RESULTS OF THE COGNITIVE INTERVIEWING STUDY OF THE
2012 WHO VERBAL AUTOPSY INSTRUMENT
IN NYANZA PROVINCE, KENYA

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This report documents results of the cognitive interviewing study to examine the performance of 2012 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 to throughout this report as "adult")[2]. 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. While organizations and agencies throughout the world have already fielded the 2012 simplified VA questionnaire set, no cognitive or other systematic qualitative testing has been performed to investigate the construct validity of the questions on the questionnaires. This project was designed to address this gap in the VA research agenda.

In addition to the general goal of investigating the respondents' interpretations of the questions on the VA questionnaires, three specific goals drove both the methodology and field site selection of this cognitive interviewing project. These goals were to investigate the following:

1. The extent to which proxy respondents know the information about the decedent that is requested during the VA interview.
2. Whether and how the respondents understand the medical and health-related terms used throughout the VA questionnaires.
3. The ability of the respondents to identify and distinguish between medically-relevant signs and symptoms.

During the initial planning phase of this cognitive interviewing project a fourth goal—to investigate how the structure and length of the questionnaire affects not only interpretation, but also respondent fatigue and item non-response—was dropped as no counter-positive was developed. However, as the data

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[2] These questionnaires are presented in full at the end of this report, in Appendices A, B, and C, respectively.

collection proceeded, *interviewer* usability—particularly the effectiveness of the questionnaires' many skip patterns—emerged as a concern. As such, skip patterns were analyzed and are detailed below in the question-by-question analysis.

Besides the overarching research goals, members of the WHO's Verbal Autopsy working group suggested more specific research questions relating to questions that emerged as problematic throughout previous field tests. These question-specific issues were incorporated into the interview guide used by the cognitive interviewers.

The majority of this report will present a question-by-question analysis. Not all of the questionnaires' questions were probed during the cognitive interview, due largely to time constraints. As explained in detail in the methods section below, all of the cognitive interviewers probed on a specific set of questions, and then had leeway to probe on additional questions as they saw fit. Because of this, not all of the questions presented in the question-by-question analysis section have cognitive findings. For those questions that were probed, the reported findings of each question include descriptions of respondents' interpretations and the types of experiences that respondents considered in their answer.

The next section presents an overview of cognitive interviewing methodology generally, as well as the specific methodology used while testing the VA instrument in western Kenya. Next, a summary of conclusions is presented, centering upon the research goals outlined above. The final section of the report presents findings for each question.

METHODS

This section details the methodology of this study. First, an overview of cognitive interviewing methodology will be presented. Then, the specific methods used for this project will be described.

Cognitive Interviewing

The aim of a cognitive interviewing study is to investigate how well survey questions perform when asked of respondents, that is, if respondents understand the questions according to their intended design and if they can provide accurate answers based on that intent (Miller et al, 2014; Willis 2004). As a qualitative method, the primary benefit of cognitive interviewing is that it provides rich, contextual insight into the ways in which respondents 1) interpret a question, 2) consider and weigh out relevant aspects of their lives and, finally, 3) formulate a response based on that consideration. As such, cognitive interviewing provides in-depth understanding of the ways in which a question operates, the kind of phenomena that it captures, and how it ultimately serves the scientific goal. Findings of a cognitive interviewing project typically lead to recommendations for improving a survey question, or results can be used in post-survey analysis to assist in data interpretation.

Traditionally, cognitive testing is performed by conducting in-depth, semi-structured interviews with a small sample of approximately twenty to forty respondents. The typical interview structure consists of respondents first answering the evaluated question and then answering a series of follow-up probe questions that reveal what respondents were thinking and their rationale for that specific response. In this regard, cognitive interviews unfold within a narrative format. Through this semi-structured design, various types of question-response problems, such as interpretive errors or recall accuracy, are uncovered—problems that often go unnoticed in traditional survey interviews. By asking respondents to

provide textual verification and the process by which they formulated their answer, elusive errors are revealed.

As a qualitative method, the sample selection for a cognitive interviewing project is purposive. Respondents are not selected through a random process, but rather are selected for specific characteristics such as gender or race or some other attribute that is relevant to the type of questions being examined. When studying questions designed to identify persons with disabilities, for example, the sample would likely consist of respondents with a previously known disability and, to discover potential causes of false positive reporting, some respondents with no known disability. Because of the small sample size, not all social and demographic groups are represented. Analysis of cognitive interviews does not produce generalizable findings in a statistical sense, but rather, provides an explicit understanding of response processes including patterns of interpretation.

As is the case for analyses of qualitative data, the general process for analyzing cognitive interview data involves synthesis and reduction—beginning with a large amount of textual data and ending with conclusions that are meaningful and serve the ultimate purpose of the study. For analysis of cognitive interviews, reduction and synthesis can be conceptualized within five incremental steps—conducting interviews, producing summaries, comparing across respondents, comparing across subgroups of respondents, and reaching conclusions. With each incremental step, a data reduction product is created. A description of each of these steps and the resulting reduction product is presented below:

1) Conducting interviews to produce interview text: collecting narratives from respondents that reveal how each respondent made sense of and went about answering a survey question,
2) Synthesizing interview text into summaries to produce detailed summaries: detailing how and why each respondent interpreted the question as well as how they formulated their answers, including events or experiences considered as well as any difficulties answering the question,
3) Comparing summaries across respondents to produce thematic schema: identifying and mapping common themes that detail phenomena captured and the process of formulating a response,
4) Comparing identified themes across subgroups to produce an advanced schema: identifying ways in which different types of respondents may process questions differently depending on their differing experiences and socio-cultural backgrounds,
5) Making conclusions to produce final study conclusions: determining and explaining the performance of a question as it functions within the context of respondents' various experiences and socio-cultural locations.

Although these steps are described separately and in a linear fashion, in practice they are iterative; varying levels of analysis typically occur throughout the qualitative research process.

As each step is completed, data are reduced such that meaningful content is systematically extracted to produce a summary that details a question's performance. In detailing a question's performance, it is possible to understand the ways in which a question is interpreted by various groups of respondents, the processes that respondents utilize to formulate a response as well as any difficulties that respondents might experience when attempting to answer the question. It is the ultimate goal of a cognitive interviewing study to produce this conceptual understanding, and it is through data reduction that this type of understanding is possible.

While the two processes of data reduction and knowledge production may be heuristically separated, in reality the processes occur simultaneously. In reducing the cognitive interview data the analyst produces a more comprehensive understanding of a question's performance; as analysis is performed,

understanding of the question response process becomes more complex and complete. In the beginning it is only possible to understand how each individual respondent makes sense of and answers the survey question. By the end, individual interpretations are understood as well as how those interpretations relate across groups and within the overall context of the question's performance.

Verbal Autopsy Cognitive Interviewing Study

58 face-to-face cognitive interviews were conducted for the 2012 Verbal Autopsy in Nyanza Provence, Kenya Cognitive Interviewing Study. All respondents were from, and all cognitive interviews were conducted within the routine operations of, the KEMRI (Kenya Medical Research Institute)/CDC (U.S. Centers for Disease Control and Prevention) Health and Demographic Surveillance System (HDSS) site in Nyanza Provence. The HDSS includes three districts within Siaya County (Rarieda, Siaya, and Gem). The interviews were conducted by a team of four locally-based interviewers who were trained by staff of the National Center for Health Statistics (NCHS) Questionnaire Design Research Laboratory (QDRL). Field data collection occurred between the last week of January 2014 through February 2014.

The questionnaires were translated from English into, and the interviews were conducted in, the Luo language, which was the common language in this part of Western Kenya. A team of KEMRI/CDC staff translated the document with guidance from NCHS staff. The translations of each question are presented along with the English wording in the Question-by-Question results section of this report below. Additionally, the translation team re-translated the Luo instrument back into English. These re-translations can be found at the end of this report in Appendices D, E, and F (for the adult, child, and neonate questionnaires, respectively).

The structure of these cognitive interviews differs slightly from the common protocol. As the VA instrument is continually fielded in the HDSS, in order not to disrupt this ongoing data collection, the cognitive interviews were conducted as immediate follow-up re-interviews. After the VA interviewer had run through the entire instrument with the respondent, the VA interviewer left the room and the cognitive interviewer began the 100% retrospective cognitive interview.

Prior to the VA interview, respondents were asked to consent to the follow-up cognitive interview. If they consented, the cognitive interviewer observed the VA interview and took notes to facilitate the cognitive interview later. The cognitive interviews were recorded on netbooks so that the cognitive interviewers could focus on the interview itself, and not on taking notes. Respondents were offered small gifts, such as bottles of soda, as incentives to participate in the cognitive interviewing study.

During the cognitive interview, respondents were re-asked a number of survey items they received during the VA and were then asked to explain their answer. While there was a selection of questions that all the interviewers probed on, they were also given free rein to probe on any other questions they thought the respondents did not understand or questions they thought might have elicited response errors during the VA interview. The types of follow-up questions asked by interviewers depended on respondents' interpretation of the questions; however, typical follow-up questions included, "Why did you say that?" and "What were you thinking when you answered this question?"

Given that the cognitive interviewers were only probed a sub-set of the questions, there are not findings for all of the items on the three questionnaires. When this is the case, this lack of data is noted below in the question-by-question analysis. The fact that there are not data and findings for all the questionnaire items is unfortunate, in that more robust cross-question and cross-questionnaire analyses would be possible if all the questions had been probed during the cognitive interview. However, the questions that the interviewers probed on universally were specifically chosen with the three research goals in mind.

Therefore, while this cognitive interviewing project may not definitively evaluate the three VA questionnaires holistically, the findings on the individual questions are both robust and valid.

Respondents. Respondents were recruited by HDSS staff from the existing VA sample. Three separate samples were recruited: an "adult sample" of respondents answering about a deceased individual who died when they were 15 years old or more, a "child sample" of respondents answering about a deceased individual who died when they were between 28 days and 14 years old, and a "neonate sample" of respondents answering about a deceased infant who died when he or she was less than 28 days old.

The VA exclusively uses proxy reporting. As such, Table 1 below shows the sex and place of death distribution of the *deceased* individuals, and not of the respondents themselves.

Table 1: Deceased Individual's Sex and Place of Death by Sample

	Adult Sample	Child Sample	Neonate Sample
Sex			
Male	10	11	11
Female	8	9	9
Location of Death			
Home	11	14	9
Health Facility/Hospital	6	6	9
In Transit to Health Facility	1	0	2

On the other hand, Table 2 below shows the *respondents'* relationships to the deceased individuals about which they were reporting, as well as their genders.

Table 2: Respondents' Relationships to Deceased by Gender and Sample

	Adult		Child		Neonate		Total
	Female	Male	Female	Male	Female	Male	
Mother	2	0	13	0	13	0	**28**
Father	0	1	0	4	0	4	**9**
Spouse	1	0	0	0	0	0	**1**
Sibling	0	1	0	0	0	0	**1**
In-Law	8	0	0	0	0	0	**8**
Co-Wife	3	0	0	0	0	0	**3**
Grandparent	0	0	3	0	3	0	**6**
Child	0	1	0	0	0	0	**1**
Aunt/Uncle	1	0	0	0	0	0	**1**
Total	**15**	**3**	**16**	**4**	**16**	**4**	**58**

Method of analysis. After an interview was conducted, cognitive interviewers recorded summary notes for each question, in English. Summary notes included the way in which a respondent interpreted and processed individual questions, what experiences or perceptions the respondent included as they formulated their answer, and any response difficulties experienced by the respondent. Audio-recordings of interviews were utilized to ensure the accuracy of summaries.

After all interviews and summaries were completed, interviews were compared to identify common patterns of interpretation and response difficulties for each question. For this project, the interpretive patterns involving health status and environmental context were particularly salient. Once themes were identified for each question, themes were compared across questions to identify commonalities and to develop a larger conceptual understanding regarding the performance of the set as a whole. This final level of analysis provides a summary understanding of the functioning questions' performance, that is, whether together they capture the intended analytic intent of the survey.

 A data entry and analysis software application (Q-Notes) was used to conduct analysis. Q-Notes, developed by the QDRL, ensures systematic and transparent analysis across all cognitive interviews as well as provides an audit trail depicting the way in which findings are generated from the raw interview data.

SUMMARY OF CONCLUSIONS

This section provides an overview of significant findings and is organized into four sub-sections corresponding to the three research goals presented above, as well as a section on usability. The question-by-question overview following the methods section provides more detailed discussion of each question's performance.

Research Goal 1:   Feasibility of Collecting Proxy Data about a Deceased Individual

The collection of proxy data in survey environments is, of course, quite common and widely accepted. However, a number of studies have cautioned against simply assuming that proxy reports are valid, particularly in cases of parents reporting on children (i.e. Jokovic et al, 2004) and when collecting morbidity data (i.e. Halabi et al, 1992). Most of the methodological work on proxy reporting in health surveys notes that the usefulness of the method, and the validity of the ensuing data, is dependent on the cultural and individual knowledge of the respondents on the specific domains under question. In other words, while proxy reporting might produce excellent, valid data on one question, it might fail to do so in another item on the same questionnaire.

The verbal autopsy instrument collects only proxy data—and obviously, self-report is impossible in the case of deceased individuals. One of the goals of this cognitive interviewing project was to consider the feasibility of collecting valid data on deceased individuals from close family members. One of the best ways of looking into this aspect is to investigate the frequency and spread of, and reasons behind, "don't know" responses to the items on the VA questionnaires.
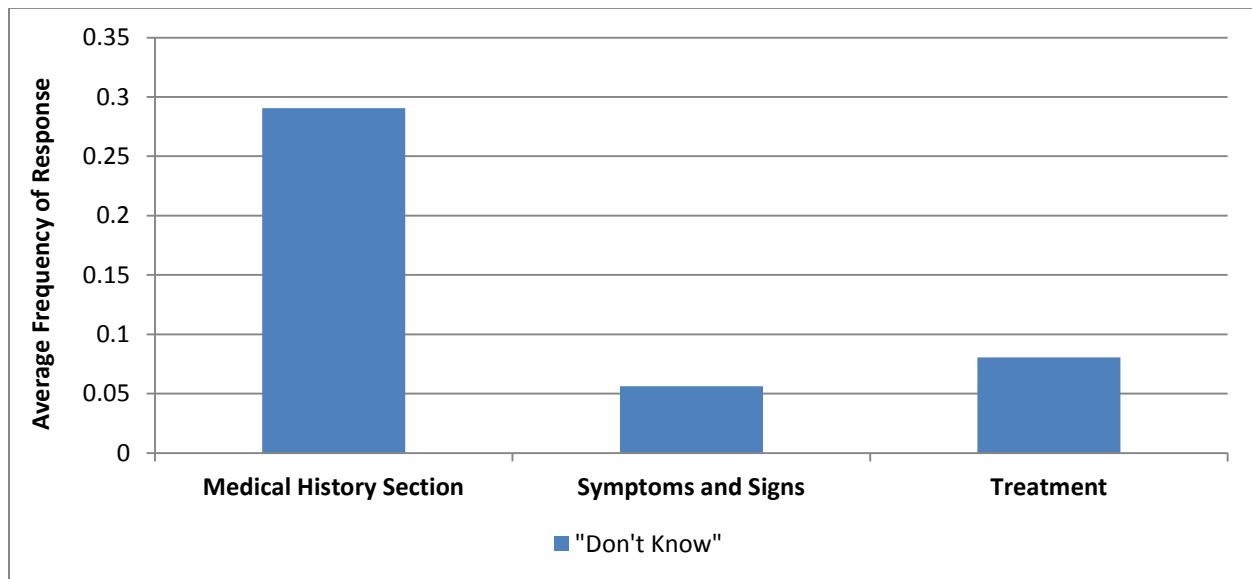

Chart 1: Relative Frequency of "Don't Know" Response across Three VA Sections

At the most basic level, the frequency of "don't know" responses across respondents illustrates a picture of which sections in the questionnaire may be more or less problematic. Chart 1 shows the distribution

of the average frequencies of "don't know" answers across three of the VA sections[3]. These three sections will be used in this analysis as they are the largest shared sections across the three versions of the questionnaire.

This distribution clearly shows that the Medical History Section is the most problematic, with over double the relative frequency of "don't knows" than the other three questionnaire sections.

As noted above, the literature on proxy reporting notes that validity is dependent not just on what information the questions are asking about (which is clear from Chart 1), but also on the individual knowledge and experiences of the respondents themselves. With this in mind, Chart 2 shows the distribution of average frequency of "don't know" responses across the same three sections, but this time by questionnaire version:
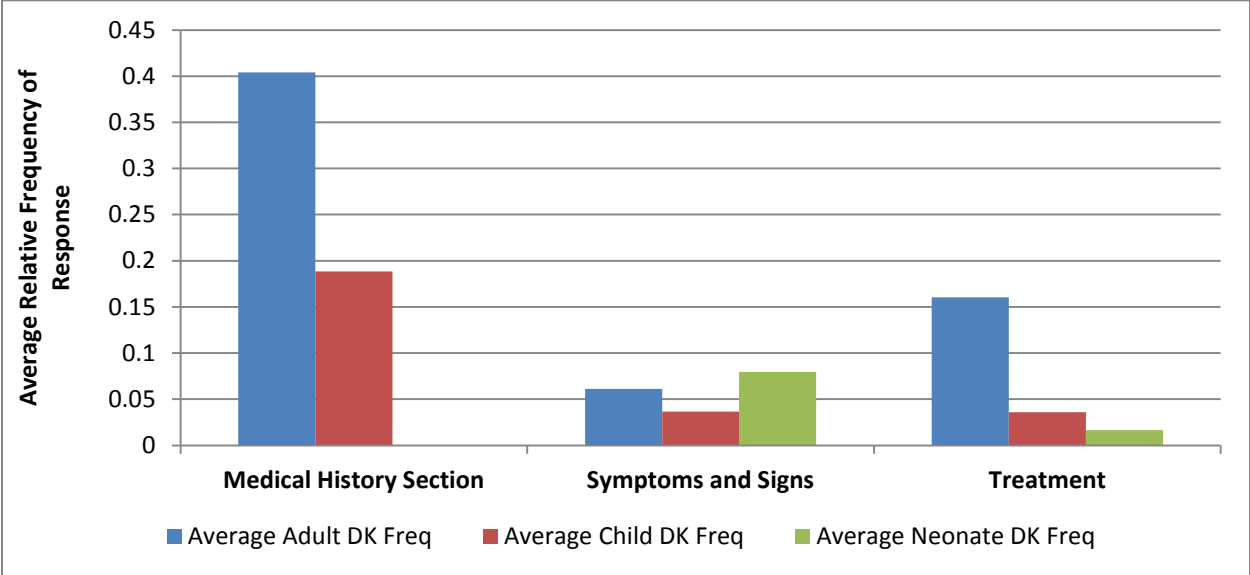
Chart 2: Frequency of "Don't Know" Response across Three VA Sections, by Questionnaire Version

The assumption here is that the respondents (all adults over the age of 18) will have a different level of familiarity (and thus ability to give either a "yes" or "no" answer) with their infants or children than they would with a fellow adult—such as a mother, father, sibling, or spouse. In all three of these sections, the adult sample respondents—again, those respondents who were answering about an deceased person over the age of 14, including children, spouses, siblings, parents, and in-laws—were much more likely to answer "don't know" than the child sample respondents (who were mostly answering about their own children, with a few answering about grandchildren).

The advantage of collecting qualitative data becomes clear when trying to explain these differences. Across the adult sample, the most common explanations the respondents gave for their "don't know" answers had to do with either *physical* or *social* distance from the deceased during a particular life event. Physical distance refers to the respondent not being somewhere, such as living in a different community

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[3] The three sections are: "Context and History of Previously Known Medical Conditions," shorted to "Medical History" henceforth; "Symptoms and Signs Noted During the Final Illness," shortened to "Symptoms and Signs;" and "Treatment and Health Services used for the Final Illness," shortened here to "Treatment." Only questions with "yes"/"no"/"don't know"/"refused" answer categories were analyzed.

than the deceased at the time of the illness, or at the hospital at death, and thus being unable to accurately report information about that time period. "Social distance" is a specialized form of physical distance, and refers to the lack of knowledge of a particular topic due to the respondent's cultural or social *inability to be with* the deceased at the time of a life event. For instance, a husband might not know about his deceased wife's "excessive vaginal bleeding" (Questions A820 and C920) during delivery if he was not culturally welcome in the room at the time.

A third major reason for a respondent answering "don't know" to a question was simple inability or difficulty in comprehending the core construct under question. This pattern emerged across all three samples, and was particularly common in the "Medical History" and "Symptoms and Signs" sections. In Chart 2 above, it is clear that in the "Symptoms and Signs" section, the members of the neonate sample were the most likely to respond "don't know" to a question. One might expect them to have the lowest frequency of "don't knows" due to the fact that they were all answering about their own infants, and one could expect them to be very familiar with the infant's medical and death history. Chart 3 dives into just the "Signs and Symptoms" section and shows the frequency of "don't knows" by questionnaire item for each of the three samples.
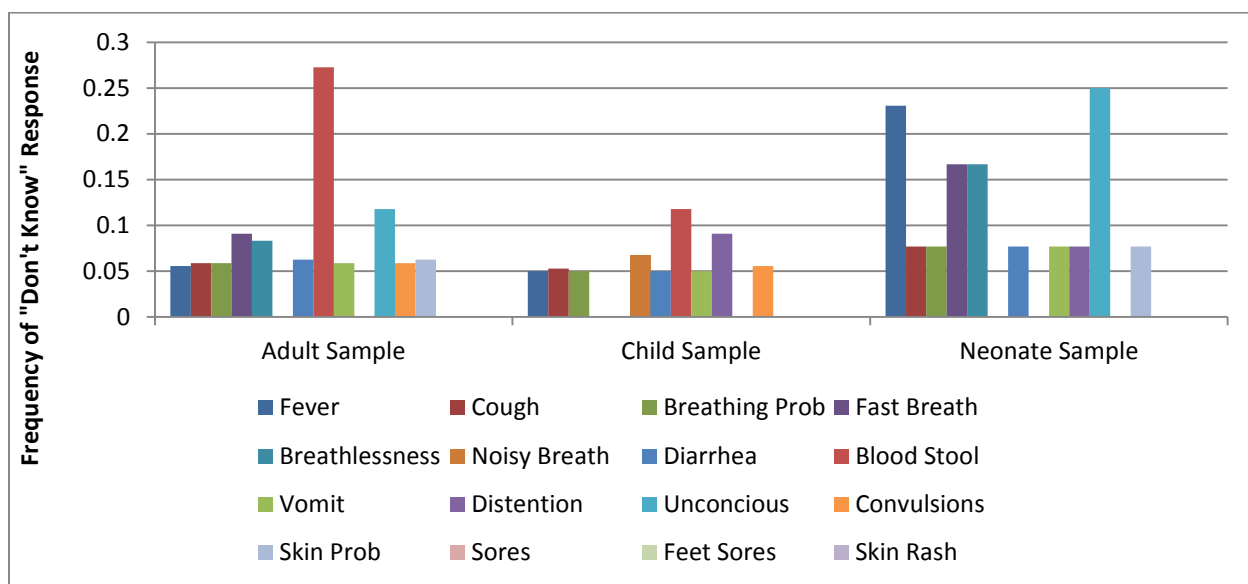

Chart 3: Frequency of "Don't Know" Response across Questions in the Signs and Symptoms Section, by Questionnaire Version

It appears, for both the adult and neonate samples at least, that the large "don't know" response to a very few specific items is driving up the average relative frequencies seen in Chart 2. The qualitative data indicates that the high number of "don't know" responses in the Blood in Stool question (Questions A919, C821, and N923) for the adult sample was mostly due to social distance—adults tended not to observe other adults' bowel movements. However, in the neonate sample, the high levels of "don't know" answers to the fever (Questions A901, C801, and N913), fast breathing (Questions A909, C810, and N918), breathlessness (Questions A911, C812, and N919), and loss of consciousness (Questions A935, C836, and N911) items appear to be almost entirely due to the respondent not *comprehending* the term and not feeling qualified to make a medical judgment (i.e. not knowing if a baby was unconscious or just sleeping).

While certainly "don't know" responses are not perfect measures of the validity of proxy responses, they do provide a convenient and general gloss of the issue. Going forward with future changes and re-

designs of the VA questions and instruments, it will be important to keep this idea of variable validity in mind and study it further.

Research Goal 2:   Comprehension of Medical and Health-Related Terms

Many of the questions throughout the Verbal Autopsy instruments ask respondents about specific diagnoses or medical and health terms. However, analysis of the respondents' narratives reveals that most respondent do not answer these questions about the specific diagnoses or medical terms themselves, but rather consider their knowledge of the deceased's habits and symptoms when answering them. It is unclear whether this general pattern of response is due to respondents *not knowing* the diagnoses, or due to the fact that they (perhaps culturally) do not understand "diagnosis" as something that must originate from a medical professional.

Throughout the questionnaires, these questions take on a few different forms. For example, Question A501 and C501 asks about the *diagnosis* of tuberculosis:

> **Question A501:**   **Was there any diagnosis of Tuberculosis?**
> **Question C501**   ***Be ne opime ma oyude ni en gi kahera/TB?***

Question A820 andC920 asks about the *medically relevant* term "excessive bleeding:"

> **Question A820:**   **Was there excessive vaginal bleeding after delivering the baby?**
> **Question C920**   ***Be ne en gi chwer mang'eny mawuok e duong'ne bang' nyuolo nyathi?***

Another example, Question A1101, C1001, and N1001 asks about "adequate vaccination."

> **Question A1101:**   **Was s/he adequately vaccinated?**
> **Question C1001**   ***Be ne oyudo chanjo kaka dwarore?***
> **Question N1001**

On the surface, the respondents did not appear to have much difficulty comprehending these diagnostic or medical questions, or others like them, throughout the VA instruments. Further analysis of the qualitative data, however, presents a much more nuanced picture of how the respondents interpreted medical and health terms. When interpreting diseases and conditions, respondents *did not generally consider the diagnosis or medical term itself*.

Rather, respondents tended to consider one of three general areas: symptoms, effect, and causes. For example, instead of interpreting something like "tuberculosis" heuristically as a common disease (or relying on medical documentation), respondents would consider whether or not the deceased individual had whatever symptoms, suffered whatever effects, or encountered any causes that they associated with tuberculosis. Based on their knowledge of the deceased individual, the respondent would then determine whether or not the deceased had that condition or disease. Of course, a few respondents did

report on the *diagnosis or medical term* itself—usually by consulting medical records or by indicating that they were with the deceased when the diagnosis was provided by a medical professional. A general schema of how the respondents interpreted these questions about diagnoses is shown below in Figure 1 showing the five major pathways the respondents used to answer medical questions:
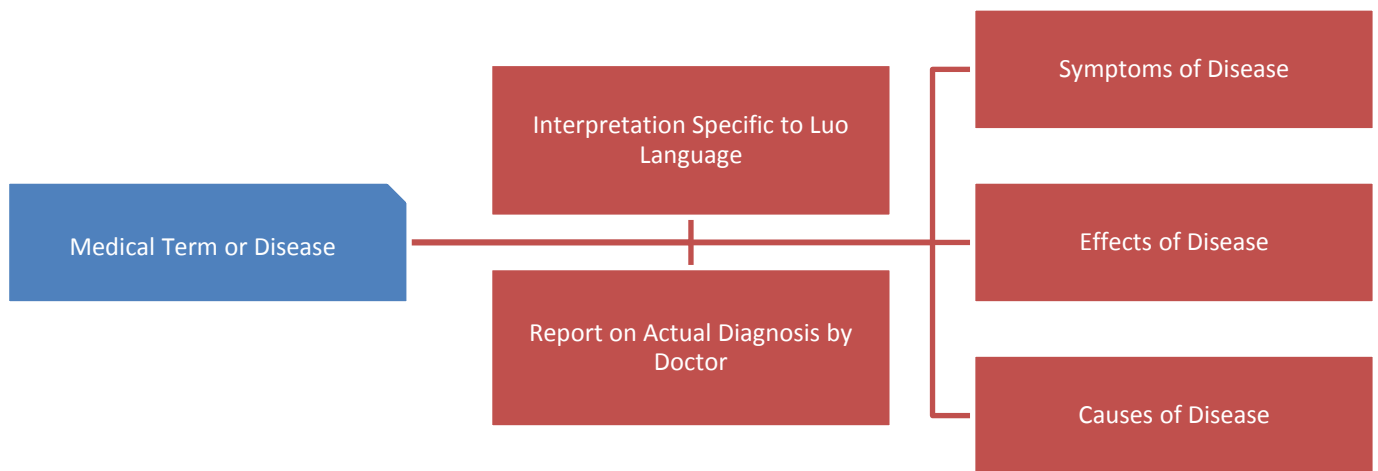

Figure 1: General Response Schema for Medical Terms or Diseases

Of the five pathways shown in the schema above, the "Symptoms" one was by far the most common across all the respondents. For instance, when asked about diarrhea (Questions A917, C819, and N922: "Did s/he have diarrhea?"), most respondents explained that they were thinking about the consistency or frequency of the stool, and considering whether or not the deceased displayed signs of those symptoms.

