COGNITIVE EVALUATION OF THE WHO VERBAL AUTOPSY QUESTIONNAIRE IN LUSAKA, ZAMBIA AND RABAT, MOROCCO

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Acknowledgements

The author would like to acknowledge the hard work and dedication of the field coordinating and interviewing teams that collected the data used in this report.


Additionally, the following NCHS staff contributed to the coordination, collection, and analysis of the cognitive interviews: Jonathan Vickers, Meredith Massey, Sam Notzon, and Brian Munkombwe.
This report documents results of a cognitive interviewing study to examine the performance of the 2016 WHO Verbal Autopsy (VA) Instrument. Composed of three questionnaires and designed under the auspices of the World Health Organization (WHO), the goal of the VA instrument is to provide timely and valid vital statistics for both national ministries/departments of health and for international health organizations.

VA is a tool that can be used for identifying probable cause of death in the absence of medical personnel to medically certify cause of death. The VA process generally involves conducting an interview with the next of kin or a caregiver of the deceased after a culturally appropriate mourning period. In July 2012, WHO released a simplified VA instrument that includes a separate questionnaire for three age groups: 1) under four weeks (referred throughout this report as “neonates”), 2) four weeks to 14 years (referred to throughout this report as “child” or “children”), and 3) 15 years and above (referred throughout this report as “adult”). The aim of the simplification process was to develop an abbreviated VA instrument that could be used on a routine basis, including in the context of a national civil registration and vital statistics system. This 2012 questionnaire was evaluated using cognitive interviewing by NCHS in 2014 in western Kenya1. The results of that evaluation, along with contributions from across a WHO working group on VA, led to a series of changes and the release of the 2016 questionnaires.

One limitation of the 2014 cognitive interviewing study was that interviews were conducted in only one country. Because of this, it was unclear if question problems and variations in question interpretations were due to item wording or cultural context. In order to avoid that in the current evaluation, cognitive interviews were conducted in two locations—Lusaka, Zambia beginning in January of 2019 and Rabat, Morocco beginning in February of 2019. (A third location—Mumbai, India—was planned, but funding and logistic issues prevented the cognitive interviews from taking place.)

The overall goals of this round of cognitive interviewing were to continue to understand how VA items are understood by respondents, the extent to which proxy respondents know the information about the decedent that is requested during the VA interview, and whether and how the respondents understand the medical and health-related terms used throughout the VA questionnaires.

Not all of the VA questionnaires’ item were probed during the cognitive interview, due largely to time constraints. Rather, a specific sub-set of questions were evaluated by the cognitive interviewers. This

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1 Scanlon and Nichols. 2015
report will present a question-by-question analysis of those items. The full VA questionnaires are available from the WHO’s website².

METHODS

Cognitive Interviewing Methodology and the Question Response Process

Cognitive interviewing is a qualitative method whose purpose is to evaluate survey questionnaires and determine which constructs the questionnaires items capture³. The primary benefit of cognitive interviewing over non-qualitative evaluation methods is that it provides rich, contextual data into how respondents interpret questions, apply their lived experiences to their responses, and formulate responses to survey items based on those interpretations and experiences. Thus, cognitive interviewing data allows researchers and survey designers to understand whether or not a question is capturing the specific social constructs they originally wanted and gives insight into what design changes are needed to advance the survey’s overall goals. Additionally, the documented findings of cognitive interviews provide data end users the context needed to more fully understand the quantitative trends that emerge from survey data.

The underlying theory that directs the conduct of cognitive interviews is that of the question response process. Individuals typically interpret survey questions through a four-step process: They first comprehend the underlying construct, then recall the information needed, judge their answer, and finally map their answer onto one of the available response categories, as visualized here in Figure 1.

![Figure 1: The Basic Question-Response Process Model](https://example.com/figure1.png)

In reality, these four stages of response are not always in the exact order shown in the basic model, and often respondents either jump around (by, for instance, considering the response categories before judging what they should or should not report on the survey) or repeat steps (if they decided to try and recall new information after they’re judged what they should or should not report on the survey). Additionally, some respondents skip steps in the model, and provide a response to the question that does not necessarily take all the constructs and information provided in the question text or instructions into account (often simply basing their answer on a personal characteristic, or perceived personal characteristic, such as health

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³ Miller et al 2014
⁴ Tourangeau 1984
status). Nonetheless, the overall goal of cognitive interviewing is to uncover the specific ways respondents perform each of these four steps.

Cognitive interviews are typically administered as one-on-one, in-depth, semi-structured qualitative interviews. Respondents are first asked survey items, and then probed about their answers and the thought processes behind them. These targeted probes attempt to ascertain exactly which constructs the respondents are considering, and how they are judging and formulating their response. This semi-structured design uncovers not only these constructs, but also question response problems that are difficult to observe directly in a survey environment—including interpretive errors and recall inaccuracy.

Cognitive interviewing projects use purposive samples that focus on respondents that have specific characteristics—such as race, education, or occupation—that are assumed to be relevant to the questions being evaluated. When studying questions related to causes of death, for instance, the sample would likely consist of both individuals answering about decedents of varying ages, genders, and illness histories, allowing for the discovery of both false positive and false negative answers. Because of the limited sample size, not all demographic or occupational groups can be covered in the sample, and the analysis of cognitive interviewing does not provide generalizable findings in a statistical sense.

The analysis of cognitive interviewing data involves the iterative synthesis and reduction of the findings—beginning with a large amount of textual data (the raw transcripts and notes from the interviews themselves) and ending with cognitive schemata and conclusions that serve the overall purpose of the study. A cognitive interviewing study’s goal is to produce a conceptual understanding of a question’s performance. This end analytic product is often best understood as a cognitive schema, examples of which are presented throughout this report and illustrated in a standard format. As shown in a prototypical cognitive schema below in Figure 2, the phenomenon or construct under consideration is shown on the left-hand side of the figure, and the various pathways respondents use to understand or judge this phenomenon branch off to the right. Each of these rectangles represent the different patterns of interpretation or judgement, depending on the individual schema, that respondents within the cognitive interviewing sample used when responding to a question. Occasionally, the actual survey answers that each of these patterns of interpretation produced across the sample are also shown and are represented by ovals to the far right-hand side of the figure.
Specific Methods

In the 2019 evaluation of the VA questionnaires, a purposive sample of 149 respondents across two sites—Lusaka, Zambia and Rabat, Morocco—was recruited to participate in cognitive interviews. An effort was made to create a sample with a range of decedent ages, so that all three questionnaires could be evaluated fully and in the same proportions for each location. Unfortunately, given the way respondents were recruited in Morocco, proportionally fewer respondents from that county received either the child or neonate questionnaire as compared to the Zambian sample. As a result, the final sample for this project is slightly skewed towards respondents who received the adult questionnaire, as shown in Table 1:

<table>
<thead>
<tr>
<th>Country</th>
<th>Adult</th>
<th>Child</th>
<th>Neonate</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morocco</td>
<td>45</td>
<td>20</td>
<td>19</td>
<td>84</td>
</tr>
<tr>
<td>Zambia</td>
<td>23</td>
<td>23</td>
<td>19</td>
<td>65</td>
</tr>
<tr>
<td>Total</td>
<td>68</td>
<td>43</td>
<td>38</td>
<td>149</td>
</tr>
</tbody>
</table>

Respondents in Zambia were sampled at a morgue in a city hospital. With the support of the Zambian government, verbal autopsies are conducted for all brought-in-dead (i.e. decedents who did not die in a hospital) in Lusaka. Cognitive interviewers recruited respondents from the pool of verbal autopsy respondents, and the cognitive interviews were conducted directly following the VA interview. In Morocco, verbal autopsies are conducted for non-hospital deaths at the Ministry of the Interior’s Vital Registration Office when family members come to register a death and obtain a burial certificate. Just as in Zambia, cognitive interviewers recruited respondents from this pool of VA respondents and conducted the cognitive interview directly following the VA. Incentives were not provided to respondents in either location. Depending on the respondents’ preference, interviews in Zambia were conducted in either English or Nyanja; in Morocco they were conducted in either French, and dialectical Arabic.
Cognitive interviewers entered their notes into CDC’s Q-Notes software\(^5\), which is a qualitative analysis program designed specifically for the storage and analysis of data from cognitive interviews. Following a week-long training course conducted by NCHS researchers, the local cognitive interviewers conducted the interviews over a period of four months (for Zambia) and one year (for Morocco). NCHS researchers were able to monitor the data collection and data quality via Q-Notes and communicated with the field teams when necessary to provide direction and assistance.

