

**Cognitive Interviewing Evaluation of the
Creatinine Phospho-Kinase (CPK) and Medical Conditions (MCQ) Questions for the
National Health and Nutrition Examination Survey**

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I. Introduction

This report summarizes the findings from a cognitive interviewing study of the Creatinine Phospho-Kinase (CPK) and Medical Conditions (MCQ) questions intended for the National Health and Nutrition Examination Survey (NHANES). The report presents a summary of the themes that emerged from the data and a question-by-question analysis of both sets of questions. An evaluation is included for all questions but particular attention is given to questions that may lead to potential response error. All questions include descriptions of how respondents interpreted question intent, explanations of why and how questions presented problems for respondents and, where appropriate, recommendations for question improvement.

The following section briefly describes the methodology of cognitive interviewing, outlines the interviewing procedures, and discusses the sampling process. The third section of this report provides a question-by-question analysis of all survey questions examined and offers recommendations for change where applicable.

II. Method

As a qualitative method, cognitive interviewing provides detailed insight into patterns of error as well as patterns of interpretation and calculation that respondents use to answer questions. With this technique, interviewers administer survey questions, obtain a response, and then probe respondents for other information relevant to the question. Probing can be conducted either concurrently (i.e., immediately after the survey question is administered) or retrospectively (i.e., after the entire survey has been administered). For this project, researchers employed a combination of concurrent and retrospective probing, with half of the interviews subject to concurrent probing, and the other half to retrospective probing.

This methodological approach results in rich and detailed information on the question-response process, allowing analysts to determine the effectiveness of survey language and respondents' ability to recall requested information. The information obtained from this intensive interviewing method allows interviewers to determine how questions perform, including

phenomena that are captured by the survey question. With this understanding, it is possible to identify *which* questions are problematic, as well as *why* and *how* questions are problematic. Such insight can lead to possible strategies for improving question design.

Interviewing Procedure and Sample

Interviewing was conducted at the Questionnaire Design Research Laboratory (QDRL) at the National Center for Health Statistics. Interviews were conducted face-to-face and the average interview length was no longer than one hour. The QDRL Respondent Database was used to recruit all respondents, and recruitment was conducted with the intent to seek out demographic diversity among respondents (*see Table 1*). We recruited a majority of respondents who had any difficulty seeing, hearing, walking, or climbing steps, and for comparative purposes we also recruited several respondents who did not meet the screening criteria. In total, we conducted twenty interviews, all in English. Respondents were selected with a purposive sample in mind, and each participant was given a \$40 remuneration for their participation.

Table 1: Demographic Profile

	N=20	Total (%)
Gender		
	Female	11 55%
	Male	9 45%
Age		
	30-39	2 10%
	40-49	9 45%
	50-59	6 30%
	60-69	3 15%
Hispanic/Non-Hispanic		
	Hispanic	0 0%
	Non-Hispanic	20 100%
Race/Ethnicity		
	Black	15 75%
	White	4 20%
	White & American Indian	1 5%
Education		
	Less than HS	1 5%
	HS/GED	8 40%
	Some college	11 55%
Income		
	\$10,000-\$20,000	12 60%
	\$20,000-\$30,000	4 20%
	\$30,000-or more	4 20%
Employed		
	Yes	11 55%
	No	9 45%
Marital Status		
	Never Married	9 45%
	Currently Married	4 20%
	Separated	2 10%
	Divorced	2 10%
	Widowed	3 15%

III. Theme Summary

This section of the report presents a summary of the overarching themes emerging out of the question-by-question analysis. Because researchers tested questions from two different sections of NHANES, analysis is organized in two parts: (A) Creatinine Phospho-Kinase (CPK) and (B) Medical Conditions (MCQ).

A. Creatinine Phospho-Kinase (CPK)

Analysis of the Creatinine Phospho-Kinase (CPK) questions points to respondents' varying patterns of interpretation around the concepts of "muscle pain" and "muscle injury." The fact that these patterns of interpretation span across questions suggests that this is not a single question issue, and instead is a conceptual issue that runs throughout the survey supplement. Particularly, respondents' narratives point to at least three different patterns of interpretation around the concepts of "muscle pain" and "muscle injury" that suggests respondents may be unclear as to what is meant by these concepts.

First, respondents might simply be unaware of what is meant by the concept of "muscle pain" or "muscle injury." This is an issue about a respondents' universe of knowledge, and it assumes that respondents *know* what muscle pain or injury actually *is*. For example, the fact that respondents discuss bruises on their skin in the context of the question on bruised muscles suggests that respondents might not know what a bruised muscle actually is, and their only frame of reference for anything bruised (whether a muscle or anything else) is a dark purple or blue mark on the surface of the skin (*see e.g., CKQ.030*). This example suggests that it may be misguided for survey designers to assume that respondents know what constitutes a muscle pain or muscle injury.