The Effects and the Causes Pathways, while less common than the Symptoms one, both emerged strongly as well. The Causes pathway is particularly interesting. Almost no respondents considered the biological causes of disease (i.e. the plasmodium for malaria, or insulin for diabetes). Rather, they considered the *actions* that might lead an individual to get or have that disease—for example getting a mosquito bite for malaria (or being in moist environments, see Questions A503 and C503, "Did s/he have a recent test for malaria?") or having a bad diet for diabetes.

Besides the heuristic discussed above where respondents answer directly about a doctor-provided diagnosis, a fifth pattern of interpretation emerged in some of these questions throughout the three questionnaires—interpretations based on the Luo language itself. The best example of this is in the multiple pregnancies question. In Luo, there is no specific phrase for "multiple pregnancy," "triplets," "quadruplets," etc. Rather, the word for "twin"—*rude*—is modified by adding a number. So saying a triplet would be the equivalent of saying "twin plus one." One respondent pointed this out, saying that she was interpreting the question to mean two babies, but that it could be changed by adding a number to the word *rude*.

That respondents have multiple pathways to follow when interpreting a term, or that they rely on symptoms or effects to understand and describe an illness, are not problems in and of themselves—they certainly *can* lead to valid survey responses. However, they can just as easily lead to decreases in construct validity and increases in response error. The more pathways and patterns of interpretation respondents can use to answer a survey question, the less focused their answers will be, and therefore more likely to capture out-of-scope constructs. Relying on symptoms or effects to answer diagnosis

questions has its own set of issues. In short, there is no easy way for interviewers or data analysts to know whether the symptoms the respondents are considering when answering a diagnosis question correctly (in a medical sense) align with the condition or diagnosis under question.

Research Goal 3:   Distinguishing Between and Comprehending Medically-Relevant Symptoms

The VA instrument presents a unique challenge for researchers: On one hand very specific medical information about diagnoses is needed for a *reliable* instrument; on the other hand, the population under study does not have the medical training necessary to ensure the *validity* of this information. One potential way to increase the construct validity needed to ensure a high level of medical reliability is to ask respondents about symptoms instead of diagnoses. For instance, if a respondent can correctly answer questions about chills, fever, and vomiting, the researchers would not necessarily need to ask about a diagnosis like malaria directly.

However, this symptoms-instead-of-diagnoses methodology has the potential to not only increase cognitive burden but also to simply fail when the respondents are asked about similar, but *medically-distinct*, symptoms. So for instance, if a particular color of vomit indicates one disease, while another color indicates another disease, respondents need to be able to comprehend and report this difference in order for the instrument's findings to be valid.

Within the context of the VA cognitive interviewing project, the best way to determine whether or not respondents can differentiate between medically-relevant symptoms is to observe how respondents understood the central symptom or medical term of one question (the "core construct" mentioned throughout this report), and compare it to the interpretation of a similar, but medically-distinct core construct in another question. The three best examples of these pairs are the two "excessive bleeding" questions (Questions A819/C919 and A820/C920, about bleeding during labor and bleeding after delivery, respectively), the "mental confusion" and "unconsciousness" questions (Question A933/C834 and A934/C835, respectively), and the "abnormal positioning" and "normal delivery" questions (Questions A822 and C922; and Questions A829, C929, and N605, respectively). While these pairs, and the respondents' conflation of their constructs, are explained in detail below, suffice to say here that, in general, respondents did indeed display difficulty distinguishing between similar, but medically-distinct terms.

In the "excessive bleeding" questions, the respondents were asked about whether a mother had excessive bleeding during labor (for Questions A819 and C919) and then after delivery (for Questions A820 and C920). While these two questions clearly provide separate reference events, the respondents generally did not see a distinction between the two, and either answered about the same event across both questions (i.e. about delivery in both QA819 *and* QA820), or about the entire birthing process in both questions. This *lack of differentiation* clearly impacts the validity of these two items: The analyst has no way of knowing which interpretation the respondent is using, and therefore cannot know if a "yes" answer to Q A820/C920 indicates 1) bleeding after delivery, 2) bleeding during labor, or 3) bleeding during the birthing process.

In the second example, the respondents appeared to be unable to distinguish between "mental confusion" (Questions A933 and C834) and "unconsciousness" (Questions A934 and C835). While these questions were not probed extensively during the cognitive interview (because, on the surface in English, they do not appear to cover very similar constructs), the respondents' answers to the question

pairs were nearly identical—so a yes in one was nearly always a yes in the other question, as illustrated in the question-by-question section in Tables 5 and 6.

Finally, the respondents also appeared to conflate the positioning of a baby during delivery and the normality of that delivery. The respondents were considering many of the same constructs across both of these questions (whose schema are illustrated below in the question-by-question section in Figures 14 and 16). As can be seen in Figure 16, the respondents did consider a wider range of constructs when thinking about the normality of delivery (including the location and the duration of the delivery). However, by far, the most common pattern of interpretation within Questions A829, C929, and N605 was to think about whether or not the baby had a head-first delivery—the same as the respondents were considering in Questions A822 and C922.

The VA program assumes that the respondents not only have enough knowledge of the decedent to answer questions about their life and death, but more importantly that they can *accurately* answer those questions to the level of specificity required by the VA analytic model. It is clear that in many cases, the respondents do not divide life events in the same way as the VA model does (i.e. differentiating between labor and the delivery), do not perceive the difference between symptoms (as in the case of mental confusion and unconsciousness), or do not distinguish between multiple concepts (considering fetal positioning and normality of birth to be the same thing, for example). This lack of differentiation between sets of symptoms, and other medical terms, throughout the Verbal Autopsy question presents a real structural challenge to the overall validity of the instruments and the resulting analysis.

Interviewer Usability

Before proceeding to the question-by-question review, a brief explanation of the usability data available from this cognitive interviewing project is necessary. As the VA uses a CAPI (Computer Assisted Personal Interview), interviewer-administered instrument, usability (for the interview*er*) issues were not originally included as part of the research agenda for the cognitive interview project. However, as data collection proceeded, it became clear that many of the skip patterns were not being followed, and the research team decided to track the outcome of the skips as a proxy for usability. Therefore in the question-by-question section below, the number of people who correctly or incorrectly received each question that has, or is affected by, a skip pattern is noted alongside that question's summary.

There are two likely candidates for explaining the skip pattern issues noted throughout. First, given the format of this cognitive interviewing project—as a fully-retrospective, immediate follow-up interview— it is possible that the cognitive interviewers did not ask the exact same questions that were given to the respondent during the actual verbal autopsy interview. In this case, the skip issues noted below are simply artifacts of this project's particular cognitive interviewing methodology, and do not indicate an issue with the VA instrument itself. However, the second candidate is that the VA instrument was either programmed incorrectly or that the VA interviewers did not follow their computer's prompts and incorrectly skipped the respondents into and out of questions.

Further analysis of the recordings is required to determine which (or if either) or these two hypothesis are correct. The skip notes provided throughout the question-by-question review can be used by KEMRI/CDC researchers in the future to focus their research on this usability issue.

This section presents detailed findings of individual questions. Findings primarily include the various phenomena captured by each question. However, when relevant, discussion also includes difficulties experienced by respondents as they attempted to answer the question as well as potential response error. Please note that any quotes given below are from the cognitive interviewers' translations of their conversations in Luo into their English field notes.

Section A3 and C3: Information on the Deceased and the Date/Place of Death

Question A317:	**Was this a woman who died more than 42 days but less than 1 year after being pregnant or delivering a baby?**
Question C320	***Be ma ne en miyo motho mokalo ndalo piero ang/wen gi ariyo to pok ochopo higa bang bedo gi ich kata nyuol?***

Seven respondents in the adult sample received Question A317; no respondents in the child sample received Question C320.

Core Construct Interpretations

All in all, this question appeared to cause a large amount of confusion for the respondents. During the verbal autopsy interview, four respondents asked for the question to be clarified or repeated.

Across the respondents who did receive the question, there was a large amount of variation around the core construct—probably relating to the confusion mentioned above. The figure below illustrates this diversity, showing that four distinct patterns of interpretation emerged during the analysis of this question:
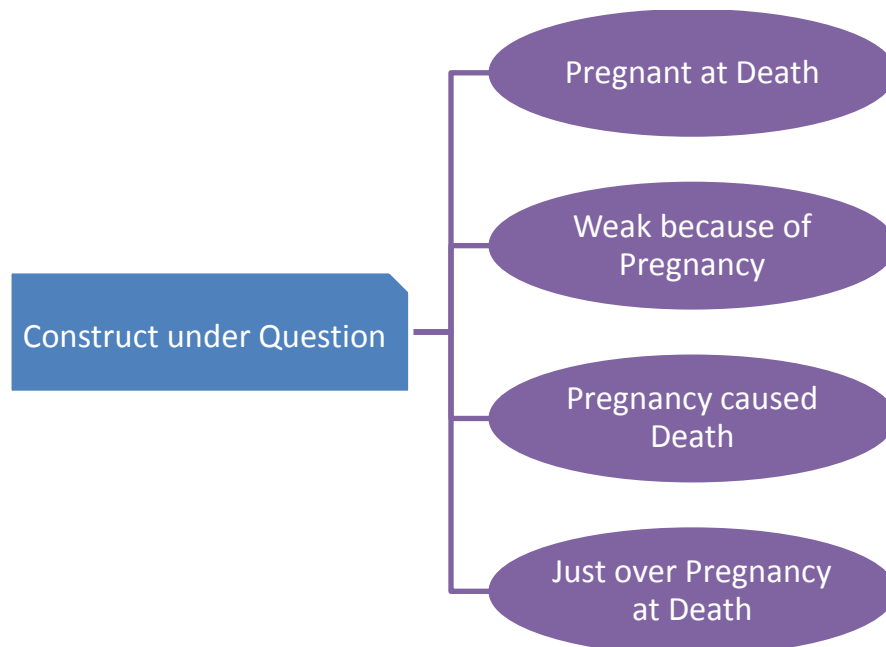

Figure 2: Response Schema for Questions A317 and C320

Therefore, when a respondent answered "yes" or "no" to this question, they were thinking of one of these four patterns of interpretation: whether or not the deceased was pregnant at death, whether she was weak because of the pregnancy, whether the respondent either believed or knew that the death was due to the pregnancy, or whether the deceased had given birth shortly before her death. Such an obvious diversity of interpretations open this question up to a strong likelihood of response errors—both false positive and false negative responses.

Section A4, C4, and N4: Respondent's Account of Illness/Events Leading to Death

Question A401: **Could you please tell me about the illness/events that led to his/her death?**

Question C401
Question N401

While this question was not probed, all of the respondents' responses were recorded and transcribed by the cognitive interviewers. There is, of course, a large amount of variation in not only the lengths of the narratives, but also the particular stories and their content. However, across the entire cognitive interviewing sample there were certain types of information that all (or at least nearly all) the respondents included in their narratives. These include:

- Duration of illness: If the cause of death was an illness, how long that illness lasted, or how long the respondent was aware of the illness

- Major Life Events During Illness/Around death: Events that give context to the narrative, including visits from the city, weddings or other deaths, or moves as a result of the illness

- Symptoms: Behaviors and signs of an illness that the respondent considers salient

- Diagnoses/Cause of Death: The cause of death, in the mind of the respondents. This could include "official" diagnoses by doctors, self-diagnoses, or (in the case of accidents) the accident or injury that occurred and led to death

- Treatment: The treatment—both medical and cultural—that was provided to the deceased. This often included not only medicines, but behaviors (i.e. exposure to fresh air) and prayers as well

- Timing of Death: How quickly the respondent died from the time of diagnosis/injury. In the case of illness, this was often expressed separately than the duration of the illness, with respondents thinking mostly about the final stretch of life.

Respondents who indicated that the deceased suffered from an injury (either accidental or not) tended to report fewer of these data points than those respondents talking about deceased with illnesses. While talking about an illness, a respondent might explain when the symptoms first presented, whether or not the deceased moved or went to hospitals during the illness, what other symptoms emerged, whether or not there was a diagnosis, and how quickly a respondent died. Take for instance the following transcribed (and translated) narrative about a woman who died of complications from a stroke:

> It all began on 14 – 11 – 2013 when we were seated at her house story telling her speech became faulty and she collapsed and was paralyzed on one side of the body after sometime she got back to her sense and was okay, I left her at home and went to prepare my supper and at around midnight her grandchild come and woke me up that her condition has returned, she slept on it and on the morning of 15 – 11 – 2013 I took her to

the nearby [Health Center] where she was referred to [District Hospital]. While at Kisumu District Hospital she was examined, she was diagnosed with heart failure and stroke and admitted at the hospital 11 days later she was discharged when we saw no change to her health status and took her home, she took slightly over a week and died.

On the other hand, respondents answering about a deceased person who suffered from (and died as a result of) an injury or accident were much more to the point. They rarely discussed "symptoms" outside of the visual signs of either a beating or a fall, and tended not to talk much about treatment. Additionally, since these were much more sudden events, these respondents did not talk at all about "duration," but rather focused on the event that led to the injury and how soon after the event the deceased passed. Compare the previous example to this transcribed and translated narrative about a man who was attacked and died of the resulting injuries:

> The respondent said that they got a phone a round 8.00pm at night that the deceased was stabbed by strangers and was rushed to [District Hospital] where he died after getting some treatment. She said the deceased's spinal cord was pierced and one of his eyes removed and people were suspecting that some of his friends might have stabbed him.

This distinction between injury and illness cases might be significant from the perspective of fully implementing the VA instrument. If the point of the narrative captured in Qs A401, C401, and N401 is to validate the rest of the instrument's answers, it might not end up being fully useful for the injury sub-population. However, given that the cognitive interviewing sample was heavily skewed towards illness causes of death over injury causes of death (only 4 respondents reported on injuries across all three sub-samples), more work would be necessary.

Question A402:   **Cause of death according to respondent?**

Question C402   *Iparo ni ang'o madine kel thone?*
Question N402

In response to Questions A402, C402, or N402, the respondents all restated the conclusion of their narratives in Qs A401, C401, or N401. In other words, no respondent gave a response to QA402 that did not correspond to what he or she had already said in QA401.

Across all three samples, 13 respondents answered "don't know" to the question. In all of these cases, they explained their lack of knowledge or certainty in their narratives to QA401, C401, or N401.

Section A5, and C5: Context and History of Previously Known Medical Conditions

Question A501:   **Was there any diagnosis of Tuberculosis?**

Question C501   *Be ne opime ma oyude ni en gi kahera/TB?*

All respondents in both the adult and child samples received Question A501 or C501, respectively.

Core Construct Interpretations

When asked why they knew that the deceased did or did not have TB, the respondents largely spoke about symptoms, and not actual diagnoses of tuberculosis given by medical professionals. In particular, respondents mentioned coughing, breathing, and chest problems.

Question A502:   **Was there any diagnosis of HIV/AIDS?**

Question C502   *Be ne opime ma oyude gi tuo mar ayaki?*

All respondents in both the adult and child samples received Question A502 or C502, respectively.

Core Construct Interpretations

Respondents across both of these samples understood "HIV/AIDS" in two distinct ways: by concentrating on the causes of HIV or by concentrating on the symptoms of AIDS. For example, one adult sample respondent was clearly thinking only about the causes when answering:

> HIV/AIDS is a disease that kills people and it is got through unprotected sexual intercourse with an infected person or sharing sharp objects used by infected people. [I]never saw [the deceased's] diagnosis but…heard [the deceased] complaining on the day he came from the hospital of how and where he got the disease at his old age.

Others thought just about the symptoms of AIDS. For example, another adult sample respondent (who answered "no" to QA502) said:

> When you have HIV/AIDS you are weak, sickly and are prone to many diseases, your body becomes weak and wasted and you vomit. You also experiences loss of appetite.

Respondents who answered "yes" to the question were slightly more likely to think about the cause, while the respondents who answered "no" to either QA502 or C502 were slightly more likely to think about the symptoms. Very few respondents thought about *both* the cause and they symptoms of HIV/AIDS.

Quite a few adult sample respondents replied "don't know" to Qs A502 and C502. In the adult sample, seven out of 18 respondents said "don't know," while in the child sample only one out of 20 respondents answered this way. In the "don't know" cases, most respondents indicated that they either did not have access to the test results, or that they just never discussed HIV with the deceased. This was not as much

of an issue for children, as most of the respondents in the child sample were the deceased's parents—who would be likely to be familiar with their children's medical records.

Question A503:   **Did s/he have a recent test for malaria?**

Question C503   ***Bende nopime machiegni ne tuo mar malaria?***

All respondents in both the adult and child samples received Question A503 or C503, respectively.

Core Construct Interpretations

Rather than answering the question about whether or not the deceased had a *test* for malaria before death, the respondents instead universally answering this question about whether or not the respondent *had* malaria before death. Since the respondents cannot know that the next question on the instrument (Questions A504 and C504) deal with the result of the test, they appeared to approach this question like the previous two questions asking specifically about *diagnoses*. Like what was observed above with Qs A502 and C502, respondents employed a similar schema focusing on the symptoms or causes of malaria in Questions A503 and C503. For symptoms, respondents tended to think about vomiting, fevers, and headaches. While most respondents who thought about the causes correctly identified mosquito bites as the common vector for malaria, a sizable number indicated that malaria is caused by cold or damn weather or environmental conditions.

Although this interpretation of the cause of malaria is clearly cultural, follow-up interviews reveal that it is common throughout the Luoland cultural region. Most respondents who mentioned the fact that malaria is caused by the cold also mentioned mosquitos. For instance, one adult sample respondent said that "[malaria is] caused by exposure to mosquitos and to the cold." A respondent in the child sample noted that:

> …this is a disease that affects every body and is spread by mosquitoes and cold. The things we eat also contribute. For example during the harvesting season, when we eat the new food or cold food then you are stand a chance of getting malaria.

It is possible that the cultural understanding of malaria has evolved in such a way that "cold" or "damp" simply function as glosses for the environmental conditions or times of day when malarial mosquitos are at their worst, and when the probability of getting bit is at its highest. Further research would be needed to test this hypothesis.

Question A504:   **What was the result?**

Question C504   ***Ka ee, douko mar pim ne en mane?***

Sixteen adult sample respondents received Question A504, and 13 members of the child sample received Question C504. Again, more respondents in the adult sample indicated that they did not know the test results (four of 16) than in the child sample (one of 13). This question was not probed extensively; detailed findings are not available.

Question A505:   **Was there any diagnosis of Measles?**

Question C505   *Be ne opime ma oyude gi tuo mar ang'iew?*

All respondents in both the adult and child samples received Question A505 and C505, respectively. Of these 38 total respondents, 13 (eight in the adult sample, and five in the child sample) answered the question with a "don't know" response, indicating a relatively low level of comprehension.

Core Construct Interpretations

Respondents understood the disease "measles" in one of two ways: by either thinking about the symptoms or about the population that is at risk of having measles. The first of these pathways is relatively unremarkable, and is similar to what was seen in the previous questions in this section. In regards specifically to measles, most respondents mentioned skin rashes and fevers, while a smaller number mentioned coughing and red eyes, lips, and mouths.

The second pathway, however, is specific to Questions A505 and C505, and led to some confusion in the adult sample. By and large, measles was understood to be a childhood disease. For instance, one child sample respondent explained what measles was by saying:

> Measles is called "Tuo matindo" in Luo and it is common in children. The child might have patches on the tongue and the mouth has a sour smell.

Similarly, an adult sample respondent said:

> Measles is an airborne disease that affects mostly children. [It presents with] cough, rashes, red lips, and red eyes.

Some few other respondents noted that measles can affect both children and adults, but most respondents either explicitly said or indicated that it was a childhood disease. This led to some confusion with adult sample respondents, as they did not understand if the question was asking about the respondent at the time of death or during his or her childhood. For example, one respondent asking about her adult sister-in-law responded "don't know" to the question and went on to explain that since she did not know the woman when she was growing up, and that measles is an exclusively childhood disease, she could not provide an answer.

Question A506:   **Was there any diagnosis of High Blood Pressure?**

Question C506   *Be ne opime ma oyude gi tuo mar remo maringo matek?*

All respondents in the adult sample received Question A506, and all members of the child sample received Question C506. Six respondents in the adult sample and four respondents in the child sample answered the question with a "don't know." This question was not probed extensively; detailed findings are not available.

Question A507: **Was there any diagnosis of heart disease?**

Question C507 *Be ne opime ma oyude gi tuo mar adundo?*

All respondents in the adult sample received Question A507, and all members of the child sample received Question C507. Seven respondents in the adult sample and four respondents in the child sample answered the question with a "don't know." This question was not probed extensively; detailed findings are not available.

Question A508: **Was there any diagnosis of diabetes?**

Question C508 *Be ne opime ma oyude gi tuo mar adundo?*

All respondents in the adult sample received Question A508, and all members of the child sample received Question C508. Seven respondents in the adult sample and five respondents in the child sample answered the question with a "don't know." This question was not probed extensively; detailed findings are not available.

Question A509: **Was there any diagnosis of asthma?**

Question C509 *Be ne opime ma oyude gi tuo mar athma/tuo mar thung'?*

All respondents in the adult sample received Question A509, and all members of the child sample received Question C509. Nine respondents in the adult sample and five respondents in the child sample answered the question with a "don't know." This question was not probed extensively; detailed findings are not available.

Question A510: **Was there any diagnosis of epilepsy?**

Question C510 *Be ne opime ma oyude gi tuo mar ndulume?*

All respondents in the adult sample received Question A510, and all members of the child sample received Question C510. Nine respondents in the adult sample and four respondents in the child sample answered the question with a "don't know." This question was not probed extensively; detailed findings are not available.

Question A511: **Was there any diagnosis of cancer?**

Question C511 *Be ne opime ma oyude gi tuo mar adhola manie ich, thuno kata del?*

All respondents in the adult sample received Question A511, and all members of the child sample received Question C511. Eight respondents in the adult sample and four respondents in the child sample answered the question with a "don't know." This question was not probed extensively; detailed findings are not available.

Question A512:   **Was there any diagnosis of Chronic Obstructive Pulmonary Disease (COPD)?**

Question C512   *Be ne opime ma oyude gi tuo mar obo?*

All respondents in the adult sample received Question A512, and all members of the child sample received Question C512. Eight respondents in the adult sample and four respondents in the child sample answered the question with a "don't know." It should be noted that "COPD" was translated into Luo as the more general "lung disease" ("*obo*"). This question was not probed extensively; detailed findings are not available.

Question A513:   **Was there any diagnosis of dementia?**

Question C513   *Be ne opime ma oyude gi tuo mar paro malal?*

All respondents in the adult sample received Question A513, and all members of the child sample received Question C513. Nine respondents in the adult sample and four respondents in the child sample answered the question with a "don't know." This question was not probed extensively; detailed findings are not available.

Question A514:   **Was there any diagnosis of depression?**

Question C514   *Be ne opime ma oyude gi tuo mar chuny ma ool kaluwre gi paro matut?*

All respondents in the adult sample received Question A514, and all members of the child sample received Question C514. Eight respondents in the adult sample and four respondents in the child sample answered the question with a "don't know." This question was not probed extensively; detailed findings are not available.

Question A515:   **Was there any diagnosis of stroke?**

Question C515   *Bende ne otho gi bathe?*

All respondents in the adult sample received Question A515, and all members of the child sample received Question C515. Nine respondents in the adult sample and four respondents in the child sample answered the question with a "don't know." This question was not probed extensively; detailed findings are not available.

Question A516:   **Was there any diagnosis of sickle cell disease?**

Question C516   *Be ne opime ma oyude gi tuo machamo remo?*

All respondents in the adult sample received Question A516, and all members of the child sample received Question C516. Nine respondents in the adult sample and four respondents in the child sample

answered the question with a "don't know." This question was not probed extensively; detailed findings are not available.

Question A517: **Was there any diagnosis of kidney disease?**

Question C517 ***Be ne opime ma oyude gi tuo mar nyarogno?***

All respondents in the adult sample received Question A517, and all members of the child sample received Question C517. Nine respondents in the adult sample and four respondents in the child sample answered the question with a "don't know." This question was not probed extensively; detailed findings are not available.

Question A518: **Was there any diagnosis of liver disease?**

Question C518 ***Be ne opime ma oyude gi tuo mar chuny?***

All respondents in the adult sample received Question A518, and all members of the child sample received Question C518. Eight respondents in the adult sample and four respondents in the child sample answered the question with a "don't know." This question was not probed extensively; detailed findings are not available.

Question A519: **In which season did <NAME> die?**

Question C519 ***<NAME> ne otho e kinde mane?***

Question N901

All respondents in the adult sample received Question A519, all members of the child sample received Question C519, and all remaining members of the neonate sample received Question N901. The answer categories for this question were "dry season" and "wet season." All the respondents across the three samples were able to provide an answer within these categories, although one child sample respondent indicated that she was not completely sure.

Core Construct Interpretations

Questions A519, C519, and N901 were not extensively probed, but some analysis is possible from the data that are available. Respondents used economic trends and natural resource availability as cognitive cues to help them recall in which season the deceased died. For instance, one adult sample respondent explained how she remembered the season based on the availability of fodder for her cattle:

> …it was a dry season because I remember coming back from the hospital and taking [the] cattle for grazing. Since there was no grass to feed them…[I] had to go further from home to look for grass.

Besides thinking about husbandry, a number of respondents considered whether or not fruits such as mangos were available. Such fruit is only available in the wet season, and a few respondents noted that they sell mangos on the side for extra money.

Question A520:   **For how long was s/he ill before s/he died?**

Question C520   *Ne otuore kuom kinde marom nade kapok otho?*

Question N902

All respondents in the adult and child samples received Question A520 or Question C520, respectively. One adult sample, and two child sample, respondents answered "don't know." Additionally, one adult sample respondent did not provide an answer, noting that their deceased had been stabbed and was not ill at all before that. 12 members of the neonate sample received Question N902, even though 15 out of the original 20 were eligible (the other five had finished the survey due to a stillbirth in QN710).

Core Construct Interpretations

Questions A520, C520, and N902 were not probed across the whole sample, but some analysis is possible from the data that are available. Among the respondents who were probed on this question, there was quite a bit of variation in what they considered to be the "starting point" of the illness (the end point was always, obviously, the death). This variation appears to be related to how the respondent specifically interprets "ill." Respondents who were thinking about general states of being—such as weakness or tiredness—tended to have "looser" starting points than did respondents thinking about *specific* symptoms or behavioral changes. For instance, one child sample respondent who reported that his child was sick for three months said that the deceased always seemed "abnormal" and "not happy." On the other hand, another child sample respondent (who said her child was sick for four hours) spoke about chest congestion and the onset of pale skin.

Question A521:   **Did s/he die suddenly?**

Question C521   *Bende ne otho apoya?*

Question N903

All respondents in the adult and child samples received Question A521 or Question C521, respectively. One adult sample, and two child sample, respondents answered "don't know." Additionally, one adult sample respondent did not provide an answer, noting that their deceased had been stabbed and was not ill at all before that. 13 out of the 15 eligible neonate respondents received Question N903. Of them, all but one answered "yes," and there was a lone "no" response.

Core Construct Interpretations

"Suddenly" is a vague term that can carry a number of definitions across a culture. Correspondingly, there was variation in the way the respondents interpreted Questions A521, C521, and N903. However, the overall construct validity of this question was tighter than some of the other questions with vague terminology (i.e. excessive bleeding, complicated delivery, etc). Overall, the respondents in both the adult and child samples thought about suddenly in two ways—either as something unexpected, or

something that happens in a very short amount of time. Within this latter interpretation of the construct, there was a relatively wide range of times that the respondents counted as "short" or "quick."
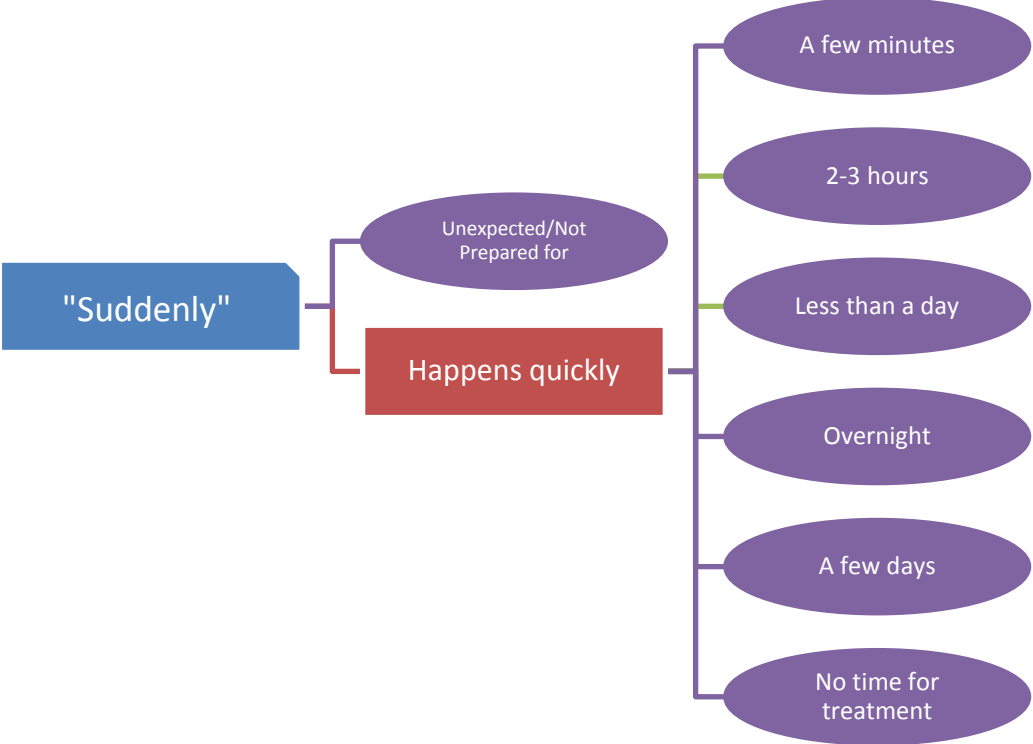
Figure 3: Response Schema for Questions A521, C521, and N903

The overall construct validity of this question is relatively tight, as most respondents considered both interpretations of the construct—expectedness and timing—together when answering this question. It appears therefore that there is a large amount of cultural agreement that something that happens "suddenly" is unexpected and happens within a "short" amount of time. For example, one respondent in the child sample explained that she considered something that happens suddenly to be unexpected and takes between 1 and 4 days.