**FINDINGS AND ANALYSIS**

While the verbal autopsy instrument has changed since the previous cognitive interviewing project in Kenya in 2014, many of the same issues regarding measurement error remain. As detailed in the report for the 2014 work\(^6\), the quality of the verbal autopsy data appears to be related to:

1. The familiarity the proxy respondent had with the decedent’s history, particularly their medical history.

2. For questions asking about specific medical diagnoses, whether or not the respondent knew either the decedent’s medical history or knew the symptoms directly related to the illness or condition

**Respondent’s Familiarity with the Decedent**

As in any situation where a survey instrument collects data via proxy response, the final data quality relies heavily on how familiar the respondent is with the person they are asking about—in this case the decedent. In order to examine this effect, the cognitive interviewing sample included a range of relationships between the respondents and the decedents, as shown in Table 2:

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\(^5\) [https://wwwn.cdc.gov/qnotes](https://wwwn.cdc.gov/qnotes)

\(^6\) Scanlon and Nichols 2015
Table 2: Cognitive Interviewing Sample by Proxy Respondent Relationship and Country

<table>
<thead>
<tr>
<th></th>
<th>Morocco</th>
<th>Zambia</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aunt/Uncle</td>
<td>0</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Child</td>
<td>26</td>
<td>6</td>
<td>32</td>
</tr>
<tr>
<td>Cousin</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Grandparent</td>
<td>2</td>
<td>9</td>
<td>11</td>
</tr>
<tr>
<td>Niece/Nephew</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Parent</td>
<td>39</td>
<td>28</td>
<td>67</td>
</tr>
<tr>
<td>Sister/Brother</td>
<td>5</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>In-Law</td>
<td>6</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Spouse</td>
<td>2</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Unrelated Friend</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>84</strong></td>
<td><strong>65</strong></td>
<td><strong>149</strong></td>
</tr>
</tbody>
</table>

As previously described for the VA\(^7\), closer family members (i.e. spouses, parents of children, and close siblings and grandparents) were more likely to be able to provide substantive responses not only to the VA, but during the cognitive interview. When asked about the decedent’s medical history, for instance, close relatives were more likely to base their answer on whether or not the decedent had directly told them they had a condition or whether or not they had heard a diagnosis from a doctor directly. On the other hand, respondents less familiar with the decedent’s medical history had to either guess or use symptoms to answer questions about conditions in order to provide a substantive response; most of the “Don’t Know” responses across the VA items came from these respondents.

One specific area where proxy response’s effects on data quality is visible is in relation to maternal and gynecological health. Men—even close family members—answering about female decedents often did not know specifics about conditions and events related to menstruation or breast cancer. As a result, among the cognitive interviewing respondents, they were more likely to either answer “Don’t Know” to these questions or refuse to provide an answer.

**Knowledge of Medical Terms and Associated Symptoms**

The cognitive interviews explored a set of “diagnosis questions” wherein the respondent was asked about whether the decedent had received a diagnosis (or test result) for a specific condition. Questions about

\(^7\) Scanlon, Paul. 2015.
HIV, dengue fever, COPD, and dementia were probed as part of the cognitive interviews. Overall, respondents used a similar set of response patterns across these questions, illustrated in the schema in Figure 3:

Across the questions asking about the decedent’s diagnoses, respondents largely based their answers either by considering whether or not the decedent had received a medical diagnosis of the condition or disease or by considering whether or not the deceased had symptoms the respondent believed to be related to the disease.

In the first case—basing their answer on the condition or disease itself—respondents considered whether they had knowledge of an affirmative diagnosis of the condition by a medical professional. This pattern of interpretation appears to elicit the exact information about which the questions ask and does not appear to be susceptible to response error. However, some respondents confused or conflated the disease under question with another condition—so even though they were answering on the basis of a diagnosis, they were thinking about the wrong disease. This was particularly common in the question about dengue fever (Question 10130, see below), where respondents were equating dengue and yellow fever.

Other respondents did not focus on an “official” diagnosis of the disease under question, but rather based their answer on whether the decedent displayed signs or symptoms the respondent believed to be related to the disease. For instance, many respondents understood COPD (Question 10138) to be a respiratory disease, and thus considered whether the person they were answering about presented any symptoms related to lung issues such as wheezing or difficulty breathing. However, not all respondents correctly paired symptoms with the disease under question—for instance, believing that COPD presents with a fever. Instances such as this are likely to produce response error.
Question-by-Question Analysis

Unless otherwise noted, the questions were tested in both Zambia and Morocco and were administered to respondents answering about male and female decedents.

**ID10090**

**ENG:** Was (s)he subject to violence (suicide, homicide, abuse)?

**FRN:** Est-ce qu’il (elle) a été soumis à une violence/agression?

**ARB:** ظُحِمت (القتل، الاعتداء، الانتحار)؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

Question ID10090 is included on both the adult and child questionnaires.

Respondents across both countries appeared to understand the question to be asking about whether the decedent had been attacked or assaulted. No instances of potential suicide emerged across the sample, so the question of whether respondents equate suicide with “violence” remains unanswered.

Most respondents in both Zambia and Morocco understood this question as if it had no reference period—that is, they answered whether the decedent was ever subject to violence, but only two respondents answered yes. This included one potential false positive response, where a respondent from the Morocco sample answered “yes” and explained that his relative had been in an aggressive traffic accident about four years prior to death. The decedent had not been subject to violence any time more recently. The other respondent who answered “yes” to this question was thinking correctly about violence as the proximate cause of death, reporting that the decedent was found with gouges across his face.
ID10099  ENG:  Was the injury self-inflicted?
FRN:  Est-ce que vous pensez qu’il (elle) s'est suicidé?
ARB:  واش كانت الإصابة أو الحادث بسبب انتشار؟

1.  Yes
2.  No
77.  [Don’t Know]
99.  [Refused]

Question ID10099 is included on both the adult and child questionnaires. Only two respondents answered “Yes” to ID10090 and went on to receive ID10099. The respondent who provided the potentially false positive response to 10090 reported that he did not know whether the injury was self-inflicted, thinking still about the traffic incident. The respondent to 10090 who was thinking about the violent death reported “No,” explaining that the decedent was apparently beaten to death by unknown people.

ID10120_unit  ENG:  For how long was (s)he ill before death?
FRN:  Pendant combien de temps était-il (elle) malade avant de mourir?
ARB:  شحال المدة اللي بقى فيها مريض(ة) قبل ما يتوفى؟

1.  Days
2.  Months
3.  Years
77.  [Don’t Know]
99.  [Refused]

Question ID10120_unit is included on all three questionnaires and was administered to all respondents. Interpretative variation emerged across the sample and across the countries, with respondents not agreeing on what “counts” as the illness asked about in this question. Practically speaking, this variation in interpretation has large down-questionnaire effects, as a number of the following questions ask directly about “the illness that led to death” (for instance, Question 10179 asks “During the illness that led to death, did his/her breathing sound like any of the following?”).

Five major patterns emerged across the respondents’ interpretations of this question, as diagramed below in Figure 4.
First, two separate patterns emerged across the respondents who answered the question “0” days or months. Some respondents understood their answers to indicate that the decedent was never sick and died suddenly or due to something other than an illness (i.e. violence), others took their “0” answer to mean that the decedent was sick for less than a day. For example, one respondent from Zambia who answered “0” indicated that the death of his housemate was related to violence, and not illness. The interviewer notes for this respondent explain:

*He left home the day before he was found dead saying he has gone for work, but he never came back until next day when he was found dead beside the railway line. [The deceased] was found with a deep cut on his forehead, injuries on belly button and his back. R said that he suspects that maybe [he] was beaten on his way home when coming back from drinking because he used to be an alcoholic.*

Similarly, respondents used an answer of “0” to indicate other sudden deaths that were seemingly not related to illness. For instance, a respondent from the Morocco sample answered “0” to this question and while he noted that his father had chronic hypertension, it had been diagnosed years ago and well treated. The notes for this respondent explain:

*The decedent was very active and in good health, it was a sudden death. After lunch with the family...the decedent went to his room for a nap, woke up at 16:30 and went back to sleep, and then died in his sleep.*

Other respondents, all from the Zambia sample, used a “0” answer to Question 10120 to indicate not that the death was not due to an illness, but rather that the symptoms of the illness lasted for less than a day. For instance, one father answered “0” and explained that his toddler son was given vaccines one day, cried that night and had a fever and turned pale, and died the next morning. This father clearly believed that his son was sick from some sort of vaccine-related symptom, but that he was ill for less than a full day.

Besides these two patterns relating to a “0” answer, respondents interpreted the scope of the illness that Question 10120 asks about in three distinct ways: by considering the length of the final severe symptoms,
the length of the final illness or condition, or how long ago a decedent had been diagnosed with a long-term or chronic condition.

Respondents using the first of these patterns—considering the length of the final, severe symptoms that the decedent suffered did not think about the full length of the decedent’s final illness, but rather the duration of the severe symptoms that directly proceeded death. For example, one respondent in Zambia explained that her husband had a severe cough and occasional fevers for the two weeks preceding his death. However, upon probing, she revealed that he had been suffering from coughs during the cold season since 1983, but that for this question she was focusing on the final bout of symptoms. Likewise, a woman from the Morocco sample answered “1 day,” and explained that her brother-in-law had chest pains the day before and morning of his death. She noted that the decedent had a heart attack in 2002 but did not base her answer on the length of time he had heart disease.

