

Q. 1a-16b (QOD1a - QOD16b)

Frequency items (QOD__a)

0 = none of the time

1 = a little bit of the time

2 = some of the time

3 = a good bit of the time

4 = most of the time

5 =all of the time

Rating of quality of experience (QOD_b)

Values 0-10

0 = terrible experience

10 = almost perfect experience

888 if Part 'a' = 999 (don't know) or 777 (no response, refuse).

The following questions require 888 if "not applicable"

Q. 12 Spending time with spouse, partner? (QOD12a,b)

Q. 13 Spending time with children (QOD13a,b)

Q. 16 Spending time with pets (QOD16a,b)

Pages 13-17 Quality of Dying and Death, Sections B,C (QODD)

Questions 17a - 28b

NOTE: VARIABLE NAMES DO NOT ALWAYS MATCH QUESTION NUMBERS.

Q. 17a, 18a, 19a, 20a, 21a, 22a, 23a, 24a, 25a, 26a, 27b, 28a
(QOD17A, QOD18A, QOD21B, QOD19A, QOD22A, QOD23A, QOD24A,
QOD25A, QOD26A, QOD27B, QOD28A, QOD20A)

1 = yes, 2 = no

Q. 17b, 18b, 19b, 20b, 21b, 22b, 23b, 24b, 25b, 26b, 27b, 28b
(QOD17B, QOD18B, QOD21C, QOD19B, QOD22B, QOD23B, QOD24B,
QOD25B, QOD26B, QOD27C, QOD28B, QOD20B)

Values 0-10

888 if Part 'a' = 999 (don't know).

Pages 17-19 Quality of Dying and Death, Sections D,E (QODD)

Q. 29a Place of death

Home (PADIE3)

Surrogate's home (PADIE6)

Other home (PADIE7)

text (HOMETX)

Hospital (PADIE12)

text (HOSPIT)

In-patient hospice (PADIE5)

text (HOSPTX)

Nursing home (PADIE4)

text (NURSTX)

Other (PADIE9)

text (OTHDIE)

Don't know

0 = not endorsed, 1 = endorsed.

If respondent answers 'don't know', 999 for all response options.

If respondent provides no response, 777 for all response options.

Q. 29b Rating of place of death (PADIEB)

Values 0-10.

888 if respondent didn't know where patient died.

Q. 30a Anyone present at moment of death? (PRESA)

1 = yes, 2 = no, 999 = don't know, 777 = no response, refuse.

Q. 30 b Rating of this aspect of death (PRESB)

Values 0-10

888 if PRESA = 999 or 777.

Q. 31a State at time of death (QOD33A)

1 = awake, 2 = asleep, 3 = in a coma/ unconscious,

999 = don't know, 777= refused, no response

NOTE: The variable label does not match the question number.

Q. 31b Importance of preferred state of death (QOD33B)

Values 0-10

888 if QOD33A = 999 or 777.

Q. 32 Rating of quality of life during last 7/30 days of patient's life?(QODQOLA)

Values 0-10

Q. 33 Rating of quality of the moment of patient's death? (QODQOLB)

Values 0-10

Did interviewer use verbal cue card for the QODD? (QODCUE)

1 = yes, 2 = no.

Page 20-21 Demographics

Questions 1-5

- Q. 1 Significant other's relationship to patient (REL)
1 = spouse
2 = child
3 = sibling
4 = friend
5 = parent
6 = other relative
7 = other text to describe other (RELTXT)
Enter text if '7' endorsed.
- Q. 2 Respondent's birthdate (BRTHMO, BRTHDY, BRTHYR)
Birth month (1-2 digits)
Birth day (1-2 digits)
Birth year (4 digits)
- Q. 3 Length of time to travel to patient's home? (CLOSEHR, CLOSEMN)
Hours to travel (1-2 digits), minutes to travel (1-2 digits, up to 60).
If significant other and patient live in same home:
CLOSEHR=0, CLOSEMN = 0
If only hours are completed, enter 0 for minutes.
If only minutes are completed, enter 0 for hours.
- Q. 4 Length of time known patient? (KNOWYR, KNOWMO)
Number of years (1-2 digits)
Number of months (1-2 digits, up to 12)
If only years are provided, enter 0 for months.
If not known, KNOWYR = 999, KNOWMO = 999.
- Q. 5 Respondent's gender (SEX)
1= female, 2 = male.

Page 21, Demographics

Questions 6-7

- Q. 6 Respondent's race, ethnicity (WHITE, AFAM, HISP, ASIAN, NATAM, RACEOTH, RACETX)
1 = yes, 2 = no.
Enter value for all race, ethnicity variables.
If RACEOTH = 1, enter text into RACETX.
- Q. 7 Respondent's education (ED)
1 = no formal school
2 = k-8
3 = some high school
4 = high school diploma or GED
5 = some college
6 = 4 year college degree,
7 = graduate or professional school.

Page 22, Interviewee Assessment

Questions 1-4

- Q. 1 Would you like to continue? (CONT)
1 = yes, 2 = no
- Q. 2. Burden? (BURDEN).
Values 0-10.
If CONT = 2 (no), BURDEN = 888.
- Q. 3 Anything about quality of dying we should have asked but didn't?
(COMMENT)
Text field
Enter NO if no comments
Use 666 if not asked
- Q. 4 Anything that would have made questionnaire easier? (EASY)
Text field
Enter NO if no comments
Use 666 if not asked

Page 23, Interviewer Assessment

Questions 1-5

- Q. 1 Completeness of interview (INT1)
1 = yes, 2 = no.
- Q. 2 Reasons for incomplete interview (INT2A-INT2F)
If interview complete, enter 888.
If interview incomplete, enter 1= yes, 2 = no.
- Q. 3 Quality of Data (INT3, INT3TXT)
1 = poor, 2=fair, 3 = good.
If data quality =good, leave INT3TXT blank.
If data quality =fair, poor, enter text into INT3TXT.
- Q. 4 Method of interview (INT4)
1= in person, 2 = by phone.
- Q. 5 Interviewer name (INTFN, INTLN)
First name and last name of interviewer.