Section N5: Pregnancy History

Question N501:   **How many births, including stillbirths (28 weeks), did the mother have before this baby?**
Koweyo nyathi mothoni, gin nyithindo adi ma isenyuologa/osenyuologa ka oriwo ma onywol ka otho?

All 20 respondents in the neonate sample received Question N501. The responses to the question ranged from 0 to 11. A few respondents indicated that they were guessing, since they did not remember how many stillbirths they had had in the past.

Although the question was not probed extensively, some comprehension errors emerged. At least three respondents did not count their living children, and only counted stillbirths and children who had previously died. One respondent changed her answer during the cognitive interviewing portion of the interview, as she did not count stillbirths in her response during the VA interview.

Question N502:   **How many weeks was the pregnancy when the baby was born?**

Ne en ich humbe adi ka ne onyuol <NAME>?

All 20 respondents in the neonate sample received Question N502; none of them answered "don't know."

Respondents were probed on their ability to remember the specific duration. Generally speaking, there were two ways they appeared to recall the duration of the pregnancy: either by looking at the death certificate or "clinic card," or through a heuristic. A heuristic is an immediate interpretation that relies not on reasoning, but on "immediately" knowing or understanding sometime based on the respondent's experiences—in this case the death of a child is a very salient life event that does not necessarily require extensive reasoning. In most cases, the respondent used both of these pathways—often "checking" their heuristic answer with the documentation.

While each of the respondents was able to provide an answer to QN502, they rarely answered within the answer categories. The answer categories—"Less than 34 weeks," "Between 34 and 37 weeks," and "More than 37 weeks" do not in any way appear to be culturally relevant categorizations within the Luo community. It is unclear whether or not the VA interviewers actually read the answer categories, or whether they simply coded the respondents' open-ended responses at the time of the interview. If indeed the answer categories are to be read, further work is needed to create culturally-relevant answer categories.

Question N503:   **During pregnancy did the mother suffer from any of the following known illnesses?**
          [i] High blood pressure
          [ii] Foul smelling vaginal discharge during pregnancy
E kinde mane en gi ich <NAME>, be min nyathi nopim ma oyud gi touché madhi somonigi?
          [i] Remo maringo matek/presa
          [ii] Tik manewuok e duong'ne mane dum marache

Question N503:   **During pregnancy did the mother suffer from any of the following known illnesses?**
         [i]   High blood pressure
         [ii] Foul smelling vaginal discharge during pregnancy

All 20 respondents in the neonate sample received Question N503. Of them, only four respondents reported illnesses—all high blood pressure. No respondents reported having "foul smelling vaginal discharge." One respondent expressed confusion over what counted as foul-smelling discharge. She eventually decided that she did not have that during the pregnancy.

Question N504:   **During the last 3 months of pregnancy did the mother suffer from any of the following known illnesses?**
         [i]   Vaginal bleeding
         [ii] Convulsions
         [iii] Blurred vision
     E dweche adek mogik mag bedo mayach, be min nyathi ne nigi moro amora kuom tuochegi mong'ere madhi somonigi?
         [i]   Chuer mawuok e duong'ne
         [ii] Talarieya
         [iii] Wang' malil

All 20 respondents in the neonate sample received Question N504. This question was not probed extensively during the cognitive interviews, and no findings are available.

Question N506:   **Was the child a single or multiple birth?**

     Kane onyuol <NAME> ne en achiel koso rude?

Question N507:   **Was the child born in a complicated delivery?**

     Be ne otho ka en gi ich mar rude kata bang' nyuolo rude?

The same general response pattern seen before with the "cultural definition" questions—excessive bleeding, size of the baby, and size of the head—was used in Question N507. The respondents determined what particular construct to focus on, determined its normal or abnormal state, and then judged the deceased's delivery against this standard. In QN507, there was considerable variation across both the core construct of "complicated delivery," and the definition of normality (like what was seen in Qs C701 and N701). Here, the constructs that the respondents considered can be grouped by time relatively to the delivery itself—some respondents were thinking about what happens before the delivery, some were thinking about the delivery and birthing, and others were thinking about what happens after the delivery:
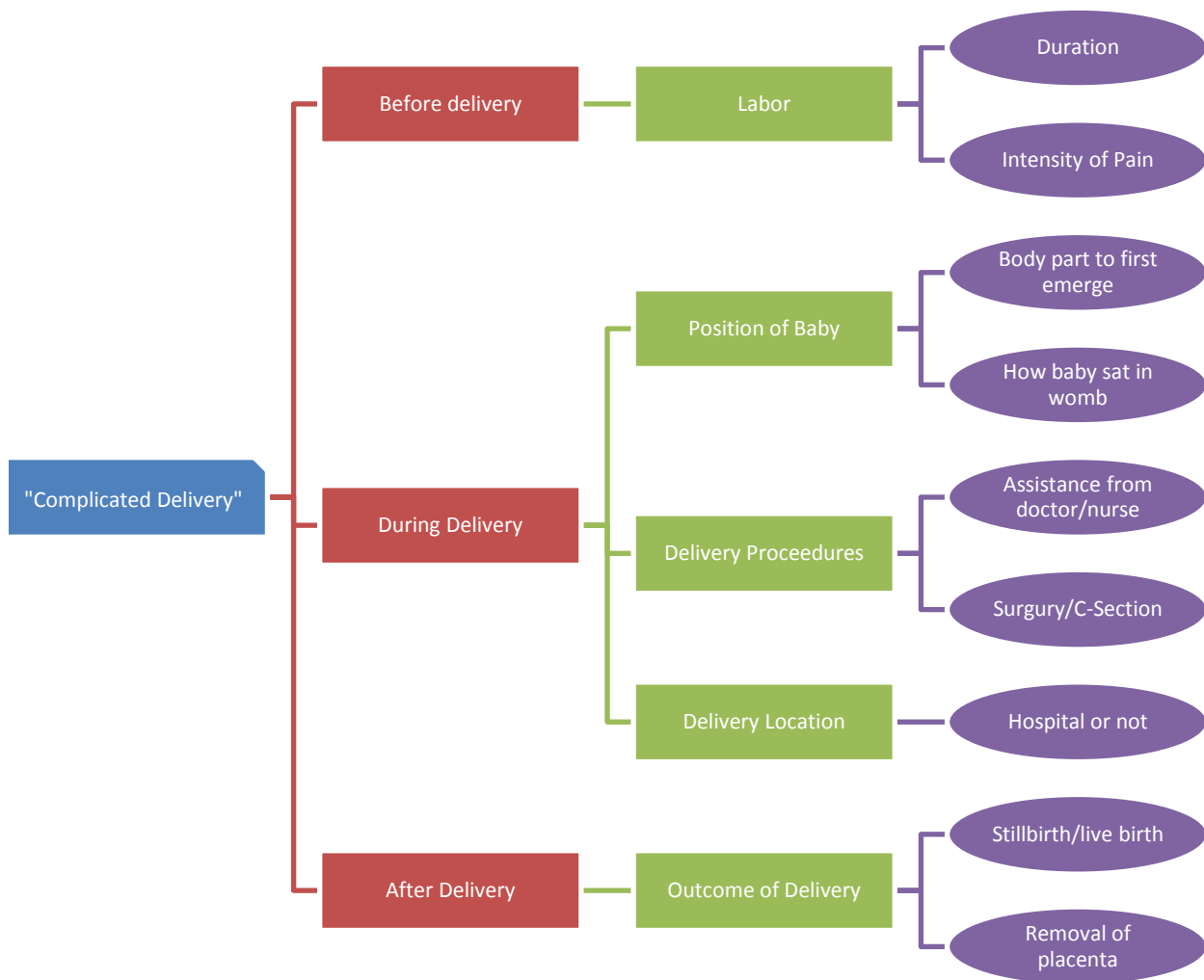
Figure 4: Response Schema for Question N507

Since normality is again undefined in the question text, across these various interpretations of the construct, the respondents defined a variety of standards for normality/abnormality. This question's response pattern and construct schema looks similar to the adult questionnaire questions asking about fetal positioning, labor duration and "normal vaginal delivery"—Questions A822/C922, A823/C923, and A829/C929/N605.

Question N601:   **Where was the child born?**

                            Nyathini nonyuol kanye?

The full neonate sample of 20 respondents received Question N601. Of them, one respondent answered "home," three used the "on the way to the hospital" answer category, and the rest said "hospital."

This question was not probed extensively during the cognitive interview. The respondents that did explain their answers all interpreted this question as asking about the place where the baby was fully delivered, and not where they were when the delivery process began or when their water broke. For instance, one respondent said that:

> …the baby started coming out at home, and then [we] rushed to the hospital since it was coming out abnormally with both its feet and one hand…

This respondent answered "hospital," since that is where the baby was delivered, and not "home" where the birth started.

Question N602:   **Who assisted with the delivery?**

                            En ng'a mane ochole/ocholi kane?

19 of the 20 neonate respondents received and answered Question N602. Of them, one answered "no one," one responded "don't know," and the other 17 answered "doctor/clinical office/nurse."

This question was not probed during the cognitive interview, and no findings are available.

Question N603:   **How many hours after the water broke was the baby born?**

                            Nyathini ne onyuol bang' seche adi ka opuyo/opiyo osetore?

All 20 neonate respondents received Question N603.

This question was not probed during the cognitive interview, and no findings are available.

Question N604:   **Did the baby stop moving in the womb before labor started?**

                            Be nyathini ne oweyo tugo/chapni/guecho ei mingi kapok muoch ochakore?

The full neonate sample received Question N604. Two respondents indicated that they did not know the answer. One respondent—a father—explained his "don't know" answer by saying that "only the mother" could say whether or not the baby was moving.

This question was not probed during the cognitive interview, and no findings are available.

Question N605:   **Was it a normal vaginal delivery?**

Be ne en nyuol makare mowuok e duong'ne?

Please see Page 26 of this report. Question N605 is detailed alongside Question A829 and Question C929.

Question N606:   **What type of delivery was it?**

Ka ok nyuol makare, ne en nyuol machal nade?

Please see Page 58 of this report. Question N606 is detailed alongside Question A830 and Question C930.

Question N607:   **Which part of the baby came first?**

En ang'on nyathini mane okuongo wuok ka inyuole?

19 members of the neonate sample received and answered Question N607. One respondent (or interviewer) incorrectly skipped it. Of the 19, three said "feet," 15 said "head," and one respondent said "don't know."

This question was not probed during the cognitive interview, and no findings are available.

Section N7: Condition of the Baby Soon After Birth

Question N701:   **At birth, what was the size of the baby?**
                Nyathini ne onyuol karom nade?

Please see Page 39 of this report. Question N701 is detailed alongside Question C701.

Question N702:   **Was the umbilical cord wrapped several times (more than once) around the neck of the child at birth?**
                Bende tond biero ne onalore ding'eny e ng'ut nyathini ka ne inyuole?

All 20 members of the neonate sample received Question N702. Five respondents said "yes," 10 respondents answered "no," and five responded "don't know." The respondents who said "don't know" explained that they did not witness the birth.

This question was not probed during the cognitive interview, and no findings are available.

Question N703:   **Did the baby have any noticeable malformation?**
                Be nyathini ne nigi ng'ol moro amora maneno?

Please see Page 42 of this report. Question N703 is detailed alongside Question C705.

Question N704:   **What kind of malformation did the baby have?**
                Nyathini ne onyuol karom nade?

No respondents received Question N704; no findings are available.

Question N705:   **What was the color of the baby at birth?**
                Nyathi ne en gi rangi machal nade kne onyuole?

All 20 neonate sample respondents received and answered Question N705.

This question was not probed extensively. All but one respondent were able to fit their responses into the answer categories provided ("normal," "pale," "blue," or "don't know"). However, one respondent refused to use the answer categories, and explained that the baby was "white" upon birth.

Question N706:   **Did the baby breathe after birth, even a little?**
                            Bende nyathini noyueyo kata matin bang' kosenyuole?

The full neonate sample received Question N706.

This question was not probed during the cognitive interview, and no findings are available.

Question N707:   **Did the baby ever cry after birth, even a little?**
                            Bende nyathini noywak kata matin bang' kosenyuole?

The full neonate sample received Question N707.

This question was not probed during the cognitive interview, and no findings are available.

Question N708:   **Was the baby given assistance to breath at birth?**
                            Bende nyathini nomi kony mondo oyue bang' nyuoline?

All 20 neonate respondents received and answered Question N708.

This question was not probed during the cognitive interview, and no findings are available.

Question N709:   **Did the baby ever move, after birth, even a little?**
                            Bende nyathini nochapni/kithni kata matin bang' nyuolne?

The full neonate sample received Question N709.

This question was not probed during the cognitive interview, and no findings are available.

Question N710:   **If the baby did not cry, breathe, or move, was it born dead?**
                            Ka nyathini ne ok oywak, oyweyo kata okithini, ne onyuole ka otho?

15 respondents received Question N710. However, only four of the 20 in the neonate sample were eligible for this question, based on their "no" answers to Qs N706, N707, and N709. Of the 15, five answered "yes," indicating that the baby was born dead. These five included all four respondents who were supposed to receive QN710, as well as one other who was supposed to skip it. These respondents skipped to the end of the survey.

This question was not probed during the cognitive interview, and no findings are available.

Question N711: **Was the baby macerated, that is, showed signs of decay?**

Be nyathini ne nigi ranyisi mag chako top ka onyuole?

10 respondents in neonate sample received Question N711.

This question was not probed during the cognitive interview, and no findings are available.

Section A6, C6, and N8: History of Injuries and Accidents

Question A601:   **Did s/he/the baby suffer from any injury or accident that led to his/her death?**

Question C601   *Bende <NAME> ne obet gi hinyruok kata masira ma tho mare ne*

Question N801   *owuokie?*

All 18 members of the adult sample received Question A601. Of them, three responded "yes," three responded "don't know," and the rest answered "no." Of the 20 respondents in the child sample, one respondent answered "yes," one answered "don't know," while the rest responded "no" to Question C601. In the neonate sample, of the 20 cases, five respondents did not receive Question N801 at all because the death was the result of a still birth and the interview ended at QN710. Of the 15 respondents who received QN801, one said "yes," three responded "don't know," and the other 11 answered "no."

Core Construct Interpretations

There is a lot of variation in the interpretation of the core constructs, the overall response pathways, and even the reference period in Qs A601, C601, and N801. First, Figure **5** below shows the overall interpretation of the constructs "accident" and "injury." Across the samples, respondents considered causes, outcomes, and specific examples of both accidents and injuries. Generally the respondents did not think across these patterns of interpretation—they would not consider both specific examples and outcomes. For example, one respondent explained that an injury could be a cut or a broken bone, but she did not think about the cause of the broken bone or what might result from it.

In addition to the large amount of variation surrounding the constructs themselves, the respondents understood the relationship between "accidents" and "injuries" in ways that also led three distinct overall response pathways. Table 3 below lays these three paths out:

<div align="center">Table 3: Relationships between "Accidents" and "Injuries"</div>

Relationship between accident and injury	Response based on...
Accidents and injuries are the same thing	Physical signs of, or communication about, accidents <u>AND</u> injuries.
Accidents lead to injuries	First: Physical signs of, or communication about, accidents. If accident occurred, then consider injury.
Accidents and injuries are different things	Physical signs of, or communication about, accidents <u>AND/OR</u> injuries.

Basically, with the first two of these three paths, the respondent is considering this question to be single-barreled. However in the third case, since the respondent is thinking about accidents and injuries to be two distinct constructs, a "yes" or "no" response to the question could indicate a yes or no to either or both of the constructs—without extensive probing, there is no way to know in the survey environment. In addition to the constructs and response pathways, there was some variation in the reference period the respondents were thinking about when judging their response. While it appears that most respondents across the samples were thinking about an injury or accident that occurred around the time of the

deceased's death, a few respondents were thinking about whether or not the deceased had an accident or injury *ever*.
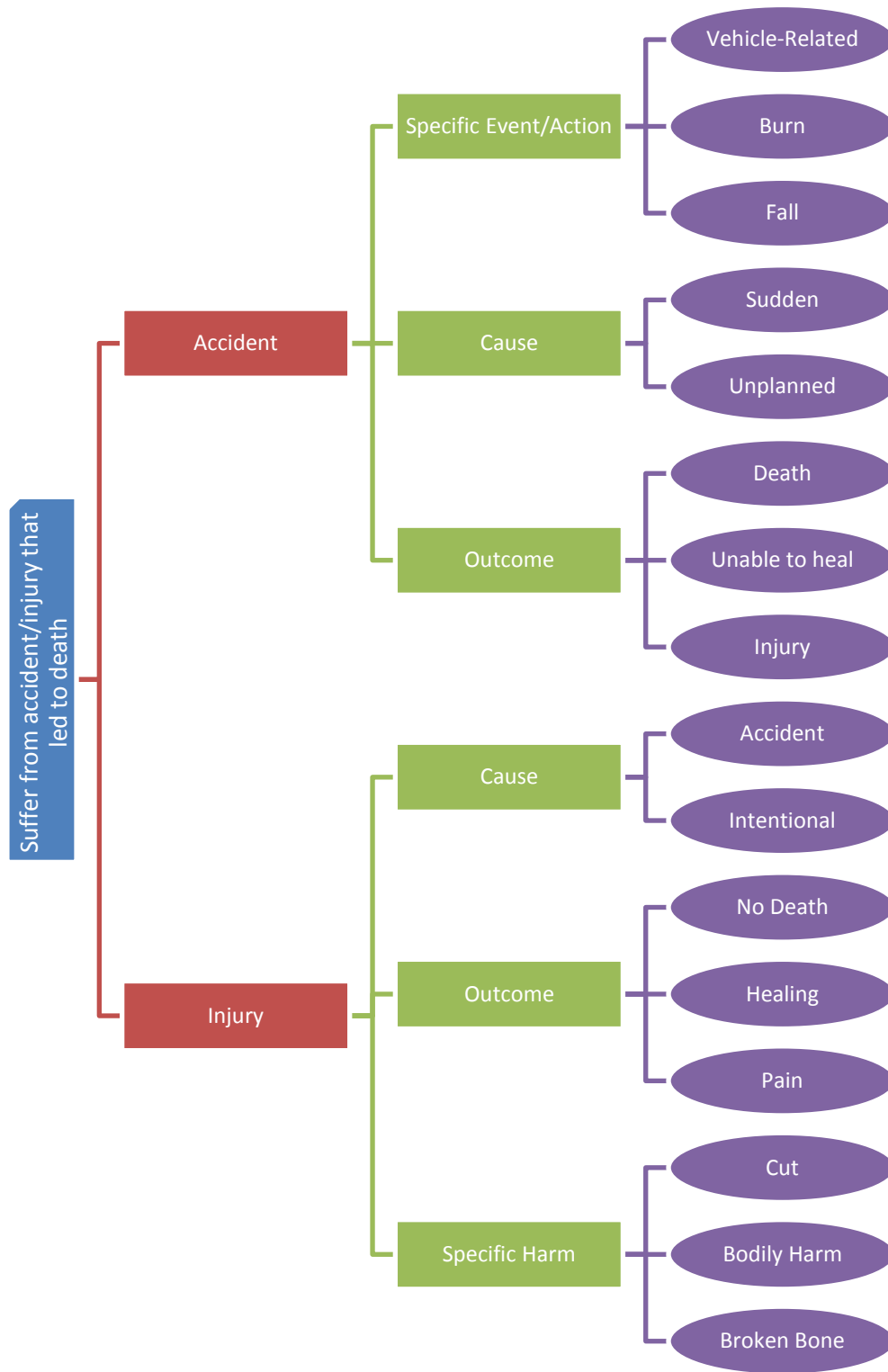

Figure 5: Response Schema for Questions A601, C601, and N801

Question A602:   **What kind of accident did s/he/the baby suffer?**

Question C602   *Ne en hinyruok kata masira mane?*

Question N802

Three members of the adult sample received Question A602, while the other 15 (who responded "no" or "don't know" to QA601) skipped it. One member of the child sample *should* have received Question C602, but incorrectly skipped it. One member of the neonate sample correctly received Question N802. While only four respondents across the three samples received this question, its answer categories were probed extensively during the cognitive interview, even with respondents who did not receive the question.

Questions A602, C602, and N802 provided the following answer categories after the main question text:

- Road Traffic Accident
- Intentionally Inflicted by Someone Else
- Violence or Assault
- Non-Road Transport Accident

Additionally, Questions A602 and C602 presented "Committed Suicide" as an answer category.

Core Construct Interpretations

Respondents carried their various interpretations of Qs A601, C601, and N801 forward into this question. Therefore, if a respondent was thinking only about "injuries" in QA601 and was specifically thinking that injuries are something from which a person can heal; in QA602 then, he or she would apply the same pattern of interpretation.

There was very little observable variation in how the respondents interpreted the various answer categories in Qs A601, C601, and N801. For instance, respondents all understood "non road traffic accident" to be something that does not occur in a motor vehicle—a few respondents gave boating accidents as an example. Likewise, they understood "road traffic accident" to mean something like a car crash or vehicle accident.

The other two categories—"violence/assault" and "intentionally inflicted by someone else" captured similar constructs. For instance, one respondent defined the violence category as when someone does something bad to a person, while defining "intentionally inflected…" as when someone does something bad and he or she is aware of it. A number of respondents simply explained that the two categories meant the same thing. This lack of *differentiation* might lead to high number of response errors if the categories are supposed to represent different events in the VA model.

Question A603:   **[Which of the following] was s/he/the baby injured as?**

Question C603   *Ka ok ne en masira mar ndara kare ne en?*

Question N803

No respondents across the three samples received Questions A603, C603, or N803. No findings are available.

Question A604: **Do you know anything about the counter-part that was hit during the road traffic accident? [If yes, what was the counter part?]**

Question C604 *Be ing'eyo ng'ato kata gimoro amoro mane otuom e masira mar ndara no*

Question N804 *[Ka ee, yie ipenj]?*

No respondents across the three samples received Questions A604, C604, or N804. No findings are available.

Question A605: **[Which of the following type of accident] was it?**

Question C605 *Ka ok ne en masira mar ndara kare ne en?*

Question N805

Nobody in either the adult or child samples received Question A605 or Question C605. One member of the neonate sample correctly received Question N805 (by answering "non-road transportation accident in QN802).

This question was not probed during the cognitive interview and no findings are available.

Question A606: **What type of animal or insect?**

Question C606 *Ne en lee kata kudni mane?*

Question N806

No respondents across the three samples received Questions A604, C604, or N804. No findings are available.

Section A7: Symptoms and Signs Associated with Illness of Women

Question A701:   **Did she have an ulcer or a swelling in the breast?**

Be ne en gi adhola manenore oko e del kata e thuno mokuot?

10 respondents received Question A701. Of these 10, two were answering about deceased males and incorrectly received the question. The other eight adult sample respondents—all answering about deceased males—correctly skipped this section. All 10 adult sample respondents who received this question answered "no."

This question was not probed extensively during the cognitive interview. Those respondents who were probed all explained their "no" answers by saying that they did not see or notice any visual indication of breast swelling. From this limited data, it appears as though QA701 may be functioning as a double-barreled question—with respondents thinking about *either* ulcers or swelling of the breasts.

Question A702:   **Did she have excessive vaginal bleeding in between her menstrual period?**
Be ne en gi remo machwer mang'eny ka oken e dwe?

Nine adult sample respondents answered Question A702, with one "male" respondent continuing to receive questions in this section incorrectly. Of these nine respondents, four answered "yes," four answered "don't know," and one (the respondent answering about a deceased male) answered "no."

Core Construct Interpretations

When determining whether or not the deceased had excessive vaginal bleeding, the respondents consistently thought not about excessive bleeding *per se*, but rather normal bleeding. As can be seen below in the schema presented in Figure 6, the respondents considered one of two constructs' normalcy: the amount of blood let or the amount of time the woman was bleeding. It is important to point out that the respondents appeared to consider one of these constructs or the other—in other words, when a respondent was trying to determine if the woman had excessive bleeding, he or she would only consider whether or not the amount or the duration of bleeding was normal. He or she would not consider both amount and duration.
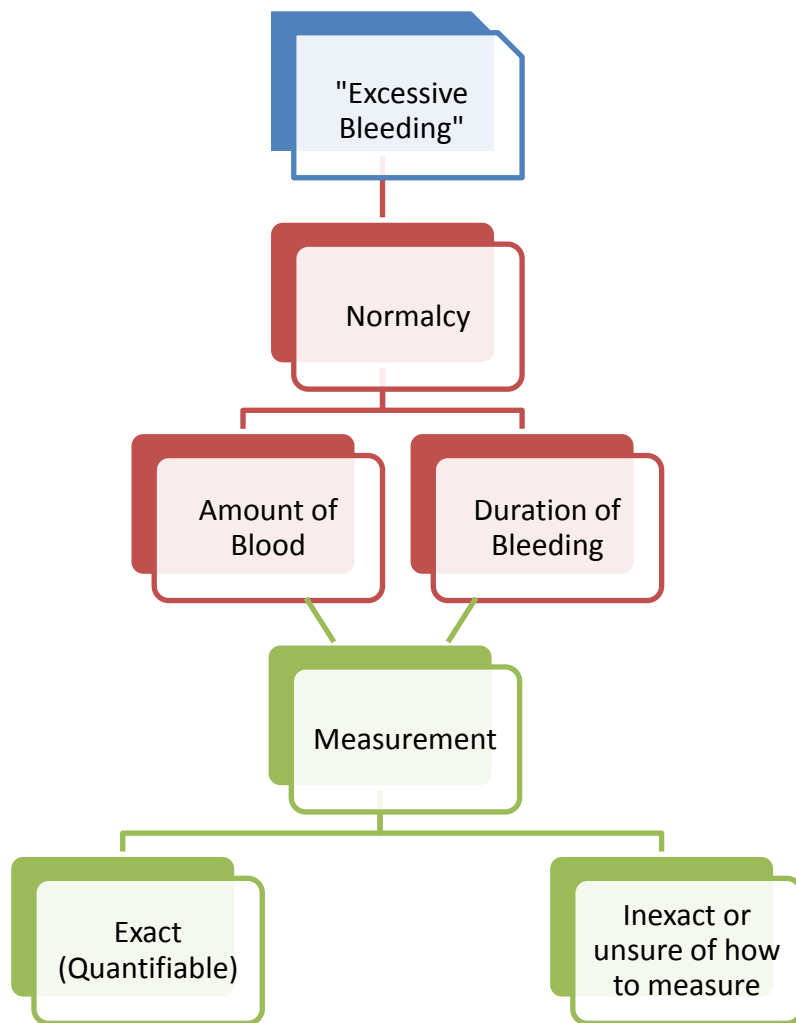
Figure 6: Response Schema for Question A702

Within both of the two constructs—amount and duration of bleeding—that the respondents considered, normalcy was measured both in exact (quantifiable) or inexact measurements. For instance, one respondent used an exact measurement of duration, noting that normal vaginal bleeding would only occur for 2 or 3 days. Another respondent said that bleeding that occurred for a long time was not normal, but did not quantify what "a long time" meant.

Regardless of whether a respondent chose to measure normalcy by an exact or inexact standard, they answered QA702 by comparing either the amount or duration of the deceased's bleeding by that standard. The respondents who answered the question "don't know," all explained that they were unable to make this comparison because they were either not present during the bleeding or felt like they did not have enough evidence to make a judgment.

Question A703:   **Did her vaginal bleeding stop naturally during menopause?**

Be ne oweyo dhi malo e saa/kinde ma owinjore?

Only one respondent in the adult sample was asked this question (answering about a 69 year-old female), while the other 17 skipped this question. Included in this number was one deceased female aged 40 or above—an incorrect skip.

This question was not probed during the cognitive interviews, and no findings are available.