This pattern was particularly common for respondents answering about children or neonates, as shown below in Figure 5. For instance, one mother from the Zambia sample explained that her son had been anemic for months. However, she answered this question “14 days,” and noted that she was thinking about the previous two weeks when he had been vomiting, having night sweats, and suffering from diarrhea. Another respondent from Zambia noted that her niece was sick for three days and was considering the duration of the baby girl’s symptoms, not a specific illness or malady, since she was not taken to a doctor for a diagnosis until the day she passed. The notes from this respondent explain:

R said that [the deceased] had been ill for three days, when she started coughing and had difficulties breathing. There was no diarrhea, fever, or rash, and [the decedent] was never taken to the hospital until today, when her condition worsened, and she started foaming at the mouth.

Other respondents did not focus on the final symptoms, but rather the length of the final illness. For instance, a father from Zambia sample who answered “2 months” explained that his baby had been sick for about two months, when he started displaying signs of malaria. While the tests at the hospital were negative for malaria, the doctors indicated that he had some sort of a stomach condition and was given oral salts for rehydration. The symptoms varied in intensity over the next two months, but never went away. These symptoms got worse in days leading to his death, and the family returned to the hospital where the child died. So, in this case, unlike the respondents using the previous pattern (who would have based their answer on these last few days of severe symptoms), this father answered based on the full length of what he perceived to be the underlying illness. Similarly, a respondent from the Morocco sample who answered “7 months,” noted that her mother became sick about seven months prior to death, following Ramadan, and had difficulty walking and moving throughout this period. While her mother’s
condition worsened in the two weeks preceding her death, the respondent interpreted the question to be asking about the full length of the illness.

In a few neonate cases, respondents did not differentiate between the length of the symptoms, the illness, and the baby’s life as they were all functionally equivalent. For example, one mother in Zambia answered “4 days” and explained that her 4-day-old son had been sick since he was born and was always feverish and disinclined to nurse.

The final pattern of interpretation, used almost exclusively with respondents answering about adult decedents, was to consider how long a person had a chronic or long-term illness that probably contributed to their death. For instance, one woman from the Morocco sample answered “5 years” and noted that her mother had been diagnosed with colon cancer. This respondent’s notes explained:

[The decedent] had colon cancer diagnosed in 2014. She was operated on several times and had several chemotherapies. The cancer spread to other organs. Four days prior to death, the decease suffered from a fever and the respondent noticed wheezing/whistling.

So, while there were severe symptoms in the decedent’s final four days, this respondent based her answer on the full duration of a diagnosed long-term condition.

The distribution of these patterns in the cognitive interviewing sample is not consistent across the three questionnaires, as shown below in Figure 5. While most respondents who answered the neonate and child questionnaires focused on the final symptoms, and not the duration of the final illness or any long-term condition, the distribution of the interpretative patterns is more consistent across the respondents who answered the adult questionnaire. This indicates that, in the cognitive sample at least, that Question 10120 in the adult questionnaire is likely capturing a different construct than the same question in either the child or neonate questionnaire, and that even within adult questionnaire-respondents the question is not reliably producing comparable data. As additional questions in the verbal autopsy instruments refer back to the duration established in this item, the interpretative variation described here may also affect the reliability of the entire instrument’s data across verbal autopsy respondents.
Questions ID10126 and ID10127 were included on all three questionnaires and were only included as part of the cognitive testing in Morocco. All respondents who received 10126 and 10127 answered either “No” or “Don’t Know;” no respondents across the sample answered “Yes.”
One of the research questions surrounding this item was whether it asked for such sensitive data (in the Moroccan context) that people would be hesitant to either answer or provide truthful responses. The analysis of the cognitive interviews does not indicate that this sensitivity was an issue, with no item non-response or indication of negative behavioral responses to the question (or the following one, Question 10127, about a diagnosis of AIDS). Rather, respondents appeared willing to not only provide an answer, but also to answer a follow-up probe from the cognitive interviewers.

Another research question regarding this item is the quality of the data, and whether the information it asks about is something that proxy respondents can accurately provide. Here, the evidence is mixed. Two patterns of response emerged across the cognitive interviews for both Questions 10126 and 10127, as diagramed in the schema below in Figure 6.

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Figure 6: Patterns of Judgement for Questions 10126 and 10127
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Some respondents based their answers to whether the decedent had received a positive HIV blood test or been diagnosed with AIDS on direct knowledge. For example, one respondent who answered “No” to 10126 explained that she was her late husband’s medical decision-maker for the final few years of his life, and had seen his entire medical record and was told when new test results came in. Other respondents answered the questions “Don’t Know” because they did not have direct knowledge. For instance, the notes for one woman answering about her brother-in-law explain that while she may believe the answer is no, she did not know for sure and thus answered “Don’t Know”:

> According to the respondent, the brother-in-law did not suffer from a contagious illness such as AIDS. But she was not sure whether or not there had been a positive result or laboratory diagnosis.

Across both questions most respondents in the sample based their answers on assumptions, instead of direct knowledge about blood tests or diagnoses. In many cases, these assumptions seem logical and valid on their face, and no obvious cases of response error emerged. For example, one respondent who was answering for his deceased brother answered “no” and provided a logical explanation of his answer.

The cognitive interviewing notes detail:
The respondent explained that the deceased was a retiree of [a public corporation]. As such, he would have a systematic, periodic checkup offered to all employees of the institution. Also, the deceased often donated blood.

In this case, the respondent assumes that because the decedent regularly gave blood, which would not be possible if his brother had HIV, he must not have ever received a positive result.

It is important to emphasize here that while this second pattern of judgement—basing an answer on a (typically logical) assumption—was more common in the cognitive interviewing sample, because the Moroccan sample was heavily skewed towards adult decedents, it is unclear if this distribution would hold across a sample more evenly distributed by age.

**Question ID10130**

ENG: Was there any diagnosis by a health professional of dengue fever?

FRN: Y a-t-il un diagnostic de la fièvre de dengue par un médecin ou un professionnel de santé?

ARB: واش كان شي تشخيص ديات دينق داً مرض الضنانك من طرف مهني صحي؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

Question ID10130 is included on both the adult and child questionnaires. Dengue fever is rare in Morocco and Zambia; although it is endemic in tropical and sub-tropical Africa, and the CDC suggests there is a risk for transmission in Zambia. Respondents expressed widespread confusion across both countries about this question, and largely adhered to the general “diagnosis” schema presented in Figure 3 on page 7 above.

Most respondents expressed that they either did not know what dengue fever was or that they had never heard of the disease. For instance, the notes for one respondent from the Morocco sample who answered “no” state:

*The respondent did not understand and does not know what dengue is. The deceased did not experience any rash accompanied by fever and the respondent could not recall this symptom ever occurring.*

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The cognitive interviewers were instructed to probe on the individual symptoms retrospectively, although in a few cases the verbal autopsy interviewers attempted to provide a definition and a list of symptoms to the respondents during the original verbal autopsy interview. For instance, one respondent in Morocco answered “No” after initially expressing confusion to the verbal autopsy interviewer, who then provided a list of symptoms, as detailed in this respondent’s notes:

The respondent asked [the VA interviewer], “Is there a difference between dengue fever and yellow fever?” He [the interviewer] said, “Yes there is a difference” and gave the respondent example symptoms. Then she said no. I [the cognitive interviewer, later] asked “what is yellow fever?” to her, and she said this is when the eyes become yellow. It was difficult for the respondent to know the difference between Dengue fever and yellow fever. The respondent only understood dengue fever after translations and giving examples.

Confusing and conflating dengue fever with other diseases—primarily yellow fever, malaria, and sickle cell anemia—was common, and in a few cases led to false positives. Across all the cognitive interviews, only five respondents answered “Yes” (all from Zambia). All of these appear to be false positives. For example, one respondent who was answering about a friend and answered “Yes” explained that the deceased had a fever. Upon further probing the respondent explained that the decedent had a negative malaria test, so he figured that dengue fever was the name of the fever that his friend suffered from at the end of his life, although he also admitted to not knowing what dengue fever was. However, when asked about other symptoms related to dengue—such as a rash—the respondent said that his friend did not have these. Similarly, another respondent who answered “Yes” appeared to think that dengue fever was the result of malaria, which his father had been diagnosed with.

ID10138  ENG:  Was there any diagnosis by a health professional of Chronic Obstructive Pulmonary Disease (COPD)?

FRN:  Y a-t-il un diagnostic par un médecin ou un professionnel de santé de maladie pulmonaire Obstructive chronique (MPOC)?

ARB:  واش كان شي تشخيص ديال مرض الانسداد الرئوي المزمن من طرف مهني صحي؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

Question ID10138 is included on both the adult and child questionnaires. This question follows a similar response pattern as that of Question 10130 above and the general “diagnoses” schema presented in Figure 3 on page 7. As compared to the question about dengue fever, fewer respondents expressed confusion
over COPD, and most respondents either considered whether they knew about an affirmative diagnosis of the condition by a physician or whether or not the descendent had lung or respiratory issues.