Question A704:   **Did she have vaginal bleeding after menopause?**

Be ne pod oneno remo ka oseweyo dhi e dwe?

Only one respondent in the adult sample was asking this question (the same 69 year-old woman). Again, it appears that there was one incorrect skip, as all deceased women aged 40 and above were supposed to be administered Question A704.

This question was not probed during the cognitive interviews, and no findings are available.

Section C7: Symptoms and Signs Noted during the Final Illness of Infants

Note that the only respondents who were supposed to receive questions in the C700 Series were those answering about children who were under 1 year old when they died. The age distribution (by sex) of the deceased individuals in the child sample is shown here in Table 4:

Table 4: Age and Sex Distribution of Respondents in Section C7

	Male	Female	Total
Less than 6 months	8	2	10
Between 6 months and 1 year	0	2	2
Greater than 1 year	3	4	7
No Answer	0	1	1

As can be seen from this distribution, only 12 of the 20 respondents in the child sample should have received the C700 Series questions. However, all 19 out of the 20 respondents received Question C701 and then continued answering the series.

Question C701:   **At birth, what was the size of the baby?**

Question N701   *Nyathini ne onyuol karom nade?*

19 child sample respondents received Question C701—seven of whom incorrectly skipped into this question based on their answer to Question C312. All 21 respondents in the neonate sample answered Question N701, as intended.

Core Construct Interpretations

The interpretation of the smaller than normal-normal-larger than normal scale varied quite a bit across both the child and the neonate sample. Overall, like what was seen in the "Excessive bleeding" questions (i.e. QA702), the respondents attempted to first define a "normal" baby then judge their response based on this interpretation of normalcy:

Step 1: Interpret Construct → Step 2: Define "normal" condition for that construct → Step 3: Judge deceased baby against the state of normalcy → Step 4: Provide survey response
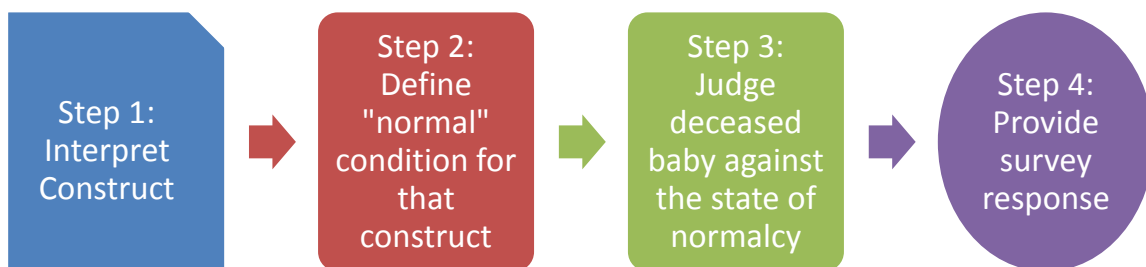
Figure 7: Response Pattern for Questions C701 and N701

While this response process might seem straight-forward on its face, different respondents applied different interpretations within each of these four stages. If we concentrate just on the first box, there were at least 3 different constructs the respondents considered—even though the question text asked them about "the size of the baby:"
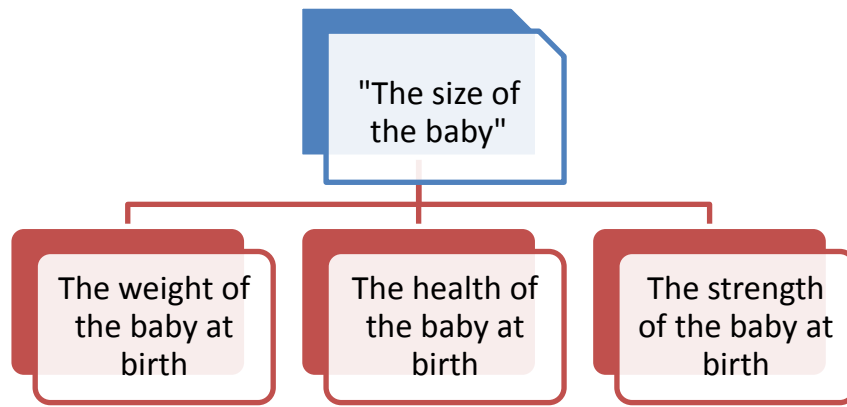
Figure 8: First Level of the Response Schema for Questions C701 and N701

Overall, it appears as though the respondents who were not thinking strictly about the weight (size) of the baby understood "the size of the baby" to be a proxy for the baby's well-being at birth.

Within each of these three constructs, there were multiple ways the respondents defined the "normal condition." For instance, one respondent in the child sample noted that a normal baby is huge and hungry, while another said that a normal baby looks healthy and has good color. Even within those respondents who were considering the weight/size of the baby, some respondents were thinking in general terms (i.e. "huge" as seen in the example above), while others were thinking about quantifiable measurements (i.e. 3.3kg is normal). By adding these various definitions of normalcy to the schema above, we can see the large amount of response variation (and thus potential response error) that is possible:
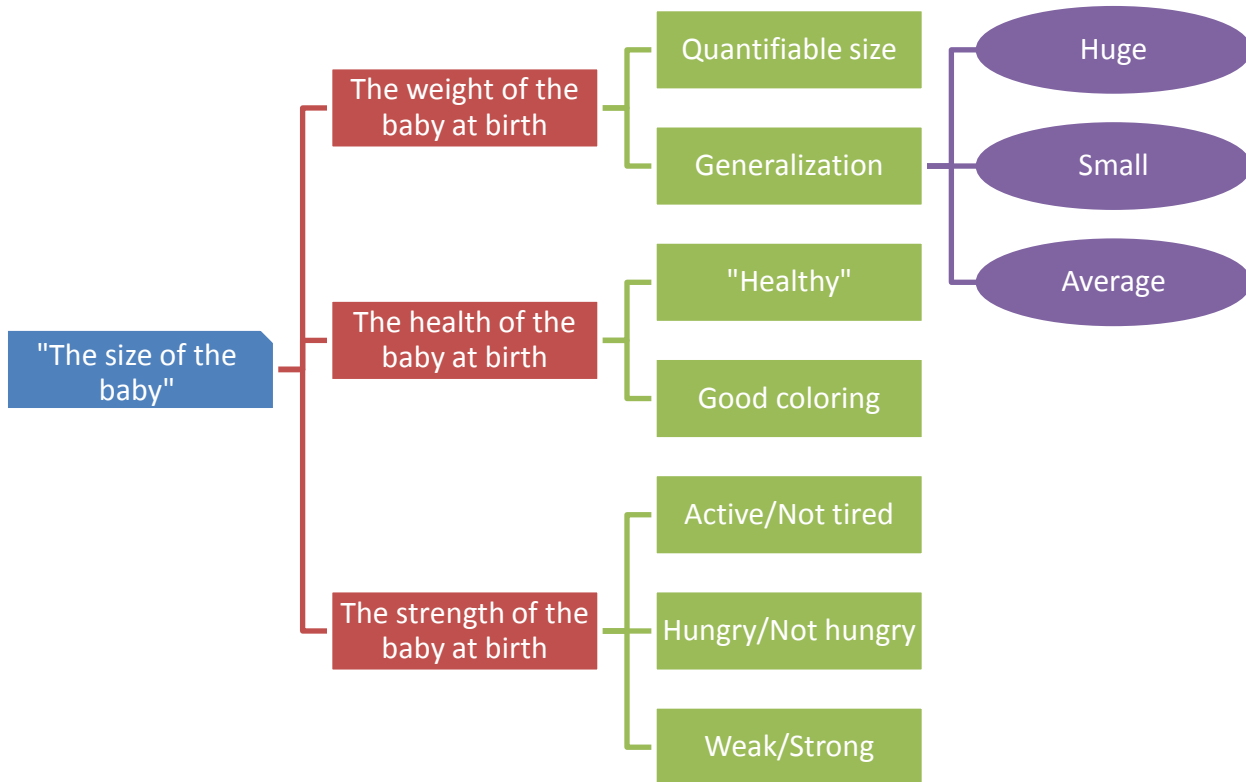

Figure 9: Response Schema for Questions C701 and N701

This potential variation increases even more when you realize that the way the respondents are judging the normalcy of the baby is not constant across the sample. What might be a "strong" baby to one respondent could be a "weak" baby to another. There was even variation within those respondents thinking about quantifiable measurements of weights—while some respondents stuck to the pre-listed ranges in the answer categories (i.e. normal = 2.5-3.9kg), others were simply applying their own knowledge of what is or is not a normal weight. For instance, one respondent said that a baby who was 4.8kg was normal, while another said that 3.0kg was small.

By using terms like "normal," instead of simply asking about set measures, the VA is asking the respondents to apply their cultural understanding of a phenomenon. Perhaps among the Luo of Western Kenya 4.0kg is "normal," whereas in another culture in another place this would be considered either "larger than normal" or even "smaller than normal."

Question C702:	**How many weeks or months was the pregnancy when the child was born?**
Question N502	*Nyanthini ne onyuol gi jumbe/dweche adi?*

19 child sample respondents received Question C702, while all 21 respondents in the neonate sample received Question N502.

Core Construct Interpretations

The respondents across both the child and neonate samples appeared to have no difficulty answering the question. Most respondents reported in months, and explained that they either remembered the date of conception or wrote down (or had it recorded on a clinic card) what the doctor informed them so they would have a record. A couple of respondents did indicate that they converted weeks into months—for example, one child sample respondent explained that she was thinking about the total number of months and then divided that by four because she knew that there were 4 weeks in a month.

None of the respondents who indicated a pregnancy period less than 9 months appeared to use the term "premature," but since this was not probed explicitly, there are no findings that show whether or not this term would make sense to respondents.

Question C703:	**Did the baby have bulging or raised fontanels during the final illness?**
Question N909	*Bende chuny wi nyathini ne kuot ei tuone mogik?*

18 members of the child sample received Question C703. Of these respondents, only one answered "yes," one answered "don't know," and the rest answered "no." 13 members of the neonate sample received Question N909. Of them, 2 answered "yes," two answered "don't know," and the remaining nine responded "no."

This question was not probed extensively, and no findings are available.

Question C704:   **Did the baby have a sunken fontanel during the final illness?**

Question N910   *Bende chuny wi nyathini ne olutore ei tuone mogik?*

14 respondents received Question C704. As 17 respondents responded either "no" or "don't know" to QC703, three respondents incorrectly skipped past QC704. The same 13 respondents who answered QN909 continued on to Question N910, including two neonate respondents who should have skipped due to their "yes" answer to the previous question.

This question was not probed, and no findings are available.

Question C705:   **Did the child have any noticeable malformation?**

Question N703   *Be nyathini ne nigi ng'ol moro amora manenore?*

18 child sample respondents received Question C705; of them, only one answered "yes." All 20 neonate respondents received Question N703. None of them answered "yes," and one respondent said "don't know."

This question was not probed, and no findings are available.

Question C706:   **Did the child have a swelling/defect on the back?**

Be nyathini ne nigi kuom?

16 respondents answered Question C706. However, since only one respondents answered "yes" to QC705, 15 of these respondents incorrectly skipped into QC706. Instead of skipping to the next section (the C800 Series), these respondents continued answering the C700 Series.

This question was not probed, and no findings are available.

Question C707:   **What was the size of the head of the baby?**

Wi nyathini ne rom nade?

17 respondents answered, and were probed on, Question C707. Again, only one of these respondents correctly received this question by answering "yes" to QC705.

Core Construct Interpretations

Question C707, much like Qs C701 and N701, asks respondents to define and apply cultural definitions of normality to the size of a baby. While there was less observable variation across the child sample, the exact same response process is at work here in QC707 as it was in Qs C701 and N701. A respondent first determined the construct under consideration and then established a state of "normalcy" for that construct. The respondent then judged the deceased baby against this standard of normalcy and applied one of three response categories—in this case, "very large," "very small," and "normal."

The biggest contributor to the decrease in variation of interpretation between Qs C701 and N701 and this question is the fact that only one construct—the physical size of the baby's head—emerged during the cognitive interviewing. However, within this construct there were still multiple ways the respondents defined "normality," as seen below in Figure 10.
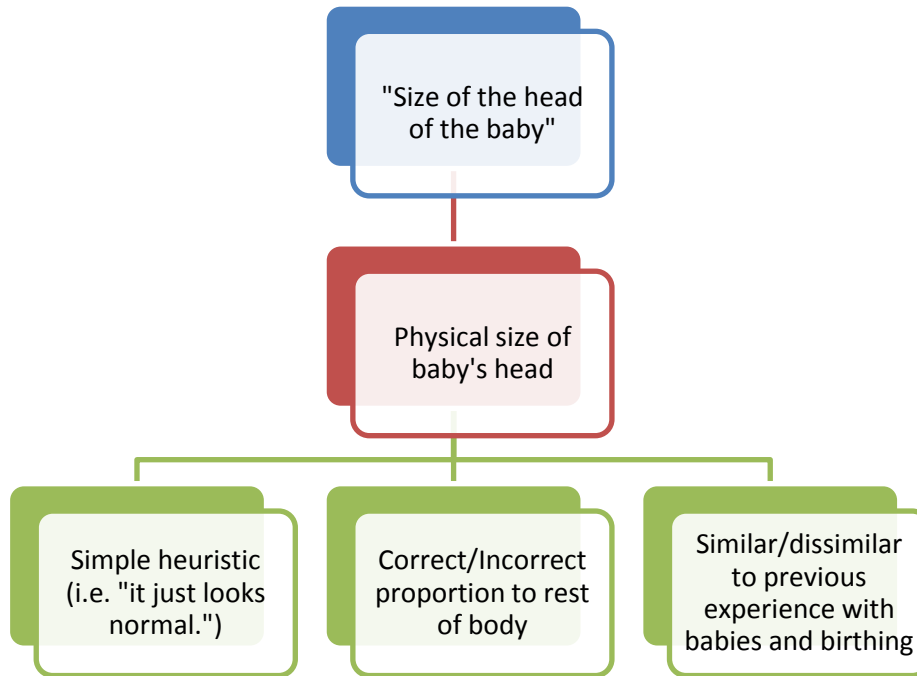
"Size of the head of the baby"

Physical size of baby's head

Simple heuristic (i.e. "it just looks normal.")

Correct/Incorrect proportion to rest of body

Similar/dissimilar to previous experience with babies and birthing

Figure 10: Response Schema for Question C707

Again too, across the respondents who received this question, there was also variation in how the respondents judged the baby in question against this standard of normalcy. For instance, one respondent who was thinking about normal proportions simply said that the baby looked right, whereas another respondent who was thinking about proportions compared the deceased baby to others she had seen. All of this variation decreases construct validity, and increases the potential for response errors and non-sample error.

Question A801: **Was she neither pregnant, nor delivered, within 6 weeks of death?**

Question C901 *El jumbe auchiel mar thone be nyalo bedo ni ok ne opek kata ok ne onyuol?*

Seven respondents in the adult sample received Question A801, while the other 11 skipped out. Of these seven, one received the question due to an incorrect skip. In the child sample, the four respondents who were answering about a female deceased over the age of 1 all correctly received Question C901. The respondents who answered yes to this question were supposed to skip to Question A901/C1101, while the respondents who answered "no" and "don't know" were supposed to continue on to Question A802/C902.

Core Construct Interpretations

Respondents understood this question to be asking one of two things. Most respondents thought that they were being asked whether or not the deceased was pregnant at the time of her death. For instance, one respondent said that she thought the question was trying to determine if the deceased was up to six weeks pregnant at the time of her death. She went on to say that it is difficult to know, because there usually are not many visual cues at that early stage of pregnancy. In in similar vein, another respondent indicated that she knew the deceased was pregnant at the time of her death because she had received a malaria test shortly before death and the doctors also ran a pregnancy test at the same time.

A second interpretation of this question was to consider whether the deceased had given birth within six weeks of her death. The one adult sample respondent who interpreted QA801 this way explained her reasoning by saying that six weeks is a normal recovery period after birth, and she thought the question was trying to determine if the deceased was still weak from child birth.

The visual schema representing the respondents' interpretations to Q A801 is displayed below in Figure 11.
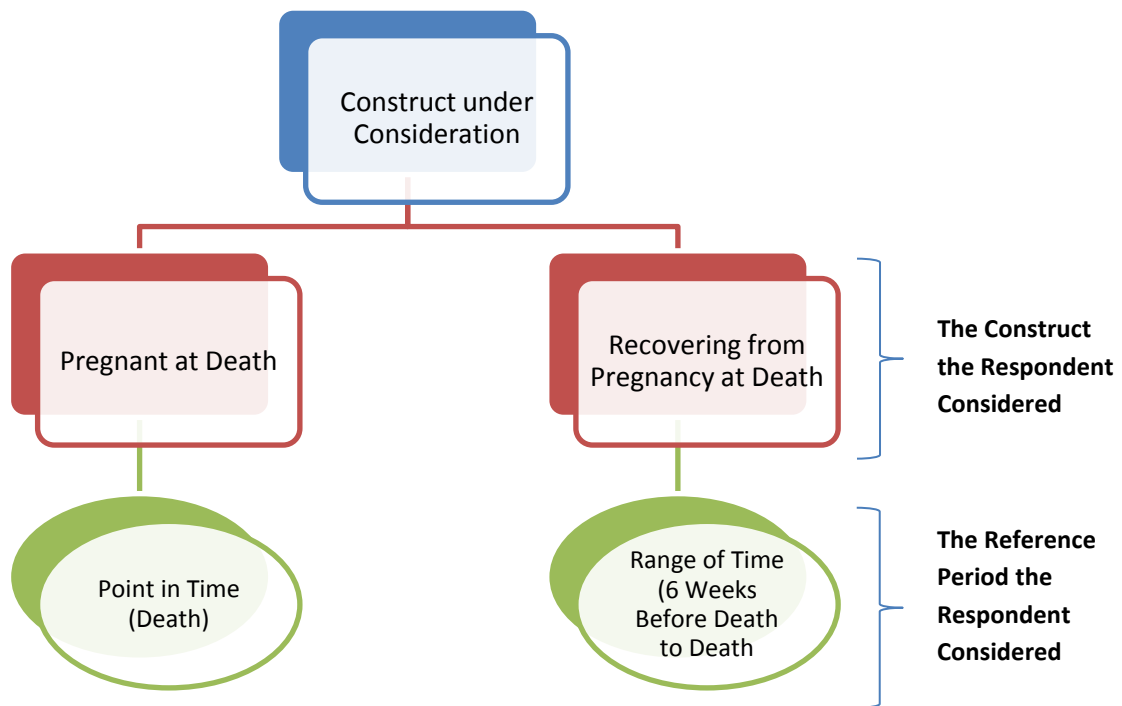
Figure 11: Response Schema for Questions A801 and C901

Reference Period

Although the question explicitly asked the respondents to think about the six week period before the deceased's passing, how the respondents actually applied the reference period depended almost entirely on which of the two patterns of interpretation they chose. Those respondents who applied the more common "pregnant at death" interpretation all but ignored the reference period and considered the binary of pregnant/not pregnant at the point of time of death. However, a respondent who used the second "recovering from birth" interpretation did apply the six week reference period. Taken together, the schema showing the relationship between the core construct interpretation and the interpretation of the reference period is shown below:

Question A802:   **Was she pregnant at death?**

Question C902   ***Bende ne otho ka opek/oyach?***

Three respondents in the adult sample received Question A802, while the other 15 skipped it. All three respondents who received QA802 correctly skipped into the question by responding either "no" or "don't know" to QA801.

No respondents from the child sample correctly skipped into Question C902. While three child respondents answered either "no" or "don't know" to QC901, all three incorrectly skipped to Question C1001. Therefore no child sample respondents answered any of the C900 Series questions following QC901.

This question was not probed during the cognitive interviews, and no findings are available.

Question A803:   **Did she die within 6 weeks of giving birth?**
Question C903   *Bende ne otho ei jumbe auchiel mar nyuol?*

Three respondents in the adult sample received Question A803, while the other 15 skipped it. All three respondents who received QA803 correctly skipped into the question by responding "no" to QA802. No respondents in the child sample received Question C903, as nobody answered "yes" to QC902.

This question was not probed during the cognitive interviews, and no findings are available.

Question A804:   **Did she die within 6 weeks of pregnancy that lasted less than 6 months?**
Question C904   *Bende ne otho ei jumbe auchiel ka en gi ich mapok oromo dweche auchiel?*

Three respondents in the adult sample received Question A804, while the other 15 skipped it. No respondents in the child sample received Question C904.

This question was not probed during the cognitive interviews, and no findings are available.

Question A805:   **Did she die within 24 hours after delivery?**
Question C905   *Bende ne otho ei seche piero ariyo gi ang'wen bang'nyuol?*

Three respondents in the adult sample received Question A805, while the other 15 skipped it. No respondents in the child sample received Question C905.

This question was not probed during the cognitive interviews, and no findings are available.

Question A806:   **Did she die during labor, but undelivered?**
Question C906   *Bende ne otho e seche mag muoch to ok onyuol?*

Two respondents in the adult sample received Question A806, while the other 16 skipped it. Both respondents who received QA806 were incorrectly skipped into the question, as the only people who should receive this question are those who answered "yes" to QA802. No respondents in the child sample received Question C906.

This question was not probed during the cognitive interviews, and no findings are available.

Question A807:   **Was she breastfeeding at death?**
Question C907   *Bende ne odhodho ei kinde mane otho?*

Two respondents in the adult sample received Question A807, while the other 16 skipped it. Both respondents who received QA806 correctly skipped into the question, as the only people who should receive this question are those who answered QA805. One other respondent who answered QA805 incorrectly skipped QA807. No respondents in the child sample received Question C907.

This question was not probed during the cognitive interviews, and no findings are available.

Question A808:   **How many births, including stillbirths, did she have before this baby?**

Question C908   *Ne osenyuol didi kiriwo ma onyuol ka otho to ka iweyo nyathini?*

Four respondents in the adult sample received Question A808, while 14 others skipped it. All four respondents correctly skipped into the question by answering either QA804 or QA807. One other respondent who answered QA805 incorrectly skipped QA808. No respondents in the child sample received Question C908.

Core Construct Interpretations

While the interviewers were not required to probe QA808, a few respondents did explain their interpretation of the question. While most respondents interpret the question as asking how many births the mother had *prior* to the one in question, one respondent included the child that died. It appears that this respondent did not hear or understand the instruction in the question text, "before this baby" (referring to the deceased child).

Question A809:   **Did she have any previous C-section?**

Question C909   *Bende osega yang'e ka onyuol?*

Three respondents in the adult sample received Question A809, while 15 others skipped it. All three respondents correctly skipped into this question; however, one respondent who answered QA808 incorrectly skipped it. No respondents in the child sample received Question C908.

This question was not probed during the cognitive interviews, and no findings are available.

Question A810:   **Did she die after or during a multiple pregnancy?**

Question C910   *Be ne otho ka en gi ich mar rude kata bang' nyuolo rude?*

Question N506:   **Was the child single or multiple birth?**

  Kane onyuol (Name) ne ne achiel koso rude?

These two questions are being considered together as they measure similar constructs and were probed with an eye to understanding if and how the respondents understood the term "multiple birth."

Core Construct Interpretations

Across the respondents who received Questions N506 and A810, there was a slight amount of variation the interpretation of the construct "multiple pregnancy," as visualized in the schema diagram below:
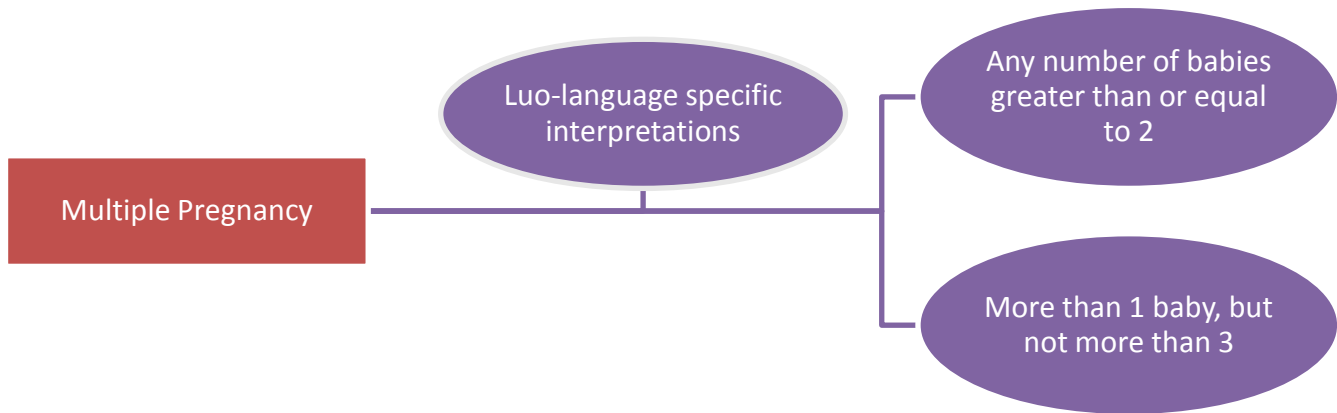
Figure 12: Response Schema for Questions A810, C910, and N506

The dominant pattern of interpretation was to consider a multiple pregnancy to be one where there are two or more babies being carried by the mother. A second interpretation that emerged from one respondent was to consider something a multiple pregnancy if a mother was carrying two or three babies. This respondent explained: "multiple births is giving birth to more than one child during birth but not more than three children." Upon probing, this respondent indicated that triplets were the most she had ever heard of a mother birthing, and that anything beyond that was unhealthy. Other respondents noted that anything beyond triplets was incredibly rare—one respondent who worked in a health clinic said she had never seen anything other than triplets.

A third interpretation, which was explicitly used by one respondent, though probably factored into the others' responses was Luo-language specific. In Luo, there is no specific phrase for "multiple pregnancy," "triplets," "quadruplets," etc. Rather, the word for "twin"—*rude*—is modified by adding a number. So saying a triplet would be the equivalent of saying "twin plus one." One respondent pointed this out, saying that she was interpreting the question to mean two babies, but that it could be changed by adding a number to the word *rude*.

Question A811:   **During pregnancy did she suffer from high blood pressure?**

Question C911   *Ka ne opek, be ne en gi tuo mar remo maringo matek?*

Three respondents in the adult sample received Question A811, while the other 15 skipped it. One respondent who was supposed to continue on from QA810 to QA811 did not. No respondents in the child sample received Question C911.

This question was not probed during the cognitive interviews, and no findings are available.

Question A812: **Did she have foul smelling vaginal discharge during pregnancy or after delivery?**

Question C912 *Be tik madum maarach ne wuok ei duong'ne kane opek kata bang' nyuol?*

The same three respondents who answered QA811 received Question A812, while the other 15 skipped it. No respondents in the child sample received Question C912.

This question was not probed during the cognitive interviews, and no findings are available.

Question A813: **During the last 3 months of pregnancy, did she suffer from convulsions?**

Question C913 *Bende ne en gi talarieya ei dweche adek mogik kane opek?*

The same three respondents who answered QA812 received Question A813, while the other 15 skipped it. No respondents in the child sample received Question C913.

Core Construct Interpretations

While the interviewers were not required to probe QA813, a few respondents did explain their interpretation of the term *convulsion*. The interpretations were consistent with one another, and they generally understood convulsions to indicate behavior where the child falls, shakes, and foams at the mouth.

Question A814: **During the last 3 months of pregnancy, did she suffer from blurred vision?**

Question C914 *Be wang'e ne li ei dweche adek mogik kane opek?*

The same three respondents who answered QA813 received Question A814, while the other 15 skipped it. No respondents in the child sample received Question C914.

This question was not probed during the cognitive interviews, and no findings are available.

Question A815: **Did she give birth to a live, healthy baby within 6 weeks of death?**

Question C915 *Ei jumbe auchiel mane othoe, be ne onyuolo nyathi mangine ber?*

The same three respondents who answered QA814 received Question A815, while the other 15 skipped it. Of these three, two had answered yes to either QA802 or QA804, and incorrectly received this question. No respondents in the child sample received Question C915.

This question was not probed during the cognitive interviews, and no findings are available.

Question A816: **Was there any vaginal bleeding during pregnancy or after delivery?**

Question C916 *Be dine bedie ni ne en gi chwer moro amora mane wuok e duong'ne kane opke kata bang' nyuol?*

The same three respondents who answered QA815 received Question A816, while the other 15 skipped it. No respondents in the child sample received Question C916.

This question was not probed during the cognitive interviews, and no findings are available.

Question A817: **Was there any vaginal bleeding during the first 6 months of pregnancy?**

Question C917 *Be ne en gi chwer moro amora e duong'ne e dweche auchiel mokwongo kane opek?*

The same three respondents who answered QA816 received Question A817, while the other 15 skipped it. Two of these respondents answered "no" to QA816, and should have skipped this question. No respondents in the child sample received Question C917.

This question was not probed during the cognitive interviews, and no findings are available.

Question A818: **Was there any vaginal bleeding during the last 3 months of pregnancy but before labor started?**

Question C918 *E dwece adek mogik ka opek be ne en gi chwer moro amora mawuok e duong'ne kapok muoch ochakore?*

The same three respondents who answered QA817 received Question A818, while the other 15 skipped it. No respondents in the child sample received Question C918.

This question was not probed during the cognitive interviews, and no findings are available.

Question A819: **Was there excessive vaginal bleeding during labor?**

Question C919 *Be ne en gi chwer mang'eny mawuok e duong'ne e kinde mane muoch kaye?*

Question A820: **Was there excessive vaginal bleeding after delivering the baby?**

Question C920 *Be ne en gi chwer mang'eny mawuok e duong'ne bang' nyuolo nyathi?*

While Questions A819/C19 and A820/C920 appear to measure two separate constructs—excessive bleeding during labor and excessive bleeding after delivery, respectively—as discussed in detail below, the respondents did not interpret them as distinct constructs and answered the two questions in generally the same way. Five respondents were probed on Qs A819 and A829, while the other 13 adult sample respondents skipped them. No respondents in the child sample received Questions C919 or C920.

Core Construct Interpretations

R applied the schema illustrated below in Figure 13 when answering Qs A819 and A820. In this cognitive schema, there is one initial set of "screening" decision points where the respondent considers their knowledge of the event, and then three distinct cognitive dimensions that the respondents consider in turn, each with a couple of patterns of interpretation.
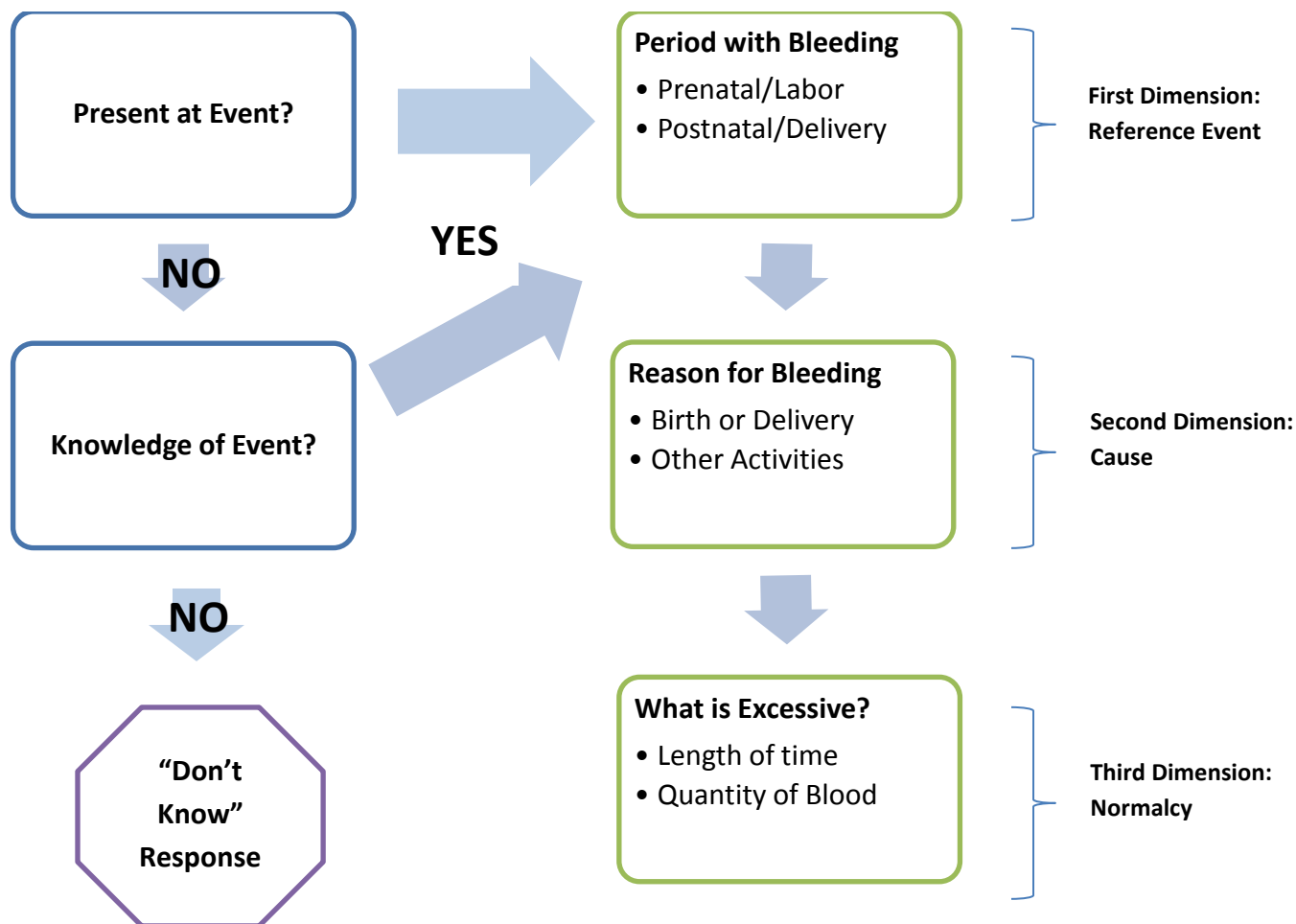

Figure 13: Response Patterns for the "Excessive Bleeding" Questions

When answering these questions, the respondents first considered a set of decision points about their knowledge of the situation. In short, they asked themselves "was I there?" and if not, "do I know what happened?" If they answered no to both of these questions, they answered the survey questions with a "don't know" response. For instance, one male respondent explained his "don't know" response to QA819 by saying that he was not with the mother while she was delivering the baby, and thus could not report on whether or not there was excess blood.

After a respondent decided that he or she had enough knowledge to continue, they interpreted the core construct of "excess bleeding" through three dimensions sequentially: the reference period, the cause of the bleeding, and the normalcy of the bleeding.

Dimension 1 - Reference Event: The first dimension, the reference event, refers to point in the childbirth process that the respondent was considering when he or she was asked if the deceased had excessive bleeding. While Qs A819 and A820 explicitly provide a reference event (labor and post-delivery, respectively) in their question text, the respondents did not always follow these instructions,

but instead tended to consider the same reference event across both questions. As a result, this set of questions was actually redundant in the eyes of most respondents, as they answered the same way, and thinking about the same thing, for both QA819 and QA20.

Adding to the complexity of this dimension, there are two distinct patterns of interpretation within this dimension—events about which the respondent is considering when answer the questions. However, these patterns do not match up completely with the reference events given in the questions' texts. Across both questions, only one respondent considered bleeding before delivery—the prenatal/labor pattern of interpretation. By and large, most respondents applied the postnatal/delivery pattern of interpretation. Within this pattern, respondents tended largely consider delivery itself, even though the reference event in the question text asks about bleeding *after delivering the baby*. One respondent, for example, explained that she knew there was blood during delivery because it was part of God's plan. Another respondent expanded the reference event to include both delivery and post-delivery, saying that it's abnormal for a woman to lose a lot of blood when the baby comes out.

Dimension 2 – Cause of Bleeding: The second dimension the respondents considered was the cause of the bleeding. There was very little diversity in the interpretation of this dimension, with most respondents thinking about bleeding due directly to the birthing process. For example, one respondent said that she was thinking about the blood that is discharged when the baby is delivered.

There was a secondary pattern of interpretation however—bleeding that was due to non-birthing activities. One respondent said that she was thinking about whether the deceased bleed after giving birth by doing lots of, or hard, work—such as cleaning or mopping, in the recovery period following pregnancy. In this pattern of interpretation, the respondent is indirectly considering the birthing process by considering how it affected the life and abilities of the deceased.

Dimension 3 – Normalcy of the Bleeding: Following a respondent's decisions about what event they were considering and the potential cause of the deceased's bleeding, they lastly had to determine what made a period of bleeding either normal or abnormal. Across the responses to both Qs A819 and 820, two patterns of normalcy emerged and were split relatively evenly. The first was the length of time the deceased bleed. In all the cases where the respondents were thinking about normal or abnormal time, they did so in general terms—"a long time" for example. They did not give any specific, quantifiable amounts of time they considered to be normal or not.

The second pattern of interpretation of normalcy was the quantity of blood the deceased let out during the reference event. Again, the respondents were thinking in general terms—"too much blood" for instance, and did not provide any sort of quantifiable metric.

Question A821:   **Was the placenta not completely delivered?**

Question C921   *Be biero ne ok owuok te?*

Across the adult sample, three respondents received and were probed on Question A821, while the other 15 skipped it. No respondents in the child sample received Question C921.

Core Construct Interpretations

There was remarkable consistency between the respondents' interpretations of QA821. While one respondent expressed confusion, the other two both reported thinking that the question was asking about whether they knew if the placenta had remained in the mother's womb and killed her. In this interpretation, the respondents were tying the death of the mother *directly* to the removal/non-removal of the placenta. As such, both these respondents answer QA821 "don't know," apparently indicating that they did not know if the placenta killed the mother.

Question A822:   **Did she deliver or try to deliver an abnormally positioned baby?**

Question C922   *Be ne onyuolo kata otemo nyuolo nyathi monindo marach?*

Five members of the adult sample were probed on this question, though only three received it during the actual verbal autopsy. The other members of the sample skipped Question A822, and were not probed during the cognitive interview. No respondents in the child sample received Question C922.

Core Construct Interpretations

The five members of the adult sample who received Q A822 interpreted this question in a number of different ways. Figure 14 below illustrates the general schema respondents used to interpret this question. Respondents first decided whether or not they believed the question was asking about the physical positioning of the fetus in the womb, or about the outcome of the fetus' position in the womb. Following this decision point, those respondents who were thinking about the positioning interpreted the question through two different dimensions: normality or abnormality.
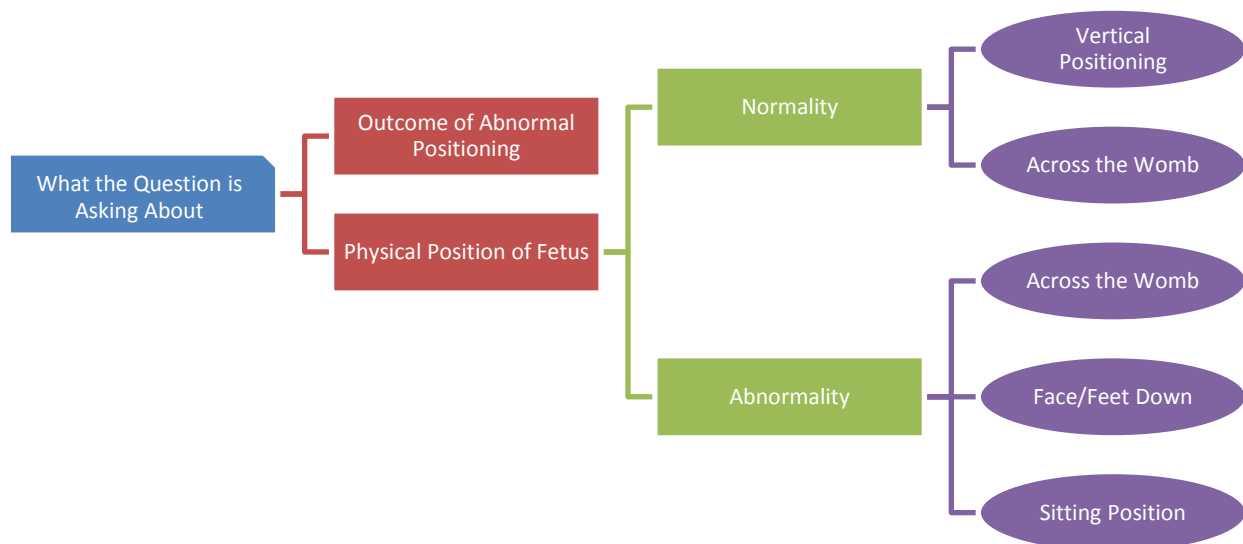

Figure 14: Response Schema for Questions A822 and C922

Decision Point – Construct under Question: Respondents understood this question to either be asking about the health outcome of an abnormally-positioned fetus or about the physical position of the fetus in the womb. For an example of the former interpretation, one respondent said that it is always "bad luck" when a baby is positioned the wrong way in the womb. The latter understanding of the construct—by far the more common one—focused on what constitutes either normal or abnormal fetal positioning.

Dimension 1 – Abnormality: Those respondents who understood the construct under question to be about the physical position of the fetus in the womb next considered what they thought constituted either abnormal or normal positioning. Across the cases, three patterns of interpretation emerged around the dimension of abnormality: face or feet down, sitting in the womb, or lying across the womb.

Dimension 2 – Normality: Most respondents considered the construct both through the lenses of abnormality and normality—providing both "positive" and "negative" examples (in reference to the term "abnormal" given in the question text). There were only two patterns of interpretation of normality. However, these two patterns—vertical positioning and lying across the womb—are nearly opposite concepts.

One interesting thing to note about the various patterns of interpretation of normality and abnormality is the overlap—"across the womb" was considered by two different respondents to be either normal or abnormal fetal positioning. Likewise, "vertical positioning' could be the same or similar to "face/feet down." Both the large amount of variation, and the overlap between what should be distinct constructs, indicates that respondents do not have a firm knowledge of what is or is not normal or abnormal fetal positioning.

Question A823:   **Was she in labor for unusually long (more than 24 hours)?**

Question C923   ***Be ne en gi muoch moyuare kata mobudho aming'a (moloyo seche piero ariyo gi ang'wen)?***

Four respondents were probed on Question A823 during the cognitive interview, although only three of these actually received the question during the verbal autopsy interview. No respondents in the child sample received Question C923.

Core Construct Interpretations

All four members of the adult sample who were probed on Q A823 understood it to be asking about the *duration* of the mother's labor, and whether or not it was abnormal. However, there was a diversity of interpretations surrounding the question of what constitutes "unusually long" labor. While a specific definition is given in the question text in parentheses ("more than 24 hours," or *moloyo seche piero ariyo gi ang'wen*" in Luo), none of the respondents used this specific duration when explaining what they considered a normal length of labor, and in fact they all cited durations significantly shorter than 24 hours.
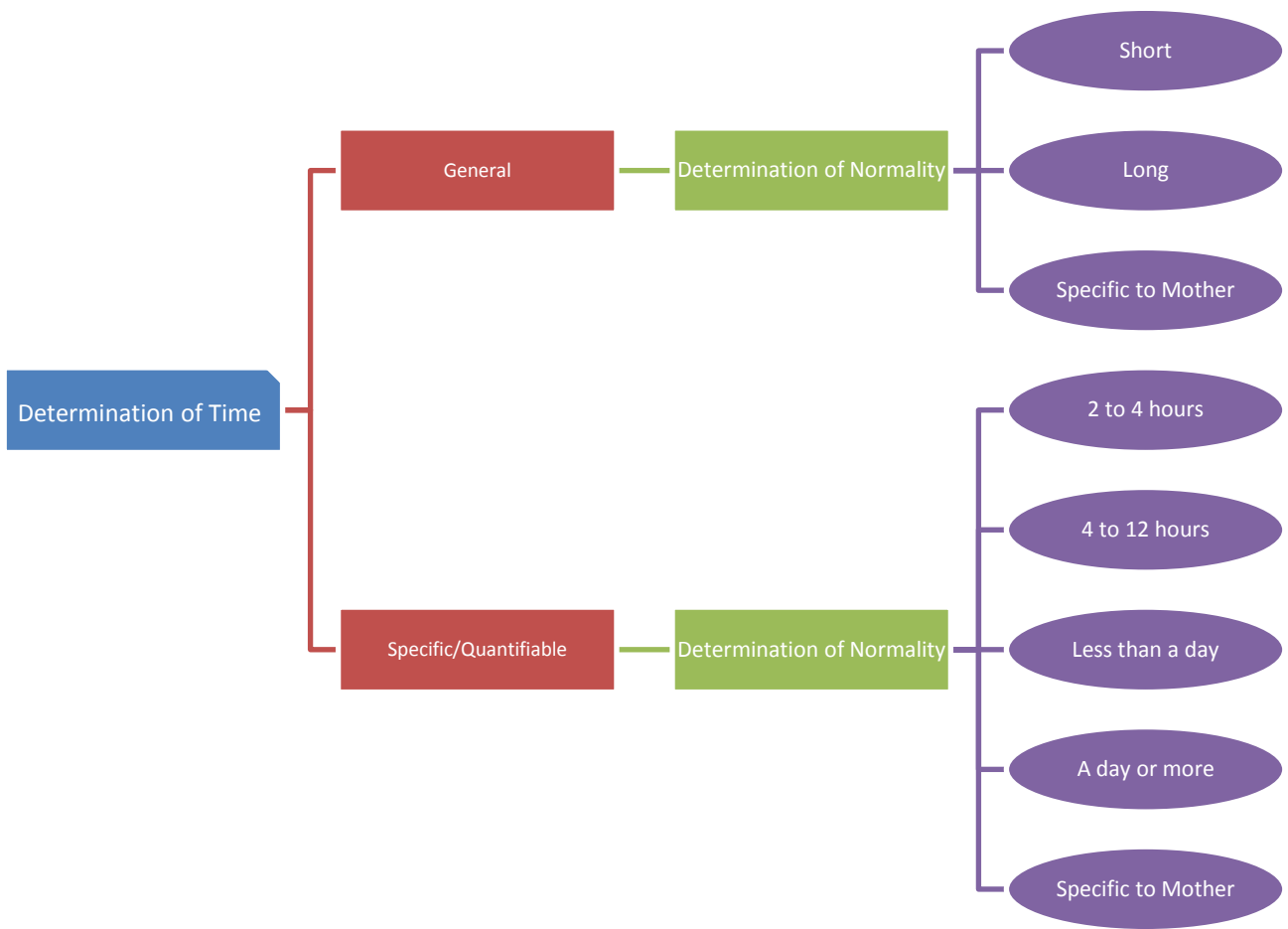
Figure 15: Response Schema for Questions A823 and C923

To arrive at their answers, the respondents applied a relatively basic schema (shown above in Figure 15) to determine what they considered to be a period of normal labor, and then determined whether or not the mother's labor was longer than this standard. In doing so, they first decided whether this standard was a specific time period (such as given in the question text, "24 hours"), or a general time period (such as "long" or "short"). Within each of these two options a few different patterns of interpretation emerged, as can be seen below. However, it is important to point out that because only a few respondents were probed on this question, these patterns of interpretation probably do not represent saturated categories, and the actual diversity of interpretations is most likely greater.

The idea that the duration of labor is very specific to an individual mother was common across both those respondents who were thinking about specific, quantifiable standards of labor duration and those who were thinking more generally. This was normally expressed by the respondent by "hedging" their answers to the cognitive probes, for instance by saying that labor can take "3 hours or 2 days—it all depends on the individual." This belief that labor duration is a very individual thing might indicate that there is no single, culturally-accepted standard of duration against which the respondents can base their answers to Q A823.

Question A824:   **Did she attempt to terminate the pregnancy?**

Question C924   *Be ne otemo golo ijno?*

Three respondents in the adult sample received Question A824, while the other 15 skipped it. No respondents in the child sample received Question C924.

This question was not probed during the cognitive interviews, and no findings are available.

Question A825:   **Did she recently have a pregnancy that ended in an abortion (spontaneous or induced)?**

Question C925   *Machiegni ni, be iye ne owuok kata ogol?*

Three respondents in the adult sample received Question A825, while the other 15 skipped it. No respondents in the child sample received Question C925.

This question was not probed during the cognitive interviews, and no findings are available.

Question A826:   **Where did she give birth?**

Question C926   *Ne onyuol kanye?*

Three respondents in the adult sample received Question A826, while the other 15 skipped it. No respondents in the child sample received Question C926.

This question was not probed during the cognitive interviews, and no findings are available.

Question A827:   **Did she receive professional assistance for the delivery?**

Question C927   *Be ne okonye gi ng'ama otieg e yor cholo?*

Three respondents in the adult sample received Question A827, while the other 15 skipped it. Of these three, two respondents reported not knowing the answer to this question. No respondents in the child sample received Question C927.

This question was not probed during the cognitive interviews, and no findings are available.

Question A828:   **Did she have an operation to remove her uterus shortly before death?**

Question C928   *Be ne oyang'e mondo ogol mfuko mar nyuol kapok otho?*

Three respondents in the adult sample received Question A828, while the other 15 skipped it. Of these three, two respondents reported not knowing the answer to this question. No respondents in the child sample received Question C928.

This question was not probed during the cognitive interviews, and no findings are available.

Question A829: **Was it a normal vaginal delivery?**

Question C929 *Be ne en nyuol makare kokalo e duong'ne maonge chandruok?*

Question N605

Three respondents received Question A829 during the verbal autopsy and were probed on it during the cognitive interview. The other 15 respondents skipped this question and were not probed. No respondents in the child sample received Question C929. All 20 members of the neonate sample received Question N605. Of them, all but one respondent answered "yes," and a lone respondent answered "no."

Core Construct Interpretations

The respondents who received QA829 and QN605 largely agreed in their interpretation of what it meant to have a normal delivery. While there were a large number of individual patterns of interpretation employed when answering this question, as can be seen in the visualization of the schema below in Figure 16, respondents tended to employ more than one of these patterns while interpreting the question. For instance, in every case, the respondents considered both what it meant to have a "normal" delivery and what it meant to have an "abnormal" delivery. All three adult sample respondents agreed that a head first delivery was normal, and two agreed that a long delivery (time wise) is abnormal.
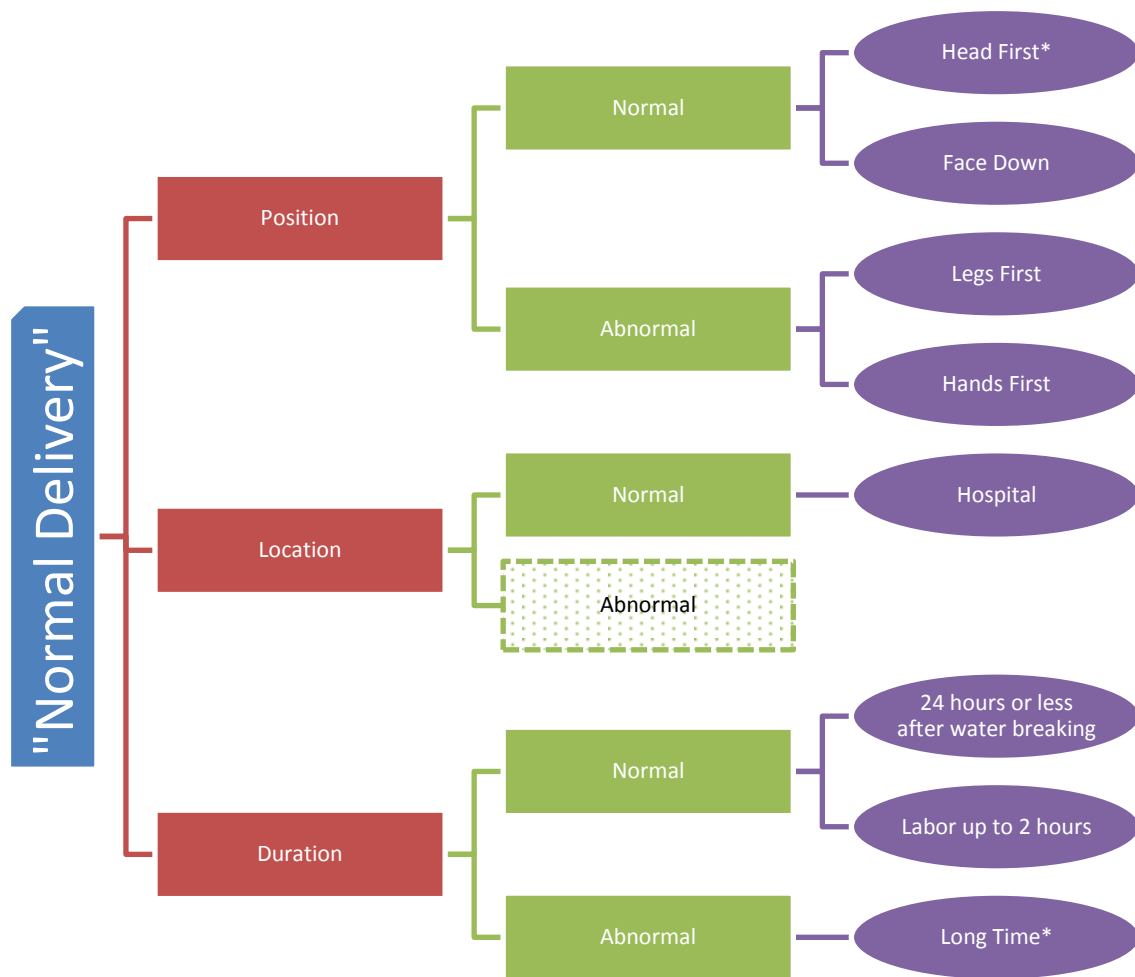
Figure 16: Response Schema for Questions A829, C929, and N605

The fact that a number of these patterns emerged strongly across the respondents who received this question (those that have asterisks in Figure 16, "head first" and "long time") indicate that there is a set cultural definition of, or understanding about, what constitutes a normal delivery. However, again because of the small number of respondents in the adult sample who actually arrived at this question (and the fact that no child sample respondents received it at all), more variation is possible. For example, because some respondents thought about the *normal* location of delivery, hypothetically other respondents would think about the *abnormality* of location. This pathway is indicated above with the dotted line, indicating that it is hypothetical. Further interviews are needed to confirm its presence or absence.

Question A830:   **What type of delivery was it?**
Question C930   *Ne en nyuol machal nade?*
Question N606

No respondents answered no to QA829, so no members of the adult sample received Question A830. No respondents in the child sample received Question C930. Two respondents received Question N606,

including one who should have skipped it due to her "yes" answer to the question about normal delivery, QN605.

This question was not probed during the cognitive interviews, and no findings are available.

Question A831: **Was the baby born more than one month early?**

Question C931 *Dende nyathini ne onyuol kapod odong' mokalo dwe achiel?*

Three respondents in the adult sample received Question A831, while the other 15 skipped it. No respondents in the child sample received Question C931.

This question was not probed during the cognitive interviews, and no findings are available.

Section A9 and C8: Symptoms and Signs Noted During the Final Illness
Section N9: Neonatal Illness History

Question A901: **Did s/he have fever?**

Question C801 ***Bende ne en gi del maowore?***

Question N913

All 18 respondents in the adult sample received Question A901. Of them, eight answered "yes" and continued on to Question A902. Of the remaining 10 who skipped directly to Question A904, one answered "don't know," while 9 answered "no." All 20 respondents in the child sample received Question C801, with three answering "no," one answering "don't know," and the remaining 16 answering "yes." 13 of the 15 eligible respondents in the neonate sample received Question N913, with two answering "yes," eight responding "no," and three saying "don't know."

This question was not probed during the cognitive interviews, and no findings are available.

Question A902: **How long did <NAME> have fever?**

Question C802 ***Kuom kinde marom nade?***

Eight respondents skipped into Question A902 by answering "yes" to QA901, while 16 respondents skipped into Question C802 by answering "yes" to QC801.

Core Construct Interpretations

While this question was not probed extensively, a few respondents explained their answers. One respondent who did not give an answer explained that she did not know when the deceased first displayed a fever, because the deceased came back to their home from the city with the fever already in progress. Another respondent similarly said that he was not sure of the duration of the fever because he was not around at the beginning of it. This second respondent actually provided an answer to QA902 ("around one month") even though he was unsure of the duration—and thus should have answered "don't know."

As seen throughout the questionnaire, there was much less uncertainty across the child sample respondents. They tended to remember the duration of the fever (and comprehend the idea of a fever) by equating it with the fatal illness itself—thus they remember how long the child had the fever because they remember how long the ill.

Question A903: **Did s/he have night sweats?**

Question C803 ***Be luya ne tuchnega gotieno?***

Eleven respondents received Question A903, while the other seven skipped it. Only eight respondents said "yes" to QA901 (and went on to QA902) and should have therefore received this question. The

other three respondents incorrectly skipped into QA903. 18 respondents in the child sample received Question C803, while two skipped it. As only 16 respondents answered QC801 with a "yes" response, two respondents incorrectly skipped into QC803.

This question was not probed during the cognitive interviews, and no findings are available.

Question A904:   **Did s/he have a cough?**

Question C804   ***Bende ne en gi ahonda/ofuolo?***

Question N915

All 18 respondents in the adult sample received Question A904. Of these, 13 responded by answering "yes" and were to continue on to Question A905. 19 of the 20 child sample respondents received Question C804, with one incorrectly skipping it. Of these 19, eight answered "yes," one answered "don't know," and the rest answered "no." 13 members of the neonate sample received Question N915, two of whom answered "yes." One other answered "don't know," and the remaining 10 answered "no."

This question was not probed during the cognitive interviews, and no findings are available.

Question A905:   **For how long did s/he have a cough?**

Question C805   ***Kuom kinde marom nade?***

While 13 adult sample respondents answered yes to QA904 and were to receive Question A905, only 12 did—with one respondent incorrectly skipping over the question. Likewise, seven members of the child sample received Question A805, with one respondent incorrectly skipping it.