Respondents thinking specifically about whether they could affirm a diagnosis of COPD often explained their answer by either explaining what other diagnoses the decedent had. For instance, one respondent from the Morocco sample who answered “No” and was reporting about his sister-in-law noted that she had been diagnosed with other respiratory diseases, specifically asthma, but that she had never been told that she had COPD and furthermore that she did not smoke—which the respondent conceptually tied to COPD. Many of these respondents who answered based strictly on whether they knew of a diagnosis did not consider symptoms at all. For instance, one respondent from the Zambia sample who answered “No” about her husband explained that the doctor never “mentioned anything about COPD,” but did tell the decedent to reduce his alcohol and tobacco consumption.

Other respondents based their answer on whether the decedent displayed any symptoms they understood to be related to COPD. For example, two respondents from the Morocco sample—one reporting as a father and the other reporting as a husband—based their “Yes” responses on the fact that their child had noticeable breathing issues in the period immediately preceding their death, and not on whether or not they knew about an affirmative diagnosis of COPD. The notes for the husband, answering about his 84-year-old wife, states:

She [the wife] had very short/quick breathing, especially at night, during the last 15 days before her death.

Similarly, the father explained the “Yes” response for his 2-year-old son by noting his breathing issues near the end of her life. The cognitive interviewer wrote the following explanation for this response:

The deceased suffered from seizures since his birth, and he was under treatment and monitored by a neurologist. He was hospitalized 1.5 months before his death and suffered from respiratory distress 20 days before his death. The deceased in intensive care and was on artificial respiration in the last days of his life.

Both of these respondents appeared to comprehend COPD as a respiratory disease and based their answer not on the fact that they had heard about an actual diagnosis of COPD, but rather because the decedent had lung issues. This approach can lead to response errors—for instance, it is unclear if either of the two decedents described above had COPD or some other lung/respiratory issue. However, the problem of response error becomes clearer when the respondent does not correctly associate symptoms with COPD. For instance, one respondent from the Zambia sample answered “Yes” to this question and noted that his father was sick for over two years, was bed-ridden, and had sores on his hips. When asked to explain
why he said “Yes” to this question, the respondent spoke about blood tests. As the cognitive interviewer reported:

_The respondent did not understand what COPD involves. As he mentioned that since blood samples were collected from the deceased for tests, he assumed that COPD is verified through the blood._

This is clearly a false positive response and illustrates the risk of asking respondents about specific diseases—which requires them to have some level of knowledge about how the disease presents and is diagnosed—instead of limiting questions to symptoms.

**ID10139**

**ENG:** Was there any diagnosis by a health professional of dementia?

**FRN:** Y a-t-il un diagnostic par un médecin ou un professionnel de santé de démence ?

**ARB:** واث كان شغ تشخيص ده مرض الخرف من طرف مهنئ صحي؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

Question ID10139 is included on both the adult and child questionnaires. The response pattern for this question generally follows the other questions about diagnoses above, as described in Figure 3 on page 7.

Most respondents across both countries in the cognitive interviewing sample related dementia to cognitive issues, most commonly basing their answers on whether the decedent had memory loss. A few respondents based their answers on other mental health symptoms—such as aggression, hysteria, and psychosis. For instance, one respondent from the Zambia sample who answered “Yes” about his friend was thinking about aggression and mental confusion. This issue of thinking about dementia as psychological symptoms beyond memory loss was only observed in Zambia and may be related to attempts to translate the questionnaire “in the field” from English to Nyanja. For instance, the interviewer for the above false positive response detailed the following in the notes:

_[The deceased] was never diagnosed with dementia. It sounds like he did have mental health issues, but the Respondent does not know if he was diagnosed with anything. Also, there may have been confusion about differences between dementia and confusion because the word is difficult to translate in Nyanja. The respondent confused memory loss with mental confusion, as he said the deceased used to wake up in the night asking and looking for the knife and he wanted to cause violence in that he was saying he wanted to stab someone. When asked if the deceased was diagnosed with mental confusion by a health profession, the respondent said he would not really know if the deceased was diagnosed with the mental problem by a health profession because he only_
stayed with the deceased for two years and the that problem of waking up trying to look for a knife to stab someone had started even earlier when the deceased used to stay with his sister. After that the respondent was given examples of what dementia is, he was asked if he thinks the deceased had dementia he said yes because the deceased could forget people’s names. The conclusion is that the deceased might have had both dementia and mental confusing, even if the respondent failed to distinguish the two concepts.

Likewise, another interviewer noted translation issues when explaining a “Don’t Know” answer by a woman from the Zambia sample answering about her husband:

The respondent did not understand the question, she asked ‘What do you mean by dementia’ Then the interviewer asked her, ‘What do you think it is?’ The respondent said that ‘What came to my mind is that maybe dementia is a name of person’. Then after giving her examples of dementia in the local languages, she said no, actually the deceased had a very good memory and never used to forget people. The question was only understood by the respondent after translations of what dementia is, in the Zambian contexts by using examples. Based on the answers from the respondent it shows that he did not know if the deceased was diagnosed with dementia.

This issue did not appear in the notes from Morocco, indicating that the translation from English to either French or Arabic is less problematic than the translation into Nyanja. Additionally, translation into Nyanja occurred during the interviews themselves, so it is possible that a fully translated questionnaire may have avoided this issue. Further research into the validation of these translation issues may be needed.

**ID10173**

**ENG:** During the illness that led to death did his/her breathing sound like any of the following:

1. Stridor
2. Grunting
3. Wheezing
4. None of the above
77. [Don’t Know]
99. [Refused]

Question ID10173 is included on both the child and neonatal questionnaires. Respondents all focused their answers directly on the symptoms under question and did not base their answers on whether the decedent had been diagnosed with diseases that led to these symptoms. For instance, one woman from the Morocco sample answering about her son answered “No,” but in the cognitive interview noted that he
had been diagnosed with asthma—he just had not exhibited any of the sounds asked about in Question 10173 in the period preceding his death.

As to the individual sounds asked about in Question 10173, there appeared to be varying levels of comprehension across the respondents. “Wheezing” and “grunting” were well-understood across both countries (and across all four interview languages of English, Nyanja, French, and dialectical Arabic). A number of respondents who affirmed either of these sounds were able to explain their origin and demonstrate them for the interviewer. For instance, one respondent from the Zambia sample who answered “Wheezing” was able to demonstrate the sound to the cognitive interviewer, who reports in the notes that:

[The respondent] understood the question and said the baby was wheezing in the early hours of today. She then demonstrated how the baby was breathing, which sounded like wheezing.

Likewise, a grandmother from the Zambia sample answering about her deceased granddaughter answered “Grunting” and both explained that the sound began the night before death and demonstrated the sound to the cognitive interviewer.

On the other hand, “stridor” appeared to be completely unknown to the respondents in the cognitive interviewing sample. No respondents chose it as an answer, and many cognitive interviewers noted that it had to demonstrated during the verbal autopsy interview.

<table>
<thead>
<tr>
<th>ID10188</th>
<th>ENG: Did (s)he vomit?</th>
</tr>
</thead>
<tbody>
<tr>
<td>FRN:</td>
<td>Est-ce qu’il (elle) avait des vomissements?</td>
</tr>
<tr>
<td>ARB:</td>
<td>واش تُقَي (ت)?</td>
</tr>
</tbody>
</table>

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

<table>
<thead>
<tr>
<th>ID10189</th>
<th>ENG: To clarify: Did (s)he vomit in the week preceding the death?</th>
</tr>
</thead>
<tbody>
<tr>
<td>FRN:</td>
<td>A-t-il vomi au cours de la semaine précédant le décès?</td>
</tr>
<tr>
<td>ARB:</td>
<td>واش تُقَي (ت) في الأسبوع الذي سبق الوفاة؟</td>
</tr>
</tbody>
</table>

1. Yes
2. No
Questions ID10188 and ID10189 are included on both the adult and child questionnaires. They were probed together during the cognitive interviews.

Overall, the questions captured slightly different constructs, with most respondents understanding Question 10188 (“Did s/he vomit?”) as asking about whether or not the decedent vomited in the immediate period before death—which varied from the hours before death to a few weeks; whereas they understood Question 10189 to be asking about the exact week before death. For example, one respondent from the Zambia sample who answered “No” to both questions explained that while her toddler son had vomited in his life, he did not do so in either the period he was sick (a few days) or the week before his death.

This discrepancy is most clear when considering the 20 respondents who provided different answers to the two questions (n=8 No to 10188/Yes to 10189, n=4 No/Refuse, n=5 Yes/No, n=3 Yes/Refuse). For instance, one respondent from the Morocco sample who answered “Yes” to 10188 but “No” to 10189 explained that for the first question, she was considering the whole time her husband was receiving treatment for his cancer and noted that the chemotherapy made him vomit. However, he had a very reduced diet in the last weeks of his life, and thus did not vomit in the week preceding his death. Similarly, a respondent from the Zambia sample answering about his brother who also said “Yes” to 10188 but “No” to 10189 explained that while his brother vomited frequently during his illness, he did not do so in the final days of his life.