<div align="center">

Core Construct Interpretations

</div>

While the respondents were not extensively probed on this question respondents who answered "don't know" or who had a difficult time answering the question were probed. Of these respondents, two patterns of interpretation emerged to explain why they did not know or were having a hard time answering. The first is the same pattern noted above in the previous duration question (QA902/C802), dealing with the fact that a respondent who was not around the deceased when the cough started cannot know *when* the cough started.

The second pattern that explained why some respondents either could not answer, or had a difficult time answering, this question has to do with cognitive retrieval and memory. These respondents noted that since the deceased's cough was such a long-running event, they could not remember exactly when it began. Given that this pattern of interpretation did not emerge from the fever question above (QA902), it is possible that coughing is a much more common (and thus, less cognitively *salient*) symptom, though further research is needed to explore this (and coughing's resulting utility in a model such as the verbal autopsy).

Again, the members of the child sample had a much easier time remembering the duration in QC805 than the adult sample respondents did in QA905. Like what was seen above with QC802, respondents tended to equate the duration of the cough with the duration of the illness. They then remembered this

time period either by thinking of other life events or symptoms (such as when the child stopped eating) or via a heuristic (wherein they stated that they simply *knew* how long the illness lasted).

Question C806: **Did s/he make a whooping sound when coughing?**

Question N916 *Be ne en gi ahonda guogi?*

Eight members of the child sample correctly received Question C806 after answering "yes" to QC804. Likewise, two respondents in the neonate sample received Question N916 after answering "yes" to QN915.

This question was not probed during the cognitive interview, and no findings are available.

Question A906: **Was the cough productive with sputum?**

Question C807 *Be ne en gi ahonda magolo okego?*

Fourteen adult sample respondents received Question A906, even though only 12 responded "yes" to QA904. The other four respondents correctly skipped over this question. Eight respondents in the child sample received Question C807, all of whom correctly skipped into it.

This question was not probed during the cognitive interview, and no findings are available.

Question A907: **Did s/he cough out blood?**

Question C808 *Be ne ofuolo remo?*

The same fourteen adult sample respondents also received Question A907, even though only 12 responded "yes" to QA904. The same eight members of the child sample who previously answered QC807 correctly went on to answer Question C808.

This question was not probed during the cognitive interview, and no findings are available.

Question A908: **Did s/he have any breathing problem?**

Question C809 *Be ne en gi chandruok mar yueyo?*

Question N917

All 18 adult sample respondents received Question A908. Of these, 11 answered "yes." Of the remaining seven, only one respondent answered "don't know." Additionally, all 20 child sample respondents answered Question C809, with 12 answering "yes," seven responding "no," and only one replying "don't know." 13 members of the neonate sample received Question N917, with six answering "yes," six answering "no," and one responding with a "don't know."

This question was not probed during the cognitive interview, and no findings are available.

Question A909:   **Did s/he have fast breathing?**

Question C810   *Be noyueyo mapiyopiyo?*

Question N918

The 11 respondents who answered "yes" to QA908 received Question A909. Of these, four respondents replied "yes," while the others answered "no." 14 child sample respondents received Question C810, with two respondents incorrectly skipping into this question. Of these 14, nine responded "yes" to QC810, and five answered "no." The six neonate respondents who answered "yes" to QN917 went on to correctly receive Question N918.

This question was not probed during the cognitive interview, and no findings are available.

Question A910:   **For how long?**

Question C811   *Kuom kinde marom?*

Six respondents in the adult sample received Question A910. Of these six, two respondents incorrectly skipped into this question after responding "no," to the previous question (A909), while the other four answered "yes" to QA909 and correctly received this question. Similarly, 10 respondents in the child sample answered Question C811, even though only nine answered "yes" to the screening question, QC810.

This question was not probed during the cognitive interview, and no findings are available.

Question A911:   **Did s/he have breathlessness?**

Question C812   *Be muche ne ng'adore?*

Question N919

Twelve adult sample respondents received Question A911; including two who did not answer "yes" to QA908 and therefore should have skipped this question. Of the 12, six respondents answered "yes" to QA911. 14 child sample respondents received Question C812, including five individuals who should have skipped this question. Of these 14, seven answered "yes," and seven answered "no." The six neonate respondents who were eligible due to their "yes" response to QN917 all correctly received Question N919. Of these five, three answered this question with a "yes" response, one with a "no," and one other with a "don't know."

This question was not probed during the cognitive interview, and no findings are available.

Question A912:   **For how long did s/he have breathlessness?**

Question C813   *Kuom kinde marom nade?*

Five respondents received Question A912 in the adult sample. One respondent who answered "yes" to QA911 and should have received this question incorrectly skipped it instead. On the other hand, eight members of the child sample answered Question C813, including one respondent who should have skipped it because they answered "no" to QC812.

This question was not probed during the cognitive interview, and no findings are available.

Question A913:   **Was (s)he unable to carry out daily routines due to breathlessness?**

Question C814   *Be ne ok onyal tiyo tijene mapile kaluwore gi muche mane ng'adore?*

Six adult sample respondents who answered "yes" to Q A911 correctly received Question A913. Nine members of the child sample received Question C814, including two respondents who incorrectly skipped into this question (one who skipped directly from QC812, and the other who answered QC813 first).

<div align="center">Core Construct Interpretations</div>

While this question was not probed extensively, some cognitive interviewers did explore this question with the respondents. One interesting thing to emerge was the uncertainty over whether or not breathlessness was the reason that a deceased stopped his or her daily activities or changed his or her daily routine. For example, one adult sample respondent who answered "no" indicated that while the deceased did close his butcher shop because of his illness—which included breathlessness—he did not believe it had to do with the specific symptom, but rather the illness as a whole. Similarly, a child sample respondent noted that her child stopped playing as much, but she was not sure whether it was due to the breathlessness specifically or the illness in general—though she answered the question "yes" anyway.

Question A914:   **Was (s)he breathless while lying flat?**

Question C815   *Be muche ne ng'adore konindo auma kata ataro?*

Six adult sample respondents who answered "yes" to Q A911 correctly received Question A914. The number of child sample respondents incorrectly receiving questions grew again with Question C815, with a total of 10 respondents answering the question, even though only seven should have screened into it due to their "yes" answers to QC812.

This question was not probed during the cognitive interview, and no findings are available.

Question C816: **Did you see the lower chest wall/ribs being pulled in as the child breathed?**

Question N920 *Be ne ineno ka ng'edene donjokendo wuok oko ka oyueyo?*

15 members of the child sample received Question C816. This includes six respondents who should have skipped this question because they answered "no" to QC810. Eight neonate sample respondents answered Question N920, including two respondents who should have skipped it because of their "no" response to QN917.

This question was not probed during the cognitive interview, and no findings are available.

Question A915: **Did s/he have noisy breathing (grunting or wheezing)?**

Question C817 *Bende nochur kata kore ne liyo koyueyo?*

Question N921

While 11 respondents answered "yes" to QA908, only nine received Question A915. Therefore, two respondents incorrectly skipped over this question. Likewise, 17 respondents in the child sample received Question C817, even though only nine were eligible due to their "yes" responses to QC810. Seven members of the neonate sample received Question N921, though only six of them were eligible.

This question was not probed during the cognitive interview, and no findings are available.

Question A916: **Did s/he have severe chest pain?**

Question C818 *Be kore ne rame matek/ahinya?*

All 18 respondents in the adult sample received Question A916, seven of whom answered "yes." Of the remaining 11, two respondents replied "don't know" and nine answered "no." All 20 members of the child sample received Question C818, with only one respondent answering "yes," seven respondents saying "don't know," and the remaining 12 answering "no."

This question was not probed during the cognitive interview, and no findings are available.

Question A917: **Did s/he have diarrhea?**

Question C819 *Be ne odiweo?*

Question N922

16 adult sample members received Question A917, with five respondents answering "yes," 10 answering "no," and one responding "don't know." All 20 child sample respondents received Question C819, with nine answering "yes," 10 answering "no," and one responding "don't know." 13 neonate sample respondents answered Question N922, with two responding "yes," 10 responding "no," and one saying "don't know."

Core Construct Interpretations

The respondents all generally understood Questions A917, C819, and N922 to be asking about the deceased person's stool and disorders relating to stool. There was some variation in the interpretation of the term "diarrhea," as seen below in Figure 17. Across the schema respondents thought about the causes, effects, and time components of diarrhea. A few respondents expressed an inability to even define "diarrhea," interpreting it as a straight heuristic. Most respondents; however, focused their interpretations on the physical characteristics of the stool itself.
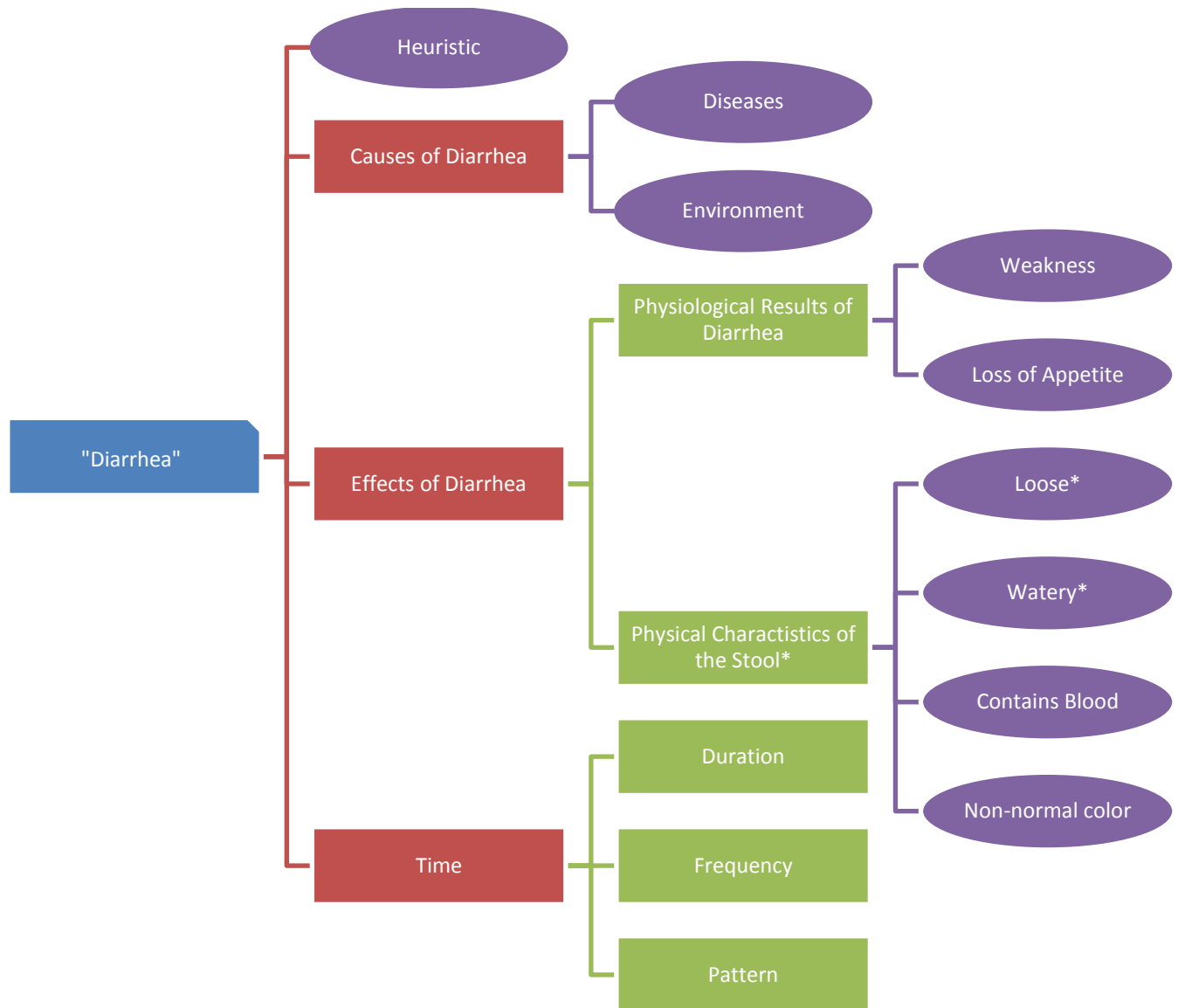
Figure 17: Response Schema for Questions A917, C819, and N922

The Luo term for diarrhea translates directly to "loose stool." There are two important things to note because of this translation. First, the fact that the most common patterns of interpretation (indicated in the figure above by the * symbol) was to think about diarrhea as either "loose" or "watery" stool is almost certainly influenced by the translation. In essence, the cognitive interviewers asked the respondents to define a definition ("what do you think *loose stool* is"?), and the respondents answered by repeating the definition ("stool that is loose and watery"). This tautology might indicate that the

respondents are so familiar with the term, that their immediate reaction is simply to repeat or rearrange it when defining it to others, thus suggesting high overall construct validity.

Second, because of this tautological response, the schema illustrated above might actually include more variation than it would have without it. Because the respondents tended to define diarrhea by using the term itself, they might have then felt obligated to "go deeper" than they would have if they had been simply defining a more jargon-like word (such as *diarrhea* itself). Basically, when the respondent replied to the probe with a definition that included "loose stool," they may have felt socially obligated to continue defining the term beyond their initial reaction and come up with secondary definitions—the other patterns of interpretation. Multi-site research would be necessary to confirm this hypothesis.

Question A918:   **For how long did s/he have diarrhea?**

Question C820   ***Kuom kinde marom nade?***

All five adult sample respondents who answered "yes" to QA917, and all nine respondents who answered "yes" to QC819, correctly received Question A918 or Question C820, respectively.

Core Construct Interpretations

Any variation in the core construct under question here—the duration of the diarrhea—depended on the respondent's interpretation of the previous question about the presence of diarrhea. As noted above, the overall interpretation of the construct of "diarrhea" in QA917 was relatively consistent, but any variation would have been carried forward into Q A918.

Any additional variation in the interpretation of this question stems from the "retrieval" stage of the cognitive question response process (a four-stage process that includes "comprehension," "retrieval," "judgment," and "response," see Tourangeau, Rips, and Rasinski 2000), and depends on the source of the respondent's information. If a respondent had first-hand knowledge about the deceased's diarrhea, he or she would determine the duration by relating it to actions in their own life. For instance, one respondent noted that he had to wash his wife's clothes for two weeks during the diarrheic period.

On the other hand, if a respondent was not around the deceased person during the diarrheic period, he or she simply based their answer to QA918 on what they were told by either the deceased or others who were around the deceased during the period.

Question A919:   **At any time during the final illness was there blood in the stools?**

Question C821   ***E saa moro amora e tuone mogik, be ne nitie remo e okone?***

Question N923

Eleven respondents in the adult sample received this question. Of these, five answered "yes" to QA917 and correctly received Question A919, while the other six respondents incorrectly skipped into this question. Of the 11 responses, three respondents answered "don't know." 17 members of the child sample answered Question C821, including eight who should have skipped this question because of their "no" response to QC819. While only two neonate respondents were eligible for this question based on

their responses to QN922, seven members of the sample received and answered Question N923. Of these nine, only one answered "yes," while the other eight answered "no."

This question was not probed during the cognitive interview, and no findings are available.

Question A920: **Did s/he vomit?**

Question C822   *Be ne ong'ok?*

Question N924

All 18 respondents in the adult sample received Question A920. Of these six answered "yes." All 20 child sample respondents received Question C822, of whom nine responded "yes." 13 respondents in the neonate sample received QN924, four of whom answered "yes."

This question was not probed during the cognitive interview, and no findings are available.

Question A921: **Did s/he vomit "coffee grounds" or bright red blood?**

Question C823   *E saa moro amora e tuone mogik, be ne nitie remo e okone?*

Question N925

The six respondents who responded "yes" to QA920 correctly received Question A921. Likewise, all nine respondents who answered QC822 "yes" went on to correctly receive Question C823, and the four respondents who answered "yes" to QN924 answered Question N925.

Core Construct Interpretations

Overall, respondents appeared to understand Questions A921, C823, and N925 as two separate questions: "What was in the vomit?" and "Was there blood in the vomit?" Though in many cases, the respondents considered both of these questions when answering Qs A921, C823, and N925, not all did. By and large, the respondents considered the "Was there blood…? sub-question more frequently. This could be due to either the fact that "bright red blood" was the last thing they heard in the question text, or because blood is a more salient term than "coffee grounds." Further, focused cognitive testing would be necessary to determine this.

This cognitive approach leaves open a large possibility of false negative answers for those respondents who only considered one of the two questions. For instance, a respondent who is only thinking about the blood question might simply answer "no" or "other" (as there is not a "no" option). This "no" answer is about the blood "sub-question" only, and does not include a response to the "coffee grounds sub-question." One respondent in the child sample answered "coffee colored fluid." During the cognitive interview, she also said that after the brown vomit, the child started to throw up blood—even though she did not select that as an answer in the VA interview.

By a large margin, the respondents answered these questions using the "other, specify" response category. When describing the vomit, they tended to focus on its color (i.e. "yellowish") and its contents (milk, food, etc).

Question A922:   **Did s/he have any abdominal problems?**

Question C824   *Be ne en gi chandruok moro amora mar ich?*

All the respondents in the adult sample received Question A922, with six respondents answering "yes," two responding with a "don't know," and the remainder with a "no." All 20 respondents in the child sample received Question C824, with seven answering "yes," 10 answering "no," and three responding "don't know."

Core Construct Interpretations

This question was not probed extensively during the cognitive interviews. One respondent did appear to conflate "abdominal issues," with diarrhea. When asked why he said yes during the cognitive interview, the respondent revealed that he was thinking about the stomach problems the deceased had *during* the diarrheal period, and that he did not know of any separate abdominal or stomach issues.

It appears possible that the other respondents were equating diarrhea with abdominal problems. For instance, in the adult sample, of the five respondents who answered "yes" to the diarrhea question (QA917/C819/N922), three also answered "yes" to QA922 (with one "no," and one who did not give a response). Targeted probing would be necessary to determine whether or not these questions are capturing the same construct and should be changed or eliminated from the questionnaire.

Question A923:   **Did s/he have severe abdominal pain?**

Question C825   *Be ne en gi ich maremo matek?*

Six adult sample respondents received Question A923, and five answered "yes." 11 child sample respondents received Question C825, including four who should have skipped it based on their "no" answer to QC824. Of the 11, six answered "yes."

This question was not extensively probed during the cognitive interview, and no findings are available. As such, it is impossible to know what these six respondents believe is (or is not) "severe…pain." Further cognitive testing would be necessary to determine whether or not respondents differentiate between pain and "severe pain," and if so, how they make this differentiation.

Question A924:   **For how long before death did s/he have severe abdominal pain?**

Question C826   *Kuom kinde marom nade?*

The five respondents who answered "yes" to QA923 all received and answered Question A924. Likewise, the six respondents who answered "yes" to QC825 all correctly received Question C826. These respondents used a variety of terms to answer the question—with one respondent answering "since marriage," another few answering in terms of days, and a couple answering in terms or weeks or months.

This question was not probed during the cognitive interview, and no findings are available. As such, it is unclear whether the durations these respondents gave could be standardized and whether or not they are simple approximations. Further testing would be necessary to address these issues.

Question A925:   **Did s/he have a more than usually protruding abdomen (Abdominal distention)?**

Question C827   *Be ne en gi ich mochielore kawuok oko ma ok ni kare?*

Question N926

The six adult sample respondents who answered "yes" in QA922 all received Question A925. Two of these six answered "yes." The same 11 child sample respondents who answered QC825 also answered Question C827. Three of these 11 answered "yes." 13 members of neonate sample received and answered Question N926, with only one of these respondents answering "yes," and another responding "don't know."

This question was not probed extensively during the cognitive interview. One respondent appeared to be thinking about whether or not the deceased was obese—thus whether or not the deceased had a protruding belly or stomach, rather than an abdomen.

Question A927:   **For how long did s/he have a more than usually protruding abdomen?**

Question C828   *Kuom kinde marom nade?*

Two respondents in the adult sample answered "yes" to QA925 and went on to receive Question A927, while the three respondents in the child sample who answered "yes" to QC827 received Question C828..

This question was not probed during the cognitive interview, and no findings are available.

Question A928:   **Did s/he have any lump inside the abdomen?**

Question C 829   *Be ne nite gima okuot ee iye matek?*

Six respondents in the adult received Question A928. Of these respondents, all answered "no," except one "don't know." 12 respondents in the child sample answered Question C829, one of whom answered "yes," another who answered "don't know," and the remaining 10 answered "no."

This question was not probed during the cognitive interview, and no findings are available.

Question A929:   **For how long did s/he have a lump inside the abdomen?**

Question C830   *Kuom kinde marom nade?*

No respondents in the adult sample received Question A929, while one respondent in the child sample received Question C830.

This question was not probed during the cognitive interview, and no findings are available.

Question A930:   **Did s/he have a severe headache?**

Question C831   *Be ne en giwich bar matek?*

All 18 respondents in the adult sample received Question A930, and all 20 respondents in the child sample received Question C831.

This question was not probed during the cognitive interview, and no findings are available.

Question A931:   **Did s/he have a stiff or painful neck?**

Question C832   *Be ne en gi ng'ut motal kata malit?*

All 18 respondents in the adult sample received Question A930. Of these, two answered "yes," three responded with a "don't know," and the rest answered "no." All 20 respondents in the child sample received Question C832. Of them, three respondents answered "yes," while one answered "don't know."

This question was not probed during the cognitive interview, and no findings are available.

Question A932:   **For how long did s/he have a stiff or painful neck??**

Question C833   *Kuom kinde marom nade?*

The two respondents who answered "yes" to QA931 received Question A932, while the three respondents who answered "yes" to QC832 received Question C833.

This question was not probed during the cognitive interview, and no findings are available.

Question A933:   **Did s/he have mental confusion?**

Question C834   *Be pache/wiye no owilore?*

All adult sample respondents received Question A933. Of these, six responded with a "yes," one with a "don't know," and the rest with a "no." Likewise, all the respondents in the child sample received Question C834. In the child sample, two respondents answered "yes," two respondents answered "don't know," while the other 16 respondents answered "no."

This question was not probed during the cognitive interview, and no findings are available.

Question A934:   **For how long did s/he have mental confusion?**
Question C835   *Kuom kinde marom nade?*

The six adult sample respondents who answered "yes" to QA933 received Question A934, and the two child sample respondents who responded "yes" to QC834 went on to answer Question C835.

This question was not probed during the cognitive interview, and no findings are available.

Question A935:   **Did s/he become unconscious?**
Question C836   *Be pache ne olal?*

All adult sample respondents received Question A933. Of these, six responded with a "yes," two with a "don't know," and the rest with a "no." There appears to be a skipping issue with Question C836 in the child questionnaire—as only 15 out of the 20 respondents received the question. Of those 15 however, six answered "yes," while 9 answered "no."

This question was not probed during the cognitive interview, and no findings are available. It is interesting to note the similarity in answers between Qs A933 and A935, and Qs C834 and C836. As seen in the table below, respondents who gave a "yes" to one of these questions tended to respond "yes" to the other.

<div align="center">Table 5: Questions A933 and A935 Responses in the Adult Sample</div>

		Question A933: Mental Confusion			
		Yes	No	Don't Know	Total
	Yes	5	1	0	6
Question A935:	No	1	9	0	10
Unconsciousness	Don't Know	0	1	1	2
	Total	6	11	1	18

This pattern is not as pronounced in the child sample (though the "no" answers appear to correlate). As mentioned above, there appears to have been a skipping problem, and five respondents who should have received this question did not, so the results may have been effected by that.

		Question C834: Mental Confusion			
		Yes	No	Don't Know	Total
Question C836:	Yes	1	4	1	6
Unconsciousness	No	0	9	0	9
	Don't Know	0	0	0	0
	Total	1	13	1	15*

Further quantitative and qualitative work is necessary, but it is possible that these questions are duplicative and are capturing the same construct.

Question A936:	**For how long was s/he unconscious?**
Question C837	***Kuom kinde marom nade?***

All six adult sample respondents who answered "yes" to QA935 received Question A936, while the rest skipped it. There again appeared to be some skipping issues in the child questionnaire, as eight respondents received Question C837, even though only six were eligible due to their "yes" response to QC836.

This question was not probed during the cognitive interview, and no findings are available.

Question A937:	**Did the unconsciousness start suddenly, quickly within a single day (fast), or slowly over many days?**
Question C838	***Be paro malalni ne ochakore apoya nono, mapiyopiyo e odiechieng' achiel kata mosmos kuom ndalo mang'eny?***

The same six respondents who received QA936 also received Question A937. In the child sample, however, only five respondents answered Question C838, even though six were eligible due to their responses to QC836 and eight responded to QC837.

This question was not probed during the cognitive interview, and no findings are available.

Question A938:	**Did s/he have convulsions or fits?**
Question C839	***Be ne oriere ma pache olal/sambwa?***

Question N906:	**Did the baby have convulsions?**
	Bende nyathini ne nigi talarieya?

All 18 adult sample respondents received Question A938. No respondents answered "yes," while one responded "don't know" and the rest answered "no." 19 out of the 20 child sample respondents received Question C839, with two answering "yes," one answering "don't know," and the remaining 16 answering "no." 13 out of the 15 eligible neonate respondents received Question N906. Of them, four answered "yes," while the remaining nine answered "no."

Core Construct Interpretations

While none of the adult sample respondents answered "yes" to this question, QA938 (as well as Questions C839 and N906) was extensively probed during the cognitive interview. The interpretation of this question varied quite a bit, with the respondents thinking about various aspects of "convulsions and fits" to determine whether or not the deceased had suffered from any. Similar to what was observed with QA917, seen above in Figure 18, across the sample, respondents considered both the cause and the symptoms (or, in this case, physical manifestations) of convulsions. The "duration" pattern was only seen in the neonate sample, even though such as pattern is present in the adult sample in previous schemas (such as the diarrhea one in QA917). In addition to the causes, signs, and duration of convulsions, some respondents also thought about how they would respond to these signs if they did see them.
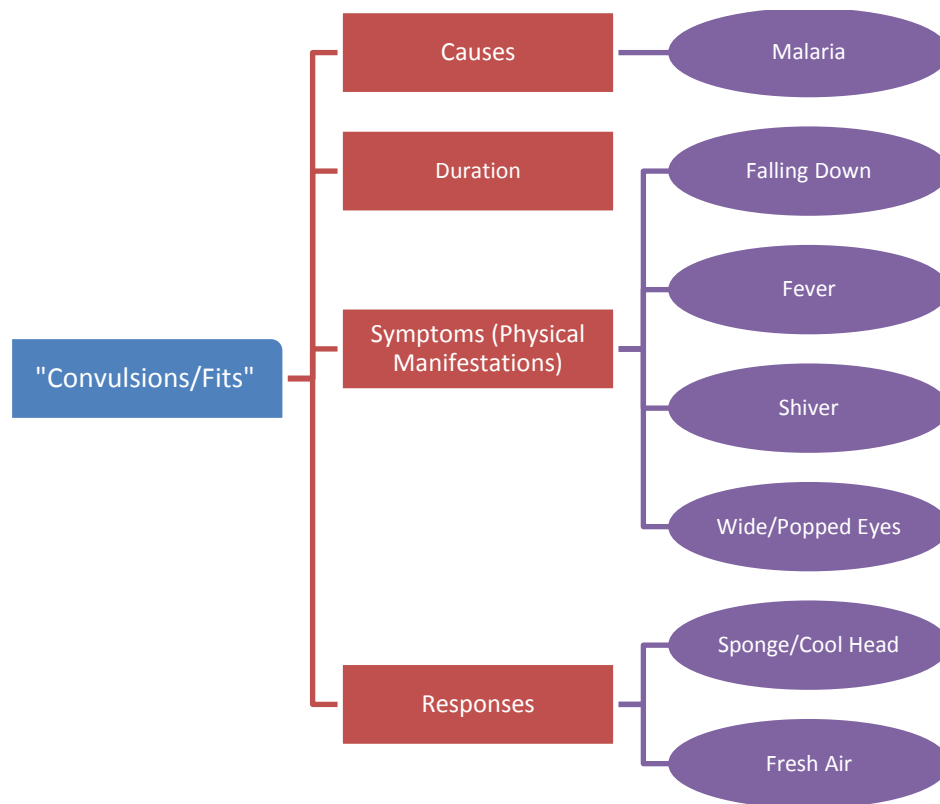

Figure 18: Response Schema for Questions A938, C839, and N906

Most respondents thought about at least two of these patterns when determining whether or not the deceased suffered from convulsions or fits.

Question A939:   **How long did the convulsions or fits last?**

Question C840   *Ne en gi sambwa kuom kinde marom nade?*

No respondents in the adult sample received Question A939. Even though only two respondents answered "yes" to QC839 and were therefore eligible for Question C840, four members of the child sample received and answered the question.

This question was not probed during the cognitive interview, and no findings are available.

Question N907:   **How soon after birth did the convulsions start?**

          Talarieya nochako ndalo adi bang' nyuolne?

The four neonate sample respondents who answered "yes" to QN906 all correctly went on to receive and answer Question N907. Three of the four answered the question in terms of days (corresponding to the *unread* answer categories), while the forth respondent answered in a non-quantifiable way: "When he was dying."

This question was not probed during the cognitive interview, and no findings are available.

Question A940:   **Did s/he become unconscious immediately after convulsion?**

Question C841   *Be pache ne olal mapiyo bang rieruok?*

No respondents in the adult sample received Question A940. Three of the four respondents who answered QC840 went on to receive Question C841.

This question was not probed during the cognitive interview, and no findings are available.

Question A941:   **Did s/he have any urine problems?**

Question C842   *Be ne en gi changruok moro amora mar layo?*

All 18 members of the adult sample received Question A941. Of these, three answered "yes," one "don't know," and the rest answered "no." 18 members of the child sample received Question C842, with four answering "yes," 13 answering "no," and one responding with a "don't know."

This question was not probed during the cognitive interview, and no findings are available.

Question A942:   **Did <NAME> pass too much urine, too little, or no urine at all?**

Question C843   *Be <NAME> ne layo mang'eny ahinya, kata matin ahinya kata ne ok ola chuth?*

Although three adult sample respondents answered QA941 "yes," and should have gone on to receive Question A942, only two did, with one respondent incorrectly skipping this question. All four respondents who answered "yes" to QC842 went on to answer Question C843.

This question was not probed during the cognitive interview, and no findings are available.

Question A943:   **Did s/he go to urinate more often than usual?**

Question C844   *Be ne olayo sate moloyo kaka pile?*

The three respondents who answered "yes" to QA941 all correctly received Question A943. The four respondents in the child sample who screened into the Urination Section all correctly received Question C844 as well.

This question was not probed during the cognitive interview, and no findings are available.

Question A944:   **During the final illness did s/he ever pass blood in the urine?**

Question C845   *E kinde mane otuo mogikni, be no olayo remo?*

The three respondents who answered "yes" to QA941 all correctly received Question A944. Although only four members of the child sample were eligible for this question, due to their "yes" response to QC842, five respondents received and answered Question C845.

This question was not probed during the cognitive interview, and no findings are available.

Question A945:   **Did s/he have any skin problems?**

Question C846   *Be ne en gi changruok e pien dende?*

Question N928

All 18 members of the adult sample received Question A945. Of these, three answered "yes," one "don't know," and the rest answered "no." 19 respondents in the child sample answered Question C846, with three replying "yes," and the other 13 saying "no." 13 members of the neonate sample received Question N928. Of them, three answered "yes," nine answered "no," and one said "don't know."

This question was not probed during the cognitive interview, and no findings are available.

Question A946: **Did s/he have any ulcers, abscess or sores anywhere except on the feet?**

Question C847 *Bende ne en gi adhonde, buche kata ruodho magolo pi kamoro amora e*

Question N929 *dende ma ok tiendene?*

The three respondents who answered "yes" to QA945 all correctly received Question A946. Although only three respondents in the child sample should have received Question C847 based on their answer to QC846, four members of the sample received and answered it. Seven members of the neonate sample received Question N929, even though only three were eligible due to their affirmative response to QN928.

This question was not probed during the cognitive interview, and no findings are available.

Question A947: **Did s/he have any ulcers, abcess or sores on the feet that were not also on other parts of the body?**

Question C848 *Bende ne en gi adhonde, buche kata ruodho magolo pi kamoro amora e*

Question N930 *dende ma ok tiendene?*

The three respondents who answered "yes" to QA945 all received Question A947. The same four child sample respondents who answered QC837 went on to receive Question C848, including one who should have skipped it. Eight neonate respondents received and answered Question N930, even though only five should have based on their answer to QN929.

This question was not probed during the cognitive interview, and no findings are available.

Question A948: **During the illness that led to death, did s/he have any skin rash?**

Question C849 *E tuone mogik kae to otho, be ne en gi del maruodho?*

Question N931

Three respondents received Question A948; five respondents received Question C849; and seven respondents received Question N931.

This question was not probed extensively during the cognitive interview. One respondent in the adult sample did question whether the deceased had an actual skin rash or simply had multiple mosquito bites.

Question A949: **For how long did s/he have any skin rash?**

Question C850 *Ne en gi del maruodho kuom kinde marom nade?*

The three respondents who answered "yes" to QA948 all correctly received Question A949. The one respondent who answered "yes" to QC849 also correctly received Question C850

Core Construct Interpretations

All four respondents expressed difficulty answering this question. One respondent simply answered "don't know," while two others attempted to set the duration but were ultimately unable. For instance, one respondent explained that the rash was "on and off," and could not remember when it started. Another respondent noted that he was not around the deceased when the rash started, so he could not correctly approximate the duration. A fourth respondent answered "1 week," but was unable to explain coherently why he thought that was correct.

| **Question A950:** | **What did the rash look like?** |
| **Question C851** | *Dende ne oruodho machal nade?* |

The three respondents who answered "yes" to QA948 all correctly received Question A950. Likewise, the one respondent who answered QC849 in the affirmative also correctly received Question C851.

This question was not probed extensively during the cognitive interview. Only one of the three adult sample respondents stuck to the answer categories provided (by saying measles rash). One other respondent said he was not able to accurately describe the rash, while the other said it looked like mosquito bites. The lone member of the child sample answered using the "measles rash" answer category.

| **Question N932:** | **Did the baby have measles rash?** |
| | *Bende I lwete kata I tiende nyathini ne olokre maratong' tong'?* |

Seven respondents received Question N932, even though only three respondents answered QN931 in the affirmative.

This question was not probed extensively during the cognitive interview. One respondent did explain her "no" answer by saying that her grandmother diagnosed the baby's skin rash as "sweat rash," and not measles. This baby died at home, so it appears that the mother was relying on folk medicine and it is unclear whether or not the baby would have been actually diagnosed with measles had it been taken to a medical center.

| **Question A951:** | **Did s/he ever have shingles or herpes zoster?** |
| **Question C852** | *Be ne en gi awang'I kata pien del makuot?* |

The three respondents who answered "yes" to QA945 all correctly received Question A951, while four child sample respondents received Question C852 (three of whom correctly received it, and one who incorrectly skipped in).

This question was not probed during the cognitive interview, and no findings are available.

Question A952:   **Did s/he have bleeding from the nose, mouth or anus?**

Question C853   *Be remo ne wuok e dhoge, ume kata e siandane?*

All 18 adult sample respondents received Question A938, and all answered the question with a "no" response. All 20 members of the child sample received Question C853, with three answering "yes," 16 answering "no," and one saying "don't know."

This question was not probed during the cognitive interview, and no findings are available.

Question A953:   **Did s/he have noticeable weight loss before death?**

Question C854   *Be dende nogore manenore kapok otho?*

All 18 adult sample respondents received Question A938. Seven of these respondents answered the question saying "yes," one said "don't know," and the rest answered "no." All 20 child sample respondents received and answered Question C854, with eight responding "yes," and 12 answering "no."

This question was not probed during the cognitive interview, and no findings are available.

Question A954:   **Did s/he look very thin or wasted?**

Question C855   *Be ne odhero ahinya?*

Although only seven respondents answered "yes" to QA953, 10 respondents received and answered Question A954—so three respondents incorrectly skipped into this question. Likewise, 12 respondents in the child sample received Question C855, even though only eight of them answered "yes" to the screening question, QC854.

This question was not probed during the cognitive interview, and no findings are available.

Question A955:   **Did s/he have mouth sores or white patches in the mouth or on the tongue?**

Question C856   *Be ne en gi dhok mopudhore kata gik marochere e dhoge kata lewe?*

All 18 members of the adult sample received Question A955, and all 20 respondents in the child sample received Question C856

This question was not probed during the cognitive interview, and no findings are available.

Question A956:   **Did s/he have stiffness of the whole body, or was unable to open the mouth?**

Question C857   ***Be dende ne otal kata lake okare/ok onyal ng'amo dhoge?***

All 18 adult sample respondents received Question A956, and all answered the question with a "no" response, with the exception of two respondents who said "don't know." 20 child sample respondents received Question C857. Of them, four answered "yes," 15 answered "no," and one said "don't know."

This question was not probed during the cognitive interview, and no findings are available.

Question A958/958.1:   **Did s/he have any swelling/puffiness? ([If yes] Where was the swelling?)**

Question C858/859   ***Be ne nitie kamoro amora kuome mane okuot/oyienyo? (En kanye mane okuot?)***

All members of the adult sample received Question A958. Of the 18 in this sample, seven said "yes" (and moved on to the follow-up sub-question, Question A958.1, about the location of the swelling), while the rest answered "no." Likewise, all 20 members of the child sample received Question C858. Of these, three answered "yes" and went on to receive the follow-up question about location, Question C859.

Core Construct Interpretations

This question was not probed extensively during the cognitive interview. Of the seven adult sample respondents, four used the "other, specify" answer category. These respondents were thinking about single feet (as compared to the "both feet" answer category), the body above the waist (as compared to the "whole body" answer category), and the penis. None of the child sample respondents, on the other hand, used the "other" category.

Question A959/959.1:   **Did s/he have any lumps or lesions? ([If yes] Where were the lumps?)**

Question C860/861   ***Be dibedie gi kamoro amora mokuot matek e dende kaka orung'rung'? (Orung'rung' ne gin ei ang'one?)***

All 18 adult sample members received Question A959, and all of them answered the question "no." Therefore, nobody in the adult sample received the location follow-up question, Question A959.1. 18 respondents in the child sample received Question C860, and all of them responded "no." Therefore, no one received the follow-up question on location, Question C861.

This question was not probed during the cognitive interview and no findings are available.

Question A960:   **Did s/he have paralysis?**

Question C862   *Be ne otho gi dende?*

The full adult sample received Question A960. Of the 18, five respondents answered "yes," while the rest responded "no." 19 members of the child sample answered Question C862, with two respondents answering "yes," one answering "don't know," and the remaining 16 answering "no."

Core Construct Interpretations

This question was not probed extensively during the cognitive interview. A few respondents in both samples expressed quite a bit of confusion over the Luo term, but then understood the question when it was repeated in English. For instance, one of these respondents (in the adult sample) first thought that the question was asking whether the deceased had died and been resurrected.

Two respondents in the child sample used the "other" category, indicating that the child was paralyzed in the hands, noting that they could not grip objects.

Question A961:   **Did s/he have difficulty or pain while swallowing liquids?**

Question C863   *Be ne owinjo lit ka omwonyo gik ma imadho?*

The full adult sample received Question A961, and of the 18 respondents two answered "yes," two answered "don't know," and the remaining 14 answered "no." All 20 members of the child sample received Question C863, with three of them answering "yes," 14 answering "no," and 3 responding "don't know."

This question was not probed during the cognitive interview, and no findings are available.

Question A962:   **Did s/he have yellow discoloration of the eyes?**

Question C864   *Be tong wang'e ne olokore maratong'?*

The full adult sample received Question A962. Of the 18 respondents three answered "yes," one answered "don't know," and the remaining 14 answered "no." Similarly, the full child sample received Question C864. Of these 20 respondents, six answered "yes," 13 answered "no," and one answered "don't know."

This question was not probed during the cognitive interview, and no findings are available.

Question A963:   Did his/her hair color change to reddish or yellowish?

Question C865   *Be yie wiye ne olokore makwarkwar kata maratong'?*

All 18 members of the adult sample received Question A963. Besides one respondent who answered "don't know," all members of the adult sample responded "no" to this question. 18 members of the child sample received Question C865, three of whom answered "yes," 14 of whom answered "no," and one of whom responded with a "don't know."

This question was not probed during the cognitive interview, and no findings are available.

Question A964:   Did s/he look pale (thinning/lack of blood) or have pale palms, eyes or nail beds?

Question C866   *Be ne nenore ni oonge remo kata koke, I lwete gi wengene ne rachar?*

The full adult sample received Question A964. Of them, four respondents answered "yes," one answered "don't know" and the rest answered "no." The full 20 members of the child sample received Question C866. Of them, nine answered "yes," 10 answered "no," and one answered "don't know."

This question was not probed extensively during the cognitive interview. One respondent, who had previously mentioned that the deceased was told that she needed a blood transfusion, answered this question "no." Probing in the cognitive interview revealed that while the deceased was in need of blood near the end of her life, the respondent said that her physical coloring was not affected. Were it not for the doctor's examination, the respondent said that she would not have known that the deceased needed blood.

Question A965:   Did s/he have sunken eyes?

Question C867   *Be wengene ne olutore?*

All 18 members of the adult sample received Question A965. Of them, six respondents answered the question "yes," one answered, "don't know," and the other 11 answered "no." The full child sample received Question C867. Of the 20, six responded "yes," 13 answered "no," and one respondent said "don't know."

This question was not probed during the cognitive interview and no findings are available.

Question C868:   During the final illness was the child growing normally?

E tuone mogik, be nyathini ne dongo makare?

All 20 members of the child sample received and answered Question C868. Of the 20, 12 answered the question with a "yes" response, 7 with a "no" response, and one respondent said "don't know."

This question was not probed during the cognitive interview, and no findings are available.

Question A965:   **Did s/he drink a lot more water than usual?**

Question C869   *Be ne omodho pi mang'eny moloyo kaka pile?*

The full adult sample received Question A965. Of the 18 respondents, six answered "yes," two answered "don't know," and 10 answered "no." 20 child sample respondents received Question C869, with five responding "yes," 14 saying "no," and one answering "don't know."

This question was not probed extensively during the cognitive interview. One adult sample respondent who answered "don't know," explained that he was not living in the same place as the deceased and could not observe his everyday actions.

Question N904:   **Was the baby able to suckle or bottle feed within the first 24 hours after birth?**
                        Be nyathini ne nyalo dhodho thuno kata chupa ei seche piero ariyo gi ang'wen bang' nyuolne?

13 neonate sample respondents received and answered Question N904. Of these 13, nine answered "yes," and four answered "no."

This question was not probed during the cognitive interview, and no findings are available.

Question N905:   **Did the bay stop sucking or bottle feeding 3 days after birth?**
                        Bende nyathini ne oweyo dhoth ndalo adek bang' nyuolne?

Although only nine respondents should have received Question N905 based on their answer to QN904, the same 13 people who answered the previous question continued on to answer this one as well.

This question was not probed during the cognitive interview, and no findings are available.

Question N911:   **Did the baby become unresponsive or unconscious soon after birth?**
                        Bende nyathini pache ne olal mapiyo bang' nyuolne?

13 members of the neonate sample received Question N911, one of whom answered "yes," 11 of whom answered "no," and one of whom said "don't know."

This question was not probed during the cognitive interview, and no findings are available.

Question N912:   **How long after birth did the baby become unresponsive or unconscious?**

Ne en kinde marom nade bang' nyuolne mane pach nyathini olal?

The one respondent who answered "yes" to QN911 went on to receive and answer Question N912. The answer categories for this question were "less than 24 hours," "more than 1 day" and "don't know." The lone respondent reported "less than 24 hours."

This question was not probed during the cognitive interview, and no findings are available.

Question N914:   **Did the baby become cold to the touch before it died?**

Bende dend nyathi ne ng'ich thi kimule kapok otho?

13 neonate sample respondents received Question N914. Of them, three said "yes," nine answered "no," and one responded "don't know."

This question was not probed during the cognitive interview, and no findings are available.

Question N927:   **Did the baby have redness or discharge from the umbilical cord stump?**

Bende pend nyathi kama ne ong'adi ne olokore makwar kata ne chwer?

13 neonate sample members received Question N927. Of them, two responded "yes," 10 answered "no," and one said "don't know."

This question was not probed extensively during the cognitive interview. One respondent, who answered the question "yes," revealed upon probing that she was thinking of the umbilical cord itself (and not the stump) bleeding. More research would be necessary to determine how much variation exists around the comprehension of the phrase "umbilical cord stump."

Question N933:   **Did the baby have yellow palms or soles?**

Bende I lwete kata I tiende nyathini ne olokre maratong' tong'?

13 neonate respondents received and answered Question N933, with only one of them answering "yes," another one responding "don't know," and the remaining 11 saying "no."

This question was not probed during the cognitive interview, and no findings are available.

Question N934:   **Did the mother receive tetanus toxid (TT) vaccine?**

Bende min nyathini ne oyudo chanjo mar tetanus?

Again, 13 members of the neonate sample received Question N934. Three respondents answered "don't know," while the other 10 responded "yes."

This question was not probed during the cognitive interview, and no findings are available.

Section A10: Risk Factors

Question A1001:   **Did s/he drink alcohol?**
                          Be ne omadho kong'o?

All 18 members of the adult sample received Question A1001.

This question was not probed during the cognitive interview and no findings are available.

Question A1002:   **Did s/he smoke tobacco?**
                          Be ne omadho ndawa/kwesi/akota/puga?

All 18 members of the adult sample received Question A1002.

This question was not probed during the cognitive interview and no findings are available.

Section A11, C10, and N10: Treatment and Health Service Use for the Final Illness

Question A1101:   **Was s/he adequately vaccinated?**

Question C1001   *Be ne oyudo chanjo kaka dwarore?*

Question N1001

At this point in the interview only 16 of the original 18 members of the adult sample remained—two respondents dropped out because of fatigue. All 16 remaining adult sample members received this question. The entire 20 member child sample received Question C1001. All of the remaining 13 members of the Neonate sample (20 less 5 stillbirths and two dropouts) received Question N1001.

Core Construct Interpretations

There is a wide understanding of what constitutes adequate vaccination, as well as a variety of response pathways a respondent can use to determine his or her answer, as can be seen in Figure 19 below. In terms of the core construct, respondents tended to think about either when a vaccination occurred (or should occur) or what was in the vaccination when determining whether or not the deceased was adequately vaccinated.

Within both of these pathways, some respondents used location cues to determine what counted as "adequate." For example, a respondent who was thinking about a vaccination that occurred at birth might directly think about that time period, or he or she could think about a vaccination that occurred at the hospital as a proxy for that time period. Similarly, some respondents thought about where vaccinations were administered—on the arm, leg, or orally—as a proxy for what specific vaccinations the deceased had received.
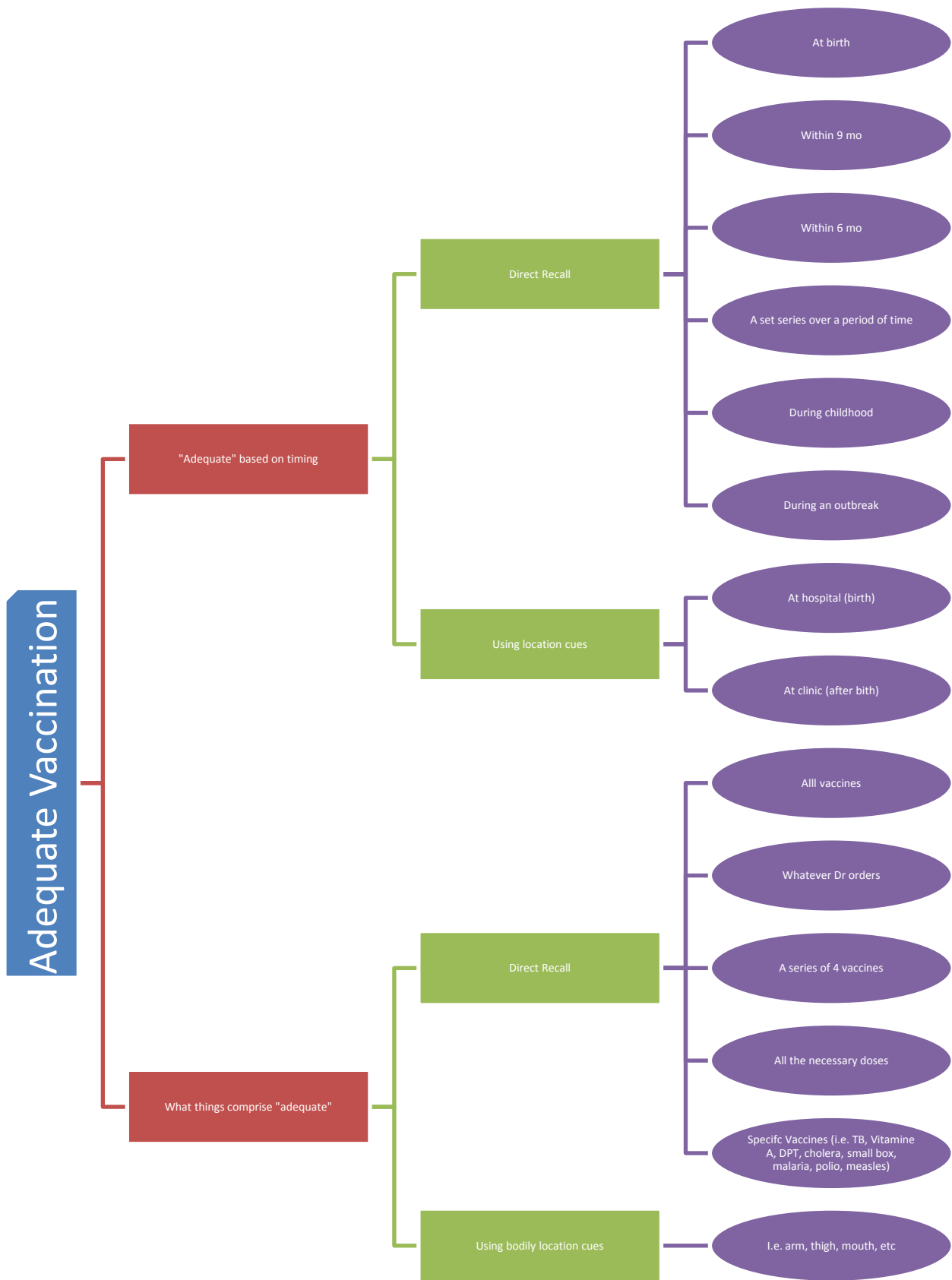
Figure 19: Response Schema for Questions A1101, C1001, and N1001

Question A1102: **Did s/he receive any treatment for this illness that led to death?**

Question C1002 *Be ne oyudo thieth moro amora ne tuo mane okelo thoneno?*

Question N1002

The entire remaining adult sample received this question. Of them, 13 respondents answered "yes," one responded "don't know," and two replied "no." Likewise, the whole child sample received Question C1002, with 12 respondents answering "yes," seven saying "no," and one replying "don't know." The remaining 13 members of the neonate sample received Question N1002. Of them, only one respondent answered "yes," while 11 answered "no," and another one answered "don't know."

This question was not probed during the cognitive interview, and no findings are available.

Question A1103: **What treatment did s/he receive?**

Question C1003 *En thieth mane mane oyudo?*

Question N1003

While only 13 adult sample respondents answered "yes" to QA1102, 15 respondents answered Question A1103—indicating that two respondents improperly skipped into this question. 13 respondents in the child sample also received and answered Question C1003, including one who should have skipped over this question. Three neonate sample members received Question N1003, even though only one respondent was eligible. None of these three respondents (including the one who correctly received the question) were able to answer the question. They all indicated that their baby did not receive any of the listed treatments.

This question was not probed during the cognitive interview, and no findings are available.

Question A1104: **Please tell me at which of the following places/facilities did <NAME> receive treatment during the illness that led to death?**

Question C1004 *Akwayi ni inyisa kuonde mane <NAME> oyude thieth ne tuo mane okelo*

Question N1004 *thone kume somogi?*

In the case of Question A1104, all 16 remaining respondents in the adult sample received and answered the question, even though only 13 should have skipped in based on their answers to QA1102. 14 out of the 20 child sample respondents received and answered Question C1004, even though only 12 were eligible based on their "yes" answers to QC1002. The three neonate respondents who received QN1003 went on to receive Question N1004 as well.

This question was not probed during the cognitive interview, and no findings are available.

Question A1105:   **Did s/he have any operation for the illness?**

Question C1005   *Be ne oyang'e ne tuono?*

Question N1005

All remaining adult sample members received Question A1105. All 16 of these respondents answered the question in the negative. Although the entire child sample should have received Question C1005, only 15 out of the 20 did. All 15 answered QC1005 "no." Only 10 members of the neonate sample received Question N1005, and like the other two samples, all of these respondents answered "no."

This question was not probed during the cognitive interview, and no findings are available.

Question A1105.1:   **How long before death did s/he have this operation?**

Question C1005.1   *Ne oyang'e bang' ndalo adi kapok otho?*

Question N1005.1

No respondents in the adult, child or neonates samples received Question A1105.1, Question C1005.1, or Question N1005.1, respectively; no findings are available.

Question A1106:   **Was s/he discharged from the hospital very ill?**

Question C1006   *Be ne owuok/ogole e osiptal kapod otuo ahinya?*

Question N1006

All 16 remaining adult sample respondents received Question A1106. The entire child sample received Question C1006. However, only nine members of the neonate sample received Question N1006.

Core Construct Interpretations

Similar to what was observed previously in QA829/C929/N605 (about "normal" deliveries), while there are quite a few patterns of interpretation found across the samples (seen below in Figure 20), most respondents actually employed multiple patterns when considering the differences between 'ill' and "very ill." This triangulation almost certainly increases the overall validity of the term "very ill," which all the respondents generally understood to be a more intense or serious illness.

Basically, respondents thought about the difference between someone who is ill and very ill in terms of abilities and the results of the illness. The respondents appeared to separate physical abilities (such as eating and walking) and social abilities (such as social interaction). In a number of cases, a cause-and-effect relationship emerged between these two sub-constructs—with respondents reporting that (for instance) a person who is very ill cannot do their household chores because they cannot walk very well.
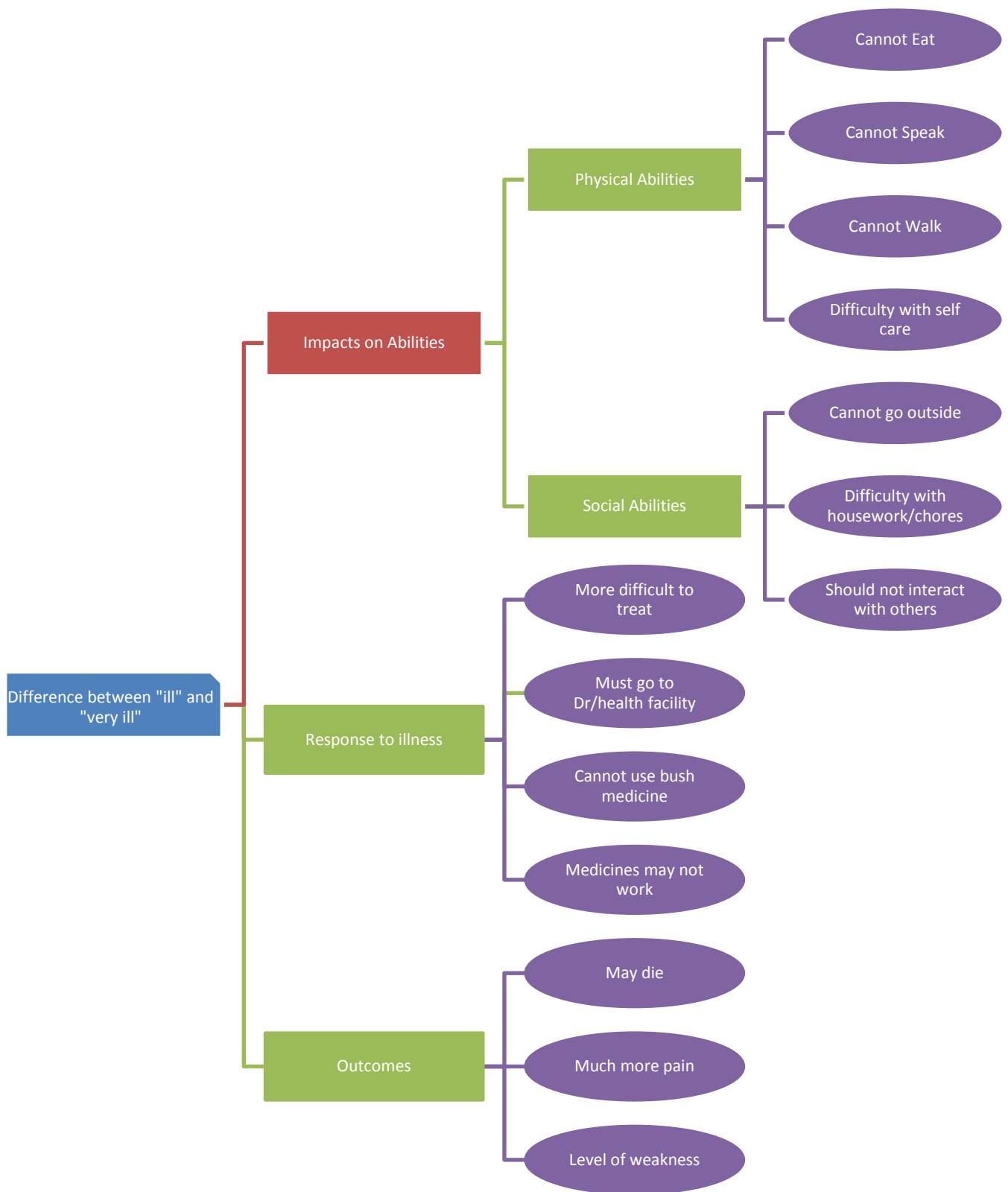
Figure 20: Response Schema for Questions A1106, C1006, and N1006

Question A1107:   **In the final days before death, did s/he travel to a hospital or health facility?**

Question C1007   *Ee ndaone magik kapok otho, nodhi/notere e osiptal kata od thieth?*

Question N1007

All 16 remaining members of the adult sample received Question A1107. Of these respondents, 10 answered "yes," one responded "don't know," and the other five answered "no." 19 out of 20 members of the child sample answered Question C1007, with 10 responding "yes," 8 answering "no," and one respondent saying "don't know." 11 members of the neonate sample received Question N1007, with four respondents saying "yes" and the other seven answering "no."