However, because no reference period was given in the question text for 10188, and respondents largely understood it to be asking about the period of the final illness, there were other cases where 10189 (with a set reference period of a week) represented the longer period of time than 10188. For example, one respondent from the Morocco sample answering about her uncle noted that he stayed with her during his final few days of life, when he was very sick. And in that time the decedent did not vomit. However, the respondent went on to explain that her uncle did vomit in the last week of life—just not in the final three days that she was thinking about for the first question.
Questions ID10193, ID10194, ID10200, and ID10204 are included on both the adult and child questionnaires and were probed together during the cognitive interviews. The research question behind
this approach was whether or not it is necessary to ask all four questions of all respondents, or if their answer to Question 10193 could be used a controlling “gateway” question that either skips respondents into or past the other abdomen questions. A simple way of examining this is to explore whether Question 10193 produces false negative responses—i.e. respondents answer “No” to that question, but “Yes” to one of the other three—and why.

Across the cognitive interviewing sample, only two respondents who answered “No” to Question 10193 went on to answer “Yes” to 10194, 10200, or 10204—and probing reveals that in these cases, the answers to 10193 are not clear-cut examples of response error. This first respondent—a mother from the Zambia sample answering about her 4-month-old daughter answered “Yes” to 10200, indicating that the decedent had a protruding belly, even though she said that the child did not have a belly problem, which she indicated she understood as a stomach illness or condition. The notes explain her thinking for her “Yes” response to 101200, and reveal that she thought the cause of the protrusion was related to constipation:

Yes, the baby had a protruding belly in the last 3 days before death. [The respondent] said this was observed in a period when the child was failing to go to the toilet. She was asked do you think this kind of protrusion was due to sickness or because of failure to go to the toilet. She said this can’t be sickness because the baby had not been going to the toilet, so she thinks this is due to that problem of not going to the toilet. That’s why the belly was protruding.

So, in this case the respondent appears to think that the stomach protrusion does not count as a “belly problem” for Question 10193, since she believes it is not related to illness per se.

The other respondent who answered “No” to 10193 but “Yes” to one of the other three questions was a father from the Zambia sample answering about his 5-month-old daughter who answered “Yes” to the belly pain question (10194). The notes for this respondent’s answers to 10193 and 10194 are shown below:

[Question 10193]: “My baby was okay unless we just didn’t know about it. You just know babies, it’s difficult to know but I believe if she had any problem, she would have been expressing her pain through crying, but I did not notice anything. The only belly problem I heard her mother talking about is the usual stomach problem babies have when they are born.” When asked what these usual stomach problems are, the respondent said when a baby is born, they have digestion problems because its stomach is not used to any type of food, so they have stomach problem.

[Question 10194]: “She had usual digestion problems every baby has especially, during the first 3 months.” When asked how he knew that [the decedent’s] belly pains were the usual belly problems, he said that every baby experiences these pains in the first 3 months of their lives because they are still adjusting to the food that they are being fed. When asked if they had taken [his daughter] to the hospital, he said, “No I have 12
children, and they all experienced the same problem. Even if we took her to the clinic, we were just going to be told to breastfeed her frequently."
In this case, the respondent appears to be interpreting 10193 as asking about serious belly or stomach problems, whereas he does not interpret 10194 as having the same standard. In his explanation of his “Yes” response to 10194, the respondent seems to argue that all children have this stomach pain, so it is rather unremarkable—a point which is validated by his explanation of his response to 10193, wherein he explicitly said that he did not notice the baby crying, which to him indicates pain.

Besides these two respondents, all other respondents who answered “No” to 10193 went on to answer “No” to the other abdomen questions. Furthermore, all respondents who answered “Yes” to 10193 also answered “Yes” to at least one of 10194, 10200, or 10204—indicating that these three questions function as follow-up questions that can provide greater detail on the specific abdomen problem from which the decedent suffered.

As to the individual constructs that Questions 10193, 10200, and 10204 capture, respondents across both countries appeared to have consistent interpretations of “pain,” “protrusion,” and “mass,” respectively. For pain, respondents most often considered whether the decedent cried (for children) or spoke about pain (for adult decedents). Respondents understood “protrusion” as a swelling or enlargement of the belly or stomach. For instance, one wife from the Morocco sample who answered “Yes” to 10200 explained that her husband’s stomach swelled about 6 months prior to his death, and that he was subsequently diagnosed with cancer. Respondents understood “mass” to be an internal growth, such as a tumor. For example, one respondent from the Morocco sample who answered “Yes” to 10204 noted that his father had multiple tumors in his intestine, which caused swelling and eventually external hardening before his death.

ID10212

ENG: Did (s)he have mental confusion?

FRN: Est-ce qu’il (elle) avait une confusion mentale?

ARB: واش كان عندو (ها) إضطراب عقلي؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

Question ID10212 is included on both the adult and child questionnaires.
A relatively broad interpretation of “mental confusion” emerged, with respondents considering symptoms and signs such as:

- Ability to communicate logically and clearly
- Awareness of surroundings
- Consciousness
- Memory loss
- Recognition of familiar people, such as family and close friends

Of these, memory loss and ability to communicate clearly and logically were most common across the cognitive interviewing sample. However, two cases of potential response error emerged, both involving a description of communication issues of decedents from the Zambia sample. In the first case, the decedent commonly yelled incoherently and did and said illogical things. However, the respondent answered “No,” and explained that he was thinking about whether his aunt was diagnosed with a mental disease, as relayed in the interviewer’s notes:

_The respondent said that the deceased did not have mental confusion, as she only used to yell and shout and do things that did not make sense. But it was normal [behavior] for the deceased, and she was not “mentally mad.” The respondent was asked what could have led to the yelling, and he answered that maybe it was because of the malaria she had. He said he did not know if the decedent had mental confusion, because she was not diagnosed with such._

In a similar fashion, another respondent from the Zambia sample answered “No,” but went on to explain that while she did not think that her cousin had any mental confusion, she did begin to say incoherent things in the final hours of her life. In both of these cases, the respondents mentioned specific issues that the decedent had communicating but did not count those symptoms towards “mental confusion.”

However, other respondents—particularly from the Morocco sample—cited their decedents’ abilities to communicate clearly and logically as evidence that they did not have mental confusion. For instance, one man from the Morocco sample answering about his deceased aunt answered this question “No” and explained that because he had regular and coherent conversations with her, she was not mentally confused.

**ID10223**

**ENG:** Did (s)he have any urine problems?

**FRN:** Est-ce qu’il (elle) avait des problèmes d’urine?

**ARB:** واق كان عندو(هما) مشاكل في البول؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]
Question ID10223 is included on both the adult and child questionnaires.

Much like the previous question about mental confusion, respondents considered a wide range of symptoms and signs of urination problems—all of which appear to be in-scope. These include:

- Blood in the urine
- Difficulty urinating
- Discoloration of the urine
- Incontinence
- Pain while urinating

There was some variation in which symptoms respondents considered based on the age of the decedents. Specifically, respondents answering about young children commonly considered whether the child had difficulty urinating or urinated at all. For example, the notes of one mother from the Zambia sample describe:

*The respondent understood urine problems to mean a failure to pass urine. She said that the deceased [the respondent’s 6-month old daughter] did not have any urine problems, as she was able to pass urine before her death. “My daughter’s death was sudden—everything about her was ok.”*

Although the various interpretations used by the cognitive interview respondents appear initially to be in-scope, there is a potential for response error if respondents limit their thinking to one of these, while excluding others. For example, one father from the Zambia sample answering about his child answered “No” and explained that he did not see blood in her urine. However, upon further probing he revealed that the decedent did not urinate in the days prior to her death, but that neither he nor his wife thought about this as a problem at the time. It is possible that use of broad terms such as “problems” may have resulted in response error such as this.

**ID10227**

ENG: Did (s)he have sores or ulcers anywhere on the body?

FRN: Est-ce qu’il (elle) avait des plaies ou des ulcères sur le corps?

ARB: واش كان(ت) عندو(ها) قروح أو تقرحات في الجسم؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]
ID10230  ENG:  Did (s)he have an ulcer (pit) on the foot?
FRN:  Est-ce qu’il (elle) avait un puits de l’ulcère du pied?
ARB:  واشت كان(ت) عندو(ها) قرحة (حفرة) في الرجل ديانو (ها)؟

1.  Yes
2.  No
77.  [Don’t Know]
99.  [Refused]

Questions ID10227 and ID10230 are included on both the adult and child questionnaires and were probed together during the cognitive interview. Much like the research question surrounding items ID 10193, 10194, 10200, and 10204 (about stomach issues) above, these two questions were included on the cognitive interview in order to understand whether Question ID10227 could effectively skip respondents into or out of 10230, or whether asking both to all respondents is necessary.

Only one case emerged across the cognitive interviews where a respondent answered “No” to 10227, but “Yes” to 10230. In this instance, a daughter from the Morocco sample said that the decedent (her 61-year-old father) did not have any sores on his body but did develop some on his foot in the final days of life. It appears that this case is one of response error—as they said the decedent “did not have any skin problems on his body,” but then a few moments later explained that the foot ulcers began developing in last day or two life.

Beyond the research question of whether Question 10227 could be used to control the skip pattern into 10230, the terms ulcers and sores were consistently understood across both counties’ respondents. When talking about sores, most respondents described skin areas that have been rubbed raw, such as bedsores. Respondents described ulcers as pit-like or sores that display as holes in the skin.

ID10237  ENG:  Did (s)he ever have shingles or herpes zoster?
FRN:  Est-ce qu’il (elle) a déjà eu le Zona ou l’herpès zoster?
ARB:  واشت قايت فيه(ها)شي مرة مرض الزوتنا؟

1.  Yes
2.  No
77.  [Don’t Know]
99.  [Refused]
Question ID10237 is included on both the adult and child questionnaires.

While some respondents appeared to have heard about shingles, caused by the herpes zoster virus, a large proportion of the cognitive interviews revealed that these terms were unknown. As a result of this unfamiliarity, most respondents who provided a “No” response (2 cognitive interview respondents answered “Yes,” with another six answering “Don’t Know”) based this answer on the “affirmative diagnosis” pattern of interpretation in the general diagnosis question response schema illustrated in Figure 3. The basic approach in the case was that these respondents never heard the decedent specifically say that they had been diagnosed with herpes zoster or with shingles; they therefore answered “No.” For example, one woman from the Zambia sample answering about her cousin answered “No,” and went on to explain that her cousin had never mentioned having shingles or herpes. The two respondents who answered “Yes” also used this pattern and thought about specific instances when the decedent was diagnosed with shingles. For instance, one respondent from the Morocco sample answering about his mother noted that she had shingles in her eye and hair a long time ago, which was diagnosed and treated by a dermatologist.

Some respondents who expressed unfamiliarity with the disease or virus, or with this particular aspect of the decedent’s medical history, answered “Don’t Know.” For example, one woman from the Morocco sample reporting about her mother answered “Don’t Know” and indicated that she was not sure whether the deceased had been given this diagnosis. Upon further probing by the cognitive interviewer, she revealed that her mother did not have any skin pain or problems.

At least one potential case of response error emerged. One woman from the Zambia sample answering about her nephew answered “No,” but upon probing appeared to be thinking about symptoms more related to leprosy instead of shingles by saying “[the decedent] never had skin flake off.” As pointed out in previous “diagnosis” questions, by asking about a specific disease instead of particular symptoms, cases like this where respondents potentially mix up conditions and their symptoms become more probable.
ID10238  ENG: During the illness that led to death, did her/his skin flake off in patches?

FRN: Au cours de la maladie qui a conduit à la mort, sa peau s'est-elle écailleée?

ARB: ملَى كان مريض بالمرض مات بيه، واست الجلد ديالو(ها) كان كيتكشر على شكل يقع؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

Question ID10238 is included on both the adult and child questionnaires.

Most respondents based their answer on the specific symptom mentioned in the question text, that is skin coming off the decedent in patches. Almost no respondents indicated any problem answering this question (as compared to Question 10237 about a diagnosis of shingles or herpes zoster), and they explained their responses by saying they either did or did not see skin flaking off the deceased. One man from the Morocco sample answering about his sister answered “Don’t Know” as he said that had not seen the majority of her skin for quite some time, but that he never noticed any flaking on the skin that he did see.

Two potential cases of response error occurred, both from Morocco. In the first case, a son answering about his deceased father, answered “Yes” and noted that the decedent had skin burns that started on his foot, which started peeling—which appears to be a different skin symptom than that which is asked about in the question text. The other case of potential response error was a daughter answering about her mother, who explained her “Yes” answer by noting that her mother suffered from very dry skin. The daughter noted that she would help the decedent apply skin lotion near the end of her life.

ID10253  ENG: Did (s)he have any lumps?

FRN: Avait-t-il (elle) des protubérances/masses?

ARB: واش كان عندو(ها) شي أورام أوكتل ؟ (وْلَسِيس)؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]
Question ID10253 is included on both the adult and child questionnaires.
No confusion or response error emerged across the cognitive interviews for Question ID10253. Respondents understood the term “lumps,” to be referring to outwardly visible growths under a decedent’s skin. Most respondents explained their answer by noting that they did not notice any changes to the deceased’s body shape. For instance, one man from the Morocco sample answering about his sister in law explained that he did not observe any changes, and thus answered “No.” It appears that most of these respondents were thinking about lumps or visible masses on the neck, back, or armpits—areas that someone not intimately familiarly with the decedent’s body would be able to see. However, respondents answering about closer family (i.e. about their children) or about people they provided care for (i.e. elderly parents or others for whom they served as the primary caregiver) were more likely to discuss a wider range of body parts. For instance, one father from the Zambia sample answering about his daughter spoke about a growth on the small of her back, which he determined did not count and answered “No.” The notes for this respondent explain:

The respondents explained that his child did not have any lumps on her body and did not consider the growth she had as a lump. He said, “my daughter was born with a growth on her lower spinal cord, but she did not have any lumps on her body.

ID10261

ENG: Did (s)he have difficulty swallowing?

FRN: Est-ce qu’il (elle) avait des difficultés à avaler?

ARB: واش كان عندو(ها) صعوبة في البلع(الصريرط)؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

ID10264

ENG: Did (s)he have pain upon swallowing?

FRN: Est-ce qu’il (elle) avait des douleurs en avalant?

ARB: واش كان عندو(ها) ألم عند البلع(الصريرط)؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

Questions ID 10261 and ID10264 are included on both the adult and child questionnaires and were probed together during the cognitive interviews.
As in other instances where questions were probed together during the cognitive interview, the main research question with these two items was whether the first (ID 10261) could serve as a filter question for the second (ID 10264). In this instance, no respondents who answered “No” to 10261 went on to answer “Yes” in 10264, indicating that by using the former as a screener for the latter did not produce any false negative responses.

While most cognitive interviewing respondents provided the same answers to both questions (18 answered “Yes” to both, while 47 answered “No” to both), it is clear from the analysis of the notes that they comprehended the first question about difficulty to be broader conceptually than the question specifically about pain. This is very clear when examining the reasons that some (n=12) respondents answered “Yes” to 10261 but “No” to 10264. These respondents mentioned some other form of swallowing difficulty when explaining their answer to the first question, but then noted that the decedent did not express that he or she was in pain for the second. Consider for instance the interviewer notes for these two questions for a woman from the Morocco sample answering about her father:

[Question 10261]: The respondent said the deceased had difficulties swallowing especially when it came to solid foods. When asked if the deceased was able to eat, R said “Yes,” and he could only eat light meals like porridge. She further said the problem started 2 months ago.

[Question 10264]: The respondent said the deceased did not experience pain upon swallowing. When asked how she knew that her father didn't experience any pain she said he never at any point complained about pain when swallowing.

Similarly, a respondent from the Zambia sample answering about her father used similar reasoning when explaining her Yes/No split to the two swallowing questions, as shown in her interview notes:

[Question 10261]: Her father could not swallow solid foods. He only ate light porridge, the respondent said.

[Question 10264]: The respondent said that the deceased did not show any signs of pain when swallowing.

When examining the narratives of those respondents who answered “Yes” to both questions, some respondents were thinking about pain when answering both items. For instance, one man from the Zambia sample answering about his father explained his “Yes” response to 10261 by noting that his father had trouble swallowing, including pain when eating solid food, in the final few weeks of his life.
ID10265 ENG: Did (s)he have yellow discoloration of the eyes?
FRN: Est-ce qu’il (elle) avait une coloration jaune des yeux?
ARB: واتش كان عندو(ها) اصفرار فايبيض العين؟

1. Yes  
2. No  
77. [Don’t Know]  
99. [Refused]

Question ID10265 is included on both the child and neonate questionnaires.

Respondents largely understood this question to be asking whether the deceased’s eyes were shaded yellow. Only one respondent appeared to misunderstand the question as written. This respondent, a mother of a deceased neonate from the Zambia sample, answered “Yes” but upon probing explained that she was thinking about jaundiced skin, and not eyes. When asked by the cognitive interviewer if the baby also had yellowing in his eyes, the respondent said that they did not—only the baby’s skin was yellow, making this a false positive response.

ID10277 ENG: Did the baby's body become stiff, with the back arched backwards?
FRN: Est-ce que le corps du bébé est devenu raide, avec le dos arqué en arrière?
ARB: واتش جسم المولود صنح قاصح والضهر ديالو مقوس للخلف؟

1. Yes  
2. No  
77. [Don’t Know]  
99. [Refused]

Question ID10277 is included on both the child and neonate questionnaires.

Respondents universally understood this question to be asking about whether their baby’s back was stiff and arched in the period before death. All respondents who received this question answered “No” and no instances of response error emerged.
ID10294

ENG: Did she have any swelling or lump in the breast?

FRN: Est-ce qu’il (elle) avait des enflure ou nodules dans le sein?

ARB: واش كانو عندها تورمات أوكويرات في البزلة؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

Question ID10294 is included on the adult questionnaire and was only administered to respondents answering about female decedents.