<center>

Core Construct Interpretations

</center>

The respondents considered the question as to what counts as the "final days" in two ways: duration and knowledge of death. Across both of these response pathways, respondents expressed quite a bit of confusion, explaining that "final days" is a very situational phrase, and depends on whether an illness is chronic or acute as well as a number of other factors. For instance, out of the 16 respondents in the adult sample who answered this question, seven expressed confusion or had to ask for the question to be repeated.

The duration interpretation is perhaps the more obvious—these respondents were thinking about how long "final days" are in quantifiable time. There was no agreement across the three samples, however, on the length. Many respondents gave a range of time, or provided examples from their own lives. For instance, one respondent in the adult sample noted that her father-in-law died suddenly and didn't have any final days, whereas her brother was sick for a long time with a chronic illness and she thought of his final days being a few months. The actual durations the respondents cited varied from a few months to a few weeks to a few days or one day.
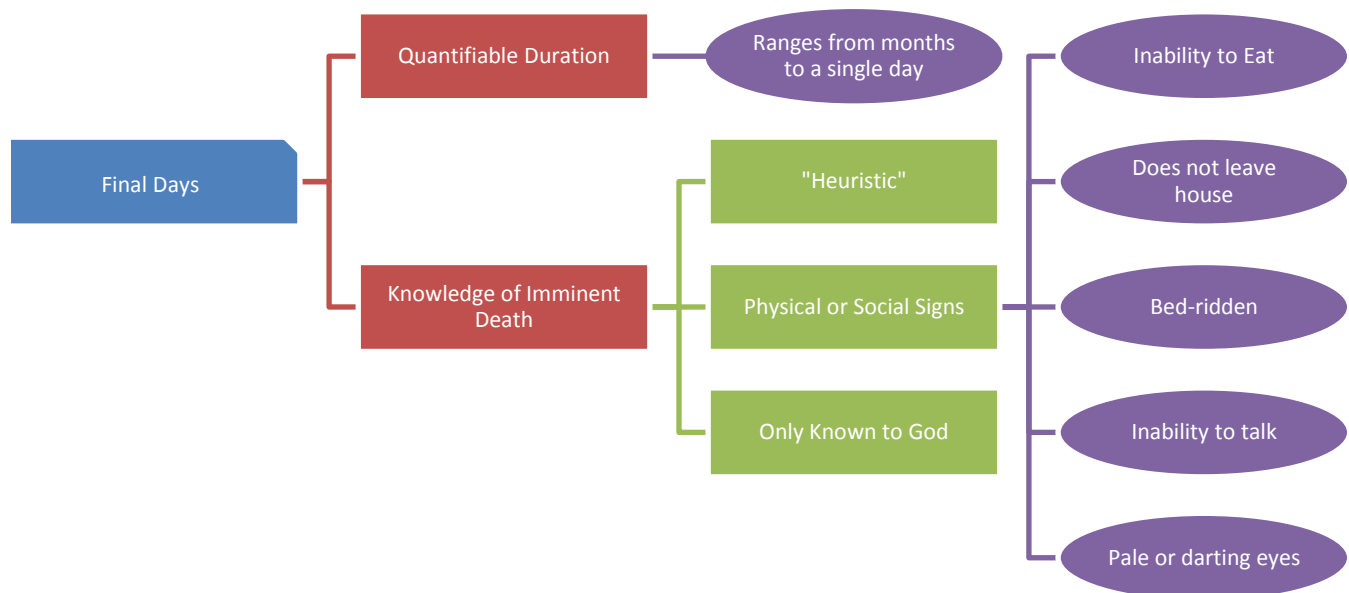

Figure 21: Response Schema for Questions A1107, C1007, and N1007

The other interpretation of the construct "final days" is the period of time when the respondents know that someone is going to die. The respondents approached this period in three different ways. Some respondents treated it as a heuristic—they just knew that someone was close to death. Others explicitly looked for (and mentioned) signs that point to a person's imminent death, while some others employed a more mystical definition, wherein "only God knows" when and how long a person's final days are. In all likelihood, the former interpretation is not a true heuristic, and these respondents are probably looking for and judging physical and social signs as well. However, they appear to have internalized these signs to the point that they report the ability to simply "know" when someone will die.

Respondents interpreted the phrase "final days" the same way across all of the questions that used this phase as a reference period—including questions A1113/C1013/N1013, A1114/C1014/N1014, and A1115/C1015/N1015. By using such an imprecise phrase as the reference period, the actual periods of the decedents' lives that the respondents consider vary greatly; this variation will clearly impact the construct validity and the overall reliability of these questionnaire items. During the revision of these questionnaires, a more concrete term (such as days or months) should be used instead of "final days."

Question A1108:   **Did s/he use motorized transport to get to the hospital or health facility?**

Question C1008   *Be ne otere/odhi e osiptal kata kar theith gi pikpiki kata mtoka?*

Question N1008

All 10 respondents who answered "yes" to QA1107 went on to correctly receive Question A1108. 16 members of the child sample received Question C1008, including six respondents who should have skipped this question. Six neonate respondents received Question N1008, including two who should have skipped over it.

This question was not probed during the cognitive interview and no findings are available.

Question A1109:   **Were there any problems during admission to the hospital or health facility?**

Question C1009   *Bende ne nitie chandruok moro amora kane irwake e osiptal kata od thieth?*

Question N1009

All 10 respondents who answered "yes" to QA1107 went on to correctly receive Question A1109. Of these adult sample respondents, one answered "yes," three answered "don't know," and six answered "no" to this question. 13 members of the child sample received Question C1009, including three respondents who should have skipped this question. Of these 13 respondents, one answered "yes," while the remaining 12 answered "no." The four respondents who answered "yes" to QN1007 correctly received Question N1007. All four answered "no" to the question.

This question was not probed during the cognitive interview and no findings are available.

Question A1110: Were there any problems with the way s/he was treated (medical treatment, procedures, interpersonal attitudes, respect, dignity) in the hospital or health facility?

Question C1010 *Bende ne nitie chandruok moro amora e yore mag theith kaka luor, rwak gi okange mag thieth?*

Question N1010

The one respondent who answered "yes" to QA1109 went on to correctly receive Question A1110. However, four child sample respondents received and answered Question C1010, even though only one of them was eligible due to their answer to QC1009. No respondents in the neonate sample received Question N1010.

This question was not probed during the cognitive interview and no findings are available.

Question A1111: Were there any problems getting medications, or diagnostic tests in the hospital or heath facility?

Question C1011 *Be dine bedie chandruok moro amora e yudo yath, pimo mar fwenyo tuo e ospital kata kar thieth?*

Question N1011

The one respondent who answered "yes" to QA1109 went on to correctly receive Question A1111. The same four respondents who answered QC1010 went on to receive Question C1011. No respondents in the neonate sample received Question N1011.

This question was not probed during the cognitive interview and no findings are available.

Question A1112: Does it take more than 2 hours to get to the nearest hospital or health facility from the deceased household?

Question C1012 *Wuok e oth kama <NAME> ne odakie nyaka e ospital/od thieth machiegni bende nyalo kawo mokalo seche ariyo?*

Question N1012

All 16 remaining members of the adult sample received Question A1112. 19 members of the child sample received Question C1012. 13 members of the neonate sample received Question N1012.

This question was not probed during the cognitive interview and no findings are available.

Question A1113: In the final days before death, were there any doubts about whether medical care was needed?

Question C1013 *Ee ndalo mogik kapok <NAME> otho, be dine bedie kiawa ka thieth mar osiptal dwarore?*

Question N1013

All 16 remaining members of the adult sample received Question A1113. The full child sample received Question C1013. The remaining 13 members of the neonate sample all received Question N1013.

Core Construct Interpretations

This question was not probed extensively during the cognitive interview. Across the samples, the respondents understood this question to be asking whether or not they believed the deceased should have gone to the hospital or medical center. It appears as though the respondents were only considering out-of-home medical care, and were not thinking about medicines or therapies the deceased could have (or did) receive at home. For instance, one respondent in the adult sample who answered "yes" explained that the family was poor, and so they had to consider whether or not the deceased absolutely had to go to a hospital.

In the child sample in particular, a number of respondents indicated or expressed confusion over this question. In each of these cases, the respondent appears to not be sure whether the question is asking about their current doubts or their doubts at the time of the illness.

It should be noted that this question is both retrospective and quasi-attitudinal. Respondents are not only being asking about something in the past, but about how they felt or thought in the past. The potential for retrospective response, or regret, bias is therefore quite high, and could have a negative impact on the validity of this question's data.

Question A1114:   **In the final days before death, was traditional medicine used?**

Question C1014   *E ndalo mogik kapok (NAME) otho, be notiyo gi yath mar nyaluo?*

Question N1014

All 16 remaining members of the adult sample received Question A1114. All 20 child sample respondents received Question C1014. The 13 remaining members of the neonate sample received Question N1014.

Core Construct Interpretations

By and large, the term "traditional medicine" has a very tight interpretation across all three samples: The term appears to function as a heuristic—no respondents expressed difficultly answering the question, and the interviewers report that they all seemed to know what they were talking about and answered the survey question quickly. Additionally, their interpretations of the core construct— "traditional medicine"—did not vary much at all: Nearly all the respondents were thinking about the use of herbs or plants from the bush that were prepared at home.

During the cognitive interview, the respondents were all asked to describe "traditional medicine," explain where they (or someone) could obtain the medicine, and how it was prepared and administered. By treating the interview notes as quasi-"freelists" (see Weller and Romney, 1988), we can begin to understand the breadth of the four cultural/cognitive domains that were probed on (Items used in traditional medicine; Locations where traditional medicine is obtained; Preparation of traditional medicine; Administration of traditional medicine), as well as the relative salience of the items within each domain. Charts4, 5, 6, and 7 below show the relative frequencies of the various items in these four domains that emerged during the cognitive interviews.
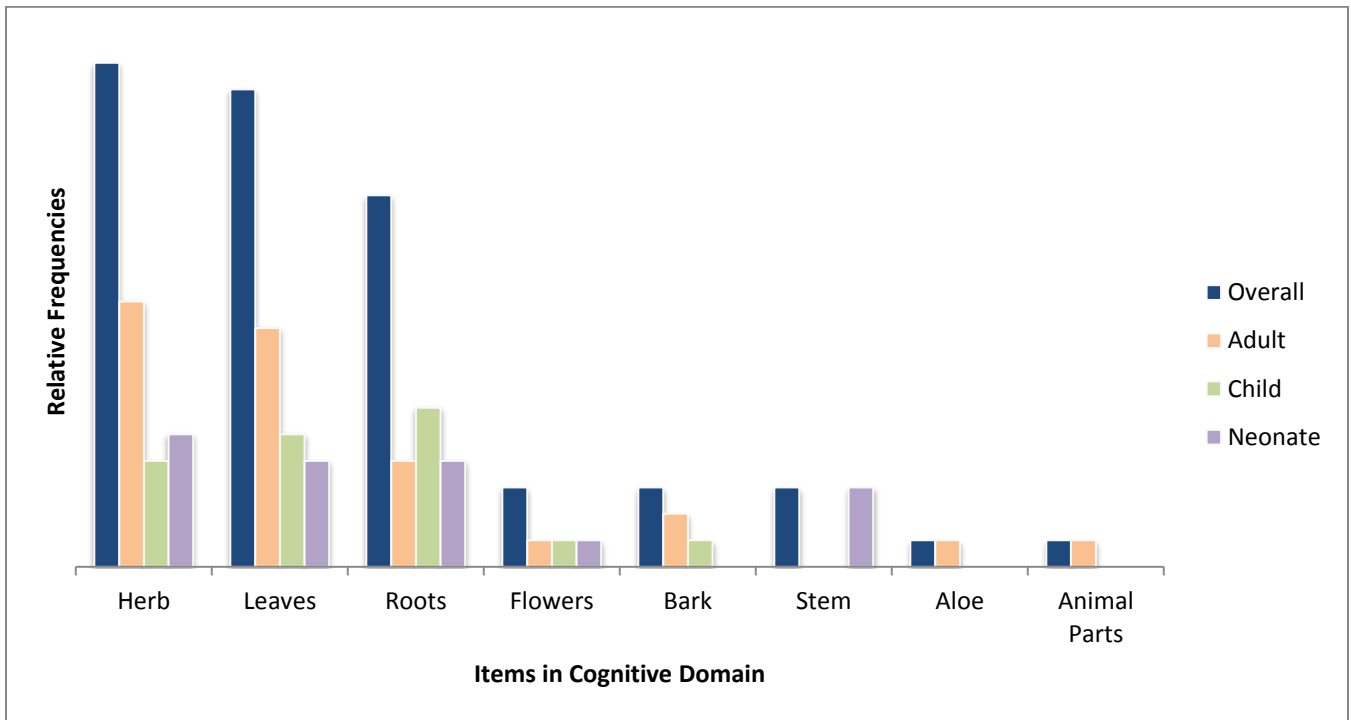
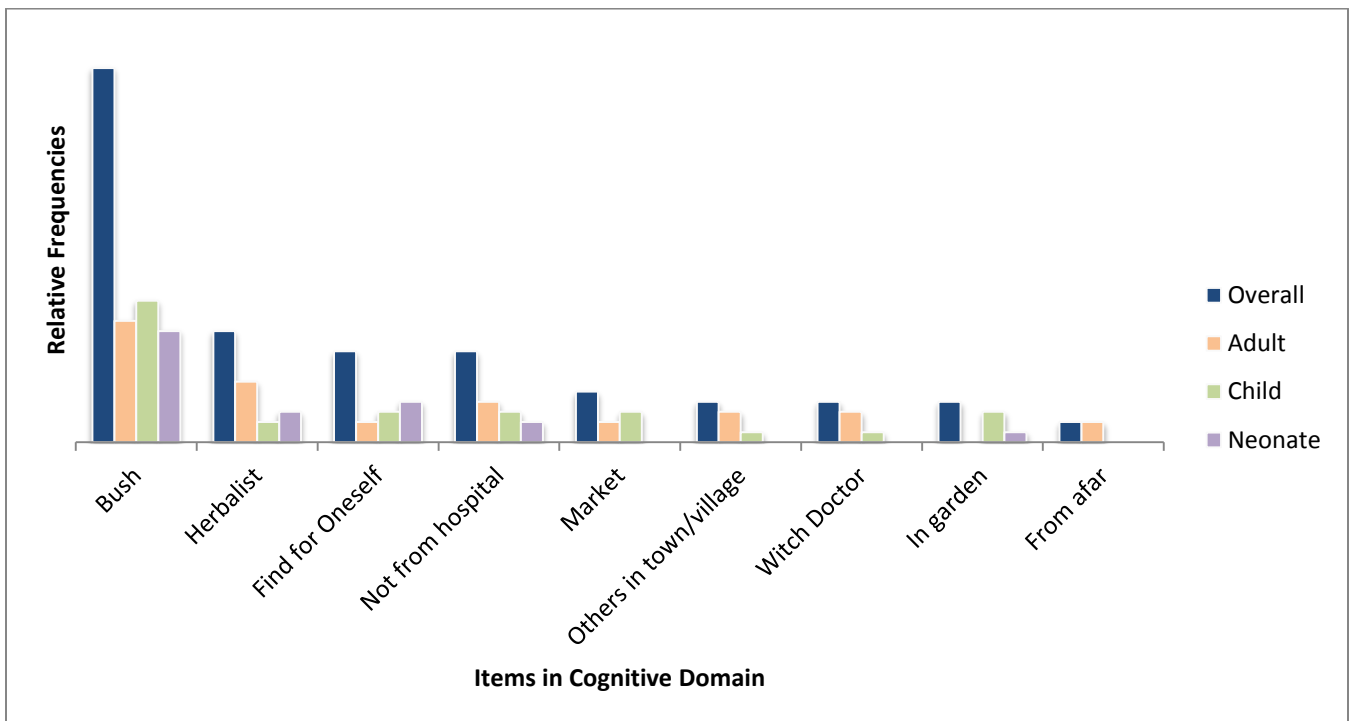**Chart 4: Relative Frequencies within the "Item Used" Domain**

Chart 5: Relative Frequencies within the "Location Obtained" Domain
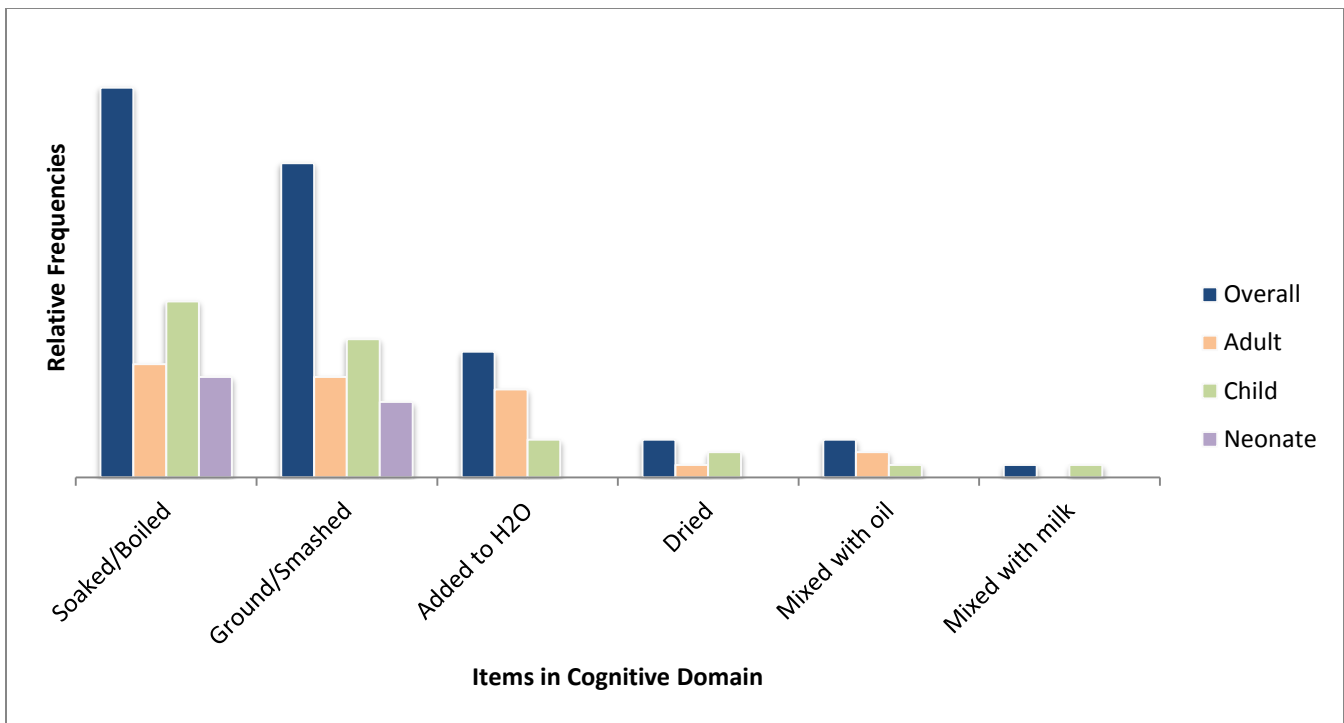
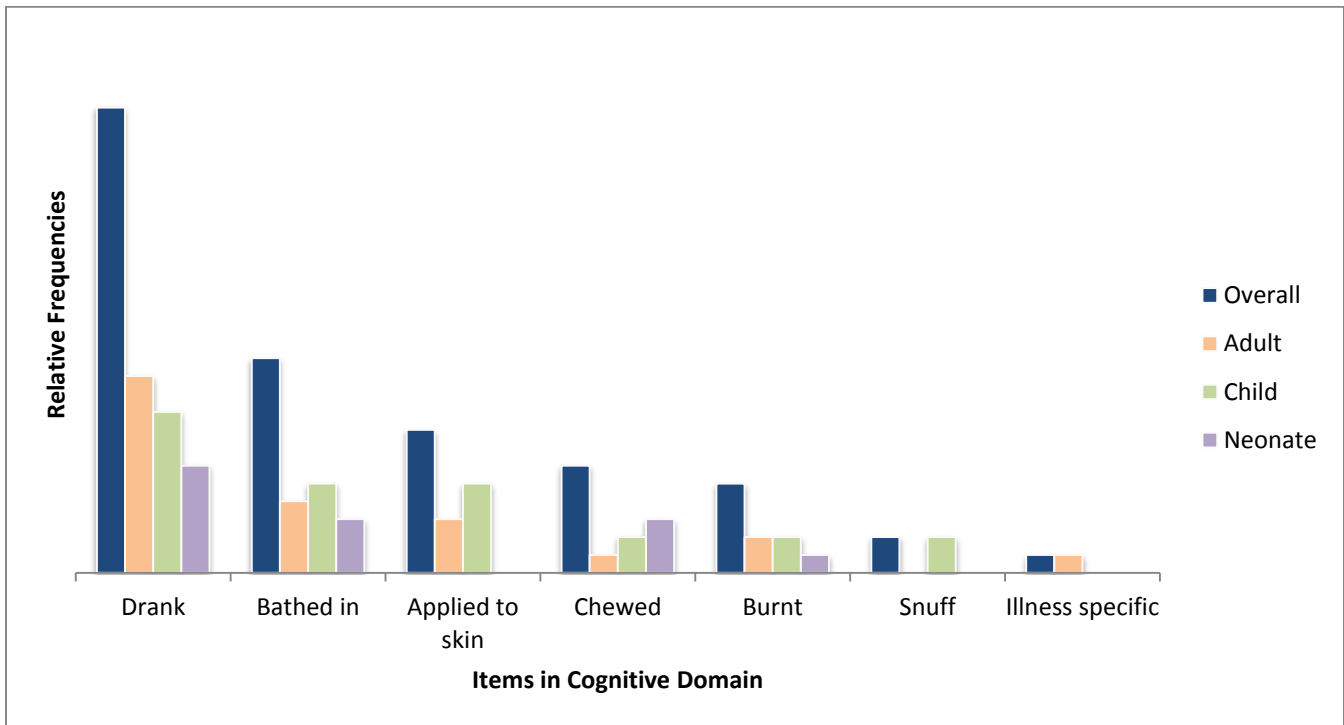**Chart 6: Relative Frequencies within the "Preparation" Domain**

Chart 7: Relative Frequencies within the "How Medicine is Administered" Domain

Generally speaking, in the analysis of freelist data the number of items that emerge indicate the breadth of the domain. In each of these four component domains of "traditional medicine," the breadth of the domain was quite low—the location domain was the widest with 10 items. Most cultural domains are much larger than this—Berlin and Kay (1969) for example found that some cultures used more than 30

color terms alone; while Scanlon (2010) found nearly 100 items in the cultural domain of "Mexican food" in the American South. Practically speaking in terms of survey methodology, the smaller (or "tighter") a domain, the fewer patterns of interpretation respondents will employ while considering a construct and answering a survey question.

In addition to the breadth and variation of items within a domain, the salience of these items can be analyzed and considered. Again generally speaking, items that are mentioned more frequently in freelists across a sample are considered to be more culturally salient. Across all four of the component domains of "traditional medicine" there are one or two items in each domain that are much more frequent than the others—indicating that these interpretations of the domain are the most important cognitively. For example, in the "location obtained" domain, it is clear that the respondents largely thought about "traditional medicine" as material obtained from the bush.

These high levels of agreement and salience do not mean that the concept of "traditional medicine" will have the same interpretation, or a similarly tight interpretation, across multiple cultures, however. It is quite possible (and in fact the ethnobotanical and ethnomedicinal literatures agree) that constructs such as "traditional medicine" and even "bush medicine" are very culturally specific. Cross-cultural research would be necessary to say anything about this question outside of the Luo tradition.

Question A1115:   **In the final days before death, did anyone use a telephone or cell phone to call for help?**
Question C1015   *E ndalo mogik kapok <NAME. otho, be ne utiyo gi simu ee manyo kony?*
Question N1015

All 16 remaining members of the adult sample received Question A1115. All 20 members of the child sample received Question C1015. The thirteen remaining members of the neonate sample all received Question N1015.

This question was not probed during the cognitive interview and no findings are available.

Question A1116:   **Over the course of illness, did the total costs of care and treatment prohibit other household payments?**
Questions C1016   *Kuom kinde mane otuo duto, kiriwo kwan mag rit gi thieth dine mon chudo mamoko mag ot?*
Question N1016

All 16 remaining members of the adult sample received Question A1116. The full child sample received Question C1016. The 13 remaining members of the neonate sample all received and answered Question N1016.

This question was not probed during the cognitive interview and no findings are available.

Question A1117:   **Did the deceased ever receive counselling and testing for HIV?**

Bende <NAME> ne oyudo hocho gi pim mar tuo mar ayaki?

All 16 remaining members of the adult sample received Question A1117. Of them, eight respondents answered "yes," six answered "don't know," and two answered "no."

This question was not probed during the cognitive interview and no findings are available.

Question A1118:   **When did the deceased have her/his last HIV test?**

Ne opime mogik karang'o?

The eight adult sample respondents who answered "yes" to QA1117 went on to correctly receive Question A1118. The other eight skipped to the end of the questionnaire.

This question was not probed during the cognitive interview and no findings are available. It is interesting to note that of the eight adult sample respondents who received this question, only three were able to give a date for the last HIV test, while the rest answered "don't know." While further research is necessary to determine the magnitude of this lack of knowledge across the population, as well as to determine its source (i.e. it may not be a salient date in the mind of the respondents), such a high incidence of "don't know" responses calls into question the validity of this question and the usefulness of its data in the VA model.

Question A1119:   **What was the last HIV test for the deceased?**

Duoko mar pim mogik mar tuo mar ayaki ne owuok nade?

The eight adult sample respondents who answered yes to QA117 all received Question A1119. Of these eight, two indicated that the deceased was HIV positive, four said that the deceased was HIV negative, and two others answered that they "didn't know." Those that said "negative" or "don't know" skipped to the end of the questionnaire.

This question was not probed during the cognitive interview and no findings are available.

Question A1120:   **Was the deceased ever assessed for ART treatment need?**

Be ne onone ka owinjore okete e thieth mar ayaki?

Only two respondents in the adult sample—those that answered QA1119 "positive"—received Question A1120. Both of these respondents answered this question "yes."

This question was not probed during the cognitive interview and no findings are available.

Question A1121:   **What date was the deceased first assessed for ART treatment?**
Ne onone mokwongo karang'o?

The two adult sample respondents who answered "yes" to QA1120 went on to receive Question 1121.

This question was not probed extensively during the cognitive interview. Both adult sample respondents appeared to have difficulty giving an exact date for the deceased's ART assessment. One of these two respondents gave a year and month in response to QA1121, while the other was not able to give any answer and replied "don't know."

Question A1122:   **Was the deceased ever prescribed ART treatment?**
Bende nosendikne thieth mag ayaki?

The two adult sample respondents who answered "yes" to QA1120 correctly received Question A1122. Both of these respondents answered "yes" to this question.

This question was not probed during the cognitive interview, and no findings are available.

Question A1123:   **Did the deceased start ART treatment?**
Bende nochako thieth mar ayaki?

The two adult sample respondents who answered "yes" to QA1122 correctly received Question A1123. Both of these respondents answered "yes" to this question.

This question was not probed during the cognitive interview, and no findings are available.

Question A1124:   **When did the deceased start ART treatment?**
Nochako thieth mar ayaki karang'o?

The two adult sample respondents who answered "yes" to QA1123 correctly received Question A1124.

This question was not probed during the cognitive interview, and no findings are available. Neither adult sample respondent who received this question was able to answer it, and responded "don't know."

Question A1125: **Was the deceased still on ART treatment when s/he died?**

Bende ne pod en e thieth mar ayaki e kinde mane otho?

The two adult sample respondents who answered "yes" to QA1123 went on to receive Question A1125. Of these two, one responded "yes," and the other answered "no." The respondent who answered "no" skipped to the end of the questionnaire.

This question was not probed during the cognitive interview and no findings are available.

Question A1126: **When did the deceased stop ART treatment?**

Noweyo thieth mar ayaki karang'o?

One respondent in the adult sample received Question A1126. However, the one respondent who *should* have received it (the one who said "yes" to QA1125) did not, and the respondent who should not have answered it (the one who said "no" to QA1125) did.

This question was not probed during the cognitive interview and no findings are available.

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