Respondents all understood the terms “swelling” and “lump” to indicate the presence of a mass or tumor in the breast. For example, one daughter from the Zambia sample answered “No” and explained that, “I used to help bath her and I did not feel any lump or see any swelling on [the respondent’s mother’s] breasts.” Similarly, another woman from the Zambia sample serving as the primary caregiver for her aunt explained her “No” by noting that since she was the person caring for and dressing the deceased, she would know if there were any lumps.

Respondents with less familiarity—typically male respondents and respondents who did not live with the decedent—with the decedents’ bodies relied on other cues when judging their answer. Most of these respondents noted that the decedent either did not mention that they had lumps or swelling in their breasts or noted that they had never heard from the decedent of any medical appointments, results, or diagnoses relating to breast issues. For example, one woman from the Zambia sample speaking about her cousin answered “No” and explained that the deceased never complained to her about any lumps or abnormal swelling in the breasts. Likewise, a man from the Morocco sample answering about his aunt noted that his “No” response was based on the fact that the decedent never told him about any specialized gynecological consultations about her breasts, and that furthermore she never complained to him about any pain or mass. While there is no evidence that any of the responses in the cognitive interviews were false negatives, there may be a potential issue with accurate responses by respondents who were not intimately familiar with the decedent.
ID10295  ENG: Did she have any ulcers (pits) in the breast?

FRN: Est-ce qu’il (elle) avait des ulcères (fosses) dans le sein?

ARB: ﻓﻲ ﺷﻲ ﺗﻘﺮﺣﺎت ﻓﻲ ﺑﺰوﻟﺔ؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

Question ID10295 is included on the adult questionnaire, and was only administered to respondents answering about female decedents.

Respondents used the same patterns of interpretations for this question as they did for the previous question (10294) on masses and swelling in the breast—with respondents who were intimately familiar with the decedent (i.e. spouses and caregivers) answering based on personal knowledge, and respondents who were not intimately familiar with the decedent’s body answering based on their conversations with the deceased.

ID10296  ENG: Did she ever have a period or menstruate?

FRN: Avait-elle déjà eu ses menstruations?

ARB: ﻓﻲ ﻟﺠﺎتﺎ ﻣﺤﻖ اﻟﺸﮭﺮ؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

Question ID10296 is included on the adult questionnaire, and was only administered to respondents answering about female decedents.

Two major patterns of interpretation emerged across the interviews for this question—with response based either on personal knowledge or deduction based on whether or not the decedent had children—as illustrated in the schema in Figure 7 below, which also depicts which survey answers are associated with these two patterns:
In the first pattern, respondents considered whether they knew about the decedent’s menstruation based on their personal knowledge and interactions with her. For instance, one woman from the Zambia sample answered “Yes” and explained that she was aware that her sister’s periods typically lasted three days, as they would talk about it. Similarly, another woman from the Zambia sample answered “No” and noted that her 12-year-old niece had slow development—she hypothesized it was due to sickle cell—and had not yet begun menstruating. The respondent lived with the decedent and served as a mother figure and claimed to be aware of this aspect of the decedent’s life.

This first pattern also led to some “Don’t Know” responses, wherein the respondent explained that they did not have access to this part of the decedent’s life and therefore could not provide a substantive answer. For instance, one man from the Morocco sample explained that he did not know about his cousin’s menstruation habits—he noted that she never had any children, but that she did have two miscarriages in the 1970s. Besides this, he said that he had no information about the decedent’s gynecological history, and that she was very reserved and did not talk about it. Thus, based on a lack of personal experience, this respondent felt that “Don’t Know” was the correct answer.

The second pattern of response is deductive in nature: respondents considered whether the decedent had children, and logically reasoned that if they had, then they must have also menstruated. For instance, one man from the Morocco sample answering about his mother answered “Yes” and when asked to explain during the cognitive interview told the interviewer “Of course, yes. If she didn’t, she would have had children.” This pattern only led to “Yes” answers, whereas the personal knowledge pattern led to “Yes,” “No,” and “Don’t Know” answers.
When she had her period, did she have vaginal bleeding in between menstrual periods?

Avait-elle des saignements vaginaux excessifs entre les menstruations?

واش كانت كثوز بالدم ما بين فترات حق الشهر؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

Question ID 10297 is included on the adult questionnaire and was only administered to respondents answering about female decedents.

This question produced a relatively high proportion of “Don’t Know” answers across the cognitive interviewing sample as compared to other gynecological questions, as illustrated in Figure 8. This appears to be due to the fact that most respondents did not have personal knowledge about the decedent’s menstruation habits. Unlike the previous question (10296, about whether the decedent had periods), respondents without personal intimate knowledge of the decedents’ gynecological history could not use some form of deductive reasoning to answer this question.

Figure 8: Proportion of Cognitive Interviewing Respondents Who Provided a "Don't Know" Answer to the Gynecological Questions

![Figure 8: Proportion of Cognitive Interviewing Respondents Who Provided a "Don't Know" Answer to the Gynecological Questions](image-url)
Some respondents attempted to use logic to answer, but this was uncommon. For instance, one woman from the Zambia sample answering about her mother answered “No” and noted that she was going through menopause, and therefore could not be bleeding between periods since she no longer had them.

A few respondents were able to answer based on personal knowledge, but again as seen in previous questions, these were respondents who have access to the decedent in intimate ways. For instance, one respondent who answered “No” explained that her mother lived with her near the end of her life. Because she helped bathe her, she would have known if her mother had vaginal bleeding.

ID10301  

ENG: Was there excessive vaginal bleeding in the week prior to death?  
FRN: A-t-elle eu des saignements vaginaux anormaux et excessifs dans la semaine précédant la mort?  
ARB: واش كانت كندوز بالدم بزاف في الأسبوع اللي قبل الوفاة؟

1. Yes  
2. No  
77. [Don’t Know]  
99. [Refused]

Question ID10301 is included on the adult questionnaire and was only administered to respondents answering about female decedents.

Unlike the previous question about vaginal bleeding between periods (10297) only one respondent indicated that they did not have enough information to respond (and thus answered “Don’t Know”), with the rest of the respondents providing a “No” answer. This discrepancy appears to be related to both the reference period (“…the week prior to death”) and the word “excessive” used in the question text.

Respondents understood the reference period of “the week prior to death” to mean they should consider whether the excessive vaginal bleeding was related to the decedent’s death. By conceptually focusing their responses to bleeding they perceived as relating to death, some of the uncertainty surrounding proxy respondents’ lack of knowledge about the decedents’ menstrual history and patterns is eliminated. For instance, one respondent who answered “Don’t Know” to the question about vaginal bleeding between periods because the decedent never discussed it with him answered “No” to this question. He explained that he spent a lot of time with his mother in her last week of life and would have known if she was experiencing excessive bleeding.
The term “excessive” bleeding also allowed respondents to feel comfortable providing a substantive answer to this question, even if they did not feel like they could for previous questions about gynecological symptoms. Respondents largely understood this term to indicate that the bleeding was copious, noticeable, and perilous—in other words, something that the decedent would certainly mention if it had occurred. For example, one man from the Morocco sample who answered “No” echoed the respondent above and said that he would have known if his cousin had excessive bleeding of any type in her last stage of life.

**ID10299**

**ENG:** Did her menstrual period stop naturally because of menopause or removal of uterus?

**FRN:** A-t-elle eu arrêt des menstruations naturellement à cause de la ménopause?

**ARB:** واس حق الشهر انقطعت منها طبيعيا بسبب سن اليأس؟

1. Yes [Skip ID10302]
2. No
77. [Don’t Know]
99. [Refused]

Question ID10299 is included on the adult questionnaire and was only administered to respondents answering about female decedents. (Please note that this question is included on the questionnaire after Question ID10301; the numbering scheme is a relic of a previous version of the questionnaire.)

Respondents all understood the term menopause and related it to the stage of a woman’s life when they stop having their periods. None of the respondents answering “Yes” did so for a decedent under age 50—and so there were no obvious false positives. All respondents who answered “No” indicated that the person they were answering about was not old enough to have reached menopause. For instance, one man from the Zambia sample answering about his wife said “No” and went on to state, “My wife has not yet reached menopause.”

Three respondents answered “Don’t Know,” all of whom from the Morocco sample. These respondents were a nephew, cousin, and brother-in-law of decedents, and indicated that they had no knowledge of the deceased’s gynecological history in each case.
No respondents in the cognitive interviewing sample appeared to consider whether the decedent’s uterus had been removed. As this is less common than naturally reaching menopause, it may be preferable to ask about this procedure in a separate question.
ID10302  ENG:  At the time of death was her period overdue?

FRN:  Avait-t-elle un retard de la menstruation au moment de sa mort?

ARB:  واش تعطلت عليها حق الشهر في وقت الوفاة؟

1. Yes  
2. No  
77. [Don’t Know]  
99. [Refused]

Question ID10302 is included on the adult questionnaire and was only administered to respondents answering about female decedents who did not reply “Yes” to ID10299. As such only seven respondents received this question across the two counties; there are not enough data across these interviews’ notes for systematic analysis and therefore no findings are available.

ID10321  ENG:  During pregnancy, did she suffer from high blood pressure?

FRN:  Pendant la grossesse, souffrait-elle d'hypertension artérielle?

ARB:  واش كان كايطلع ليها الطانسيو ملي كانت حاملة؟

1. Yes  
2. No  
77. [Don’t Know]  
99. [Refused]

ID10322  ENG:  Did she have foul smelling vaginal discharge during pregnancy or after delivery?

FRN:  Avait-elle une odeur nauséeuse des pertes vaginales pendant la grossesse ou après la délivrance?

ARB:  ملي كانت حاملة أو بعد الولادة، واش كانت كذّوز بشي ماء الريحة ديالو خايبة؟

1. Yes  
2. No  
77. [Don’t Know]  
99. [Refused]

ID10323  ENG:  During the last 3 months of pregnancy, did she suffer from convulsions?

FRN:  Pendant les 3 derniers mois de grossesse, souffrait- elle de convulsions?
ID10324  ENG: During the last 3 months of pregnancy did she suffer from blurred vision?

FRN: Au cours des 3 derniers mois de la grossesse, souffrait-elle de vision floue?

ARB: في 3 أشهر الأخيرة من الحمل، واعش فركلات شحيمرة (تعرضت لنووبات ديال التشنجات)؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

ID10325  ENG: Did bleeding occur while she was pregnant?

FRN: Avait-elle un saignement excessif pendant la grossesse, avant le début du travail?

ARB: واعش جاها نزيف منين كانت حاملة؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

ID10326  ENG: Was there vaginal bleeding during the first 6 months of pregnancy?

FRN: Avait-elle des saignements vaginaux durant les 6 premiers mois de la grossesse?

ARB: واعش كان عندها نزيف مهبلي في 6 أشهر الأولى من الحمل؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

ID10327  ENG: Was there vaginal bleeding during the last 3 months of pregnancy but before labor started?
FRN:  Avait-elle des saignements vaginaux durant les 3 derniers mois de la grossesse mais avant le début du travail?

ARB:  واش كان عندها نزيف مهني في 3 أشهر الأخيرة من الحمل ولكن قبل ما يبداها الألم دوال الولادة؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

ID10328  ENG:  Did she have excessive bleeding during labor or delivery?

FRN:  A-t-elle eu un saignement excessif pendant le travail ou la délivrance?

ARB:  واش كانت كانتنزف فراف ملي كان عندها الوجع ولم كانت كانتولد؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

ID10329  ENG:  Did she have excessive bleeding after delivery or abortion?

FRN:  A-t-elle eu un saignement excessif après l'accouchement ou l'avortement?

ARB:  واش كانت كانتنزف فراف بعد ولادة أو إجهاض؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

Questions ID10321 through ID10329 are included on the adult questionnaire and were only designed to be administered to respondents answering about female decedents who had been pregnant within the year prior to death. No respondents in the cognitive interviewing sample were answering about decedents who died within a year of being pregnant; thus, no data or findings are available.
Questions ID10362 and ID10366 are included on both the child and neonate questionnaires. They were probed together during the cognitive interviews in order to better understand 1) how respondents interpret the term “usual size” and 2) how respondents were able to recall and provide the specific weight of the baby. The purpose underlying these research questions is to determine whether both of these items need to be included on the VA questionnaire or if burden can be reduced by eliminating one of them.

As found in the previous cognitive evaluation of the verbal autopsy instrument, asking about a subjective measurement of a baby at birth leads to a variety of interpretations. In the previous version of this question, tested in Nyanza Province, Kenya, the term “normal” was used, whereas the term “usual” was used in the version tested in Zambia and Morocco. While the term itself changed from the previous version of the questionnaire, the interpretation largely did not—respondents interpreted “usual size” in terms of 1) birth weight, and 2) whether the baby was carried to full term, as illustrated in the schema in Figure 9 below:

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9 Scanlon, Paul and Erin Nichols. 2015.
10 See Pages 41-43 and Figures 8 and 9 in Scanlon and Nichols 2015.
Most of the respondents in the cognitive sample considered the birth weight when answering Question ID 10362. Many of these respondents judged the deceased child’s birth weight against some standard—typically in the 2kg to 4kg range. For example, one father from the Zambia sample answered 10362 “Yes” and said that the baby was of usual size, which he understood to be somewhere in the 2.5 to 3.5kg range. (In Question 10366, this father reported that the birth weight was 3.2kg.) Likewise, a father from the Morocco sample answered “Yes” and noted that his son was born one month premature, but was still 3.2kg at birth, which he said was a healthy weight.

Not all respondents relied on a standard weight however, but instead primarily based their response on appearance. This led to a few response errors, particularly false positives. For instance, the interview notes for one mother from the Zambia sample who answered “Yes” about her deceased neonate explain her answer by focusing on how she compared the weight of her baby to other babies’ weights and appearance:

She said the baby was of usual size because [although] she was delivered at 7 months; her body was not that small. She looked bigger comparing with other children at the hospital the mother mentioned. When asked how much the baby weighted, she said 1kg.

Beyond considering weight when answering Question 10362, one other major pattern of interpretation emerged: whether the baby was delivered full term. Respondents who used this pattern focused more on when the baby was delivered than the actual birth weight of the baby. However, in most cases, respondents used the delivery date as a proxy indicator of the baby’s weight—in other words, a baby delivered full term should be a normal weight, whereas premature babies are underweight. For instance, one mother from the Zambia sample who answered “Yes” initially asked the interviewer “Do you mean the number of months when I delivered?” After being asked what she thought the question meant, she said that her son was born at nine months, so he was normal sized. Likewise, another mother from the Zambia sample who answered “Yes” was asked what she thought that normal size was, and she explained, “It’s the weight of a baby born at 9 months.” When asked to quantify this, she said, “No less than 3kg.”
Because respondents used two different patterns of interpretation, but also did not agree on a weight range for what counts as a “normal” sized baby, there is naturally variation in the responses to 10362 and (depending on what the “normal” weight is actually supposed to be according to data users and subject matter experts) a number of response errors.

Respondents all understood 10366 as asking about the specific weight of the baby in kg at birth. Only 11 respondents indicated that they did not know the actual birth weight when asked 10366. As is typical for questions that ask respondents to recall exact numbers, some respondents judged their response by actively searching their memory for the baby’s precise weight; however, most respondents appeared to simply guess or come up with what they perceived as an accurate estimate. The low amount of “Don’t Know” response indicates that 10366 could serve as an initial question in this series with 10362 only given as a follow-up for respondents who do not know (or refuse to give) the birth weight.

**ID10411**

**ENG:** Did (s)he drink alcohol?

**FRN:** Est-ce qu’il (elle) buvait de l'alcool?

**ARB:** واش كان(ت) يشرب(تشرب) الكحول؟

1. Yes
2. No
77. [Don’t Know]
99. [Refused]

Question ID10411 is included on the adult questionnaire. It was only included as part of the cognitive testing in Morocco. This question was included in the cognitive test largely in order to determine whether asking a question about a topic that is culturally discouraged (if not actually forbidden) can be reliably administered or if social desirability biases would impede the collection of this data.

While most respondents did answer “No,” six respondents did answer “Yes” and across the entire sample, only one interviewer noted a respondent was agitated about the question. (This respondent, answering about his deceased mother, forcefully answered that the decedent did not have any unhealthy behaviors at all when asked about tobacco use during the verbal autopsy interview.) No interviewers noted any evasive behavior or any other signs that the respondents were uncomfortable answering the question.

**ID10412**

**ENG:** Did (s)he use tobacco?

**FRN:** Est-ce qu’il (elle) consommait du tabac?
Question ID10412 is included on the adult questionnaire.

Respondents universally understood the question to be asking about whether or not the decedents smoked tobacco. No respondents considered chewing tobacco without being prompted by the cognitive interviewer.

A few respondents, all of whom were in the Moroccan sample, appeared to answer this question heuristically based on their perception of the decedent’s religiosity. For instance, one man answered “No,” and explained that his mother did not use “any form of drugs, as this went against her education and religion.”
Questions ID10413 through ID10416 are included on the adult questionnaire and were administered to respondents who said “Yes” to ID10412. Only 10 respondents answered “Yes” to 10412 and skipped into the rest of the tobacco questions. As a result, these questions were not systematically probed, and no findings are available.

Question ID10416 is included on both the child and neonate questionnaire.

Unlike the other questions included in the cognitive interview, this question was not probed—cognitive interviewers were instead instructed to observe the verbal autopsy and determine whether or not the
respondent was using the decedent’s vaccine card (i.e. their record of vaccines given by a healthcare provider) or their memory when answering the question. The validity of this question relies on the fact that respondents are using a memory aid, such as a vaccine card; however, this assumption has been called into question as the verbal autopsy instrument has been evaluated over the past decade.

Only seven out of the 49 respondents who received this question used their vaccine cards to answer it; the rest either indicated that they did not know (n=13) or based their response on memory (n=29).
WORKS CITED