Second, some respondents experienced multiple types of pain simultaneously in their body. In these in cases, questions that ask respondents to focus exclusively on the pain they experience in their muscles might be challenging. Similar to the previous point, this challenge also stems from a knowledge issue; however, this knowledge issue is unique in that the survey not only assumes respondents know what muscle pain/injury is, but it also assumes that respondents know how to identify and classify pain as relating uniquely to the muscle (*see e.g., CKQ.060, CKQ.065, CKQ.070*).

Third, and related to the previous two points, the fact that respondents might not be clear as to what constitutes muscle pain/injury may lead respondents to consider other types of pain when answering these questions. For example, some respondents considered non-muscle pain and injuries such as arthritis, osteoporosis, and menstrual cramps when answering these questions (*see e.g., CKQ.030, CKQ.060, CKQ.065, CKQ.070*).

B. Medical Condition (MCQ) questions

There are two sets of MCQ questions. The first set begins with the phrase, “To lower your risk for certain diseases, during the past 12 months have you ever been told by a doctor or health professional to...” The second set begins, “To lower your risk of certain diseases, are you now doing any of the following...” Findings from analysis demonstrate that, cognitively, respondents have multiple points to connect when forming answers to the MCQ questions. For example, for the first set of questions respondents must consider only advice given to them in the past 12 months. Respondents must also consider advice that comes from only a doctor or health professional. Both questions begin by stating “to lower your risk for certain diseases,” thus respondents must know if and which diseases are lowered by participation in the specified health practices (weight control or lose, exercise, sodium reduction, and fat and calorie reduction). Additionally respondents must understand what it means to engage in the specific health practices. Ultimately, because there are many different components to these questions, respondents must consider many aspects of their experience and draw upon a range of knowledge when attempting to provide an accurate response.

Analysis demonstrates that with the exception of sodium, most respondents do not know how the specified health practices lower disease risk or which diseases are lowered as a result of increasing exercise, reducing sodium, or reducing fat or calories. Analysis reveals that this difference in conceptual understanding leads to different answers by respondents for the same reported experience. For example, some respondents question whether maintaining or monitoring weight is the same as controlling or losing weight. For the most explicit example of this see *MCQ_2c* (but note that examples can be found from *MCQ_2a-2d*). Similarly, respondents may not report engaging in a health practice because they do not perform it for the specific purpose of actively or consciously lowering risk of disease (*see e.g., MCQ_1b*).

Section IV provides a question-by-question review of the CPK and MCQ questions intended for the National Health and Nutrition Examination Survey (NHANES), further documenting and detailing the findings of this analysis.

IV. Question-by-Question Review

This section of the report presents findings from the question-by-question analysis conducted on all survey questions that were examined. Because researchers tested questions from two different sections of NHANES, analysis is organized in two parts: (A) Creatinine Phospho-Kinase (CPK) and (B) Medical Conditions (MCQ). Findings are summarized for each question and recommendations are offered where applicable.

A. Creatinine Phospho-Kinase (CPK)

The CPK section of NHANES is designed to detect certain key clinical conditions which may elevate measured levels of CPK (an enzyme typically found in the body’s muscle tissue), such as recent strenuous exercise, an acute injury involving muscle tissue, or a personal history of chronic muscle pain. In the following question-by-question review, researchers analyze

respondent answers in order to evaluate question performance. Researchers also point out areas that may lead to potential response error when applicable.

CKQ.010: In the past 3 days, did {you/SP} do any strenuous exercise or heavy physical work?

Overall, three out of the twenty respondents reported doing some kind of strenuous exercise or heavy physical work in the past three days; due to time constraints, researchers were able to probe on two of these three responses. Activities reported by these two respondents included “quite a bit of walking” and riding a recumbent exercise bike for 7 ½ miles in under 21 minutes.

Despite only three people reporting “yes” to this question, researchers solicited extensive evidence for the various ways in which respondents understood the terms “strenuous exercise” and “heavy physical work.” These included: lifting, pulling carrying or moving heavy items such as furniture or weights. During probing, one respondent mentioned “exercising in general,” while others mentioned specific exercises that would raise the heart rate, such as walking, running, playing tennis, climbing stairs, riding an exercise bike, swimming, or other sports. Other respondents spoke about the specific tasks or household chores they were thinking about upon hearing this question, such as “lifting groceries and little things like that,” and mopping or hauling trash. One respondent recalled his past experience doing construction and farm work in the context of this question, while a different respondent thought about sex as a “strenuous activity.” Finally, two respondents talked about the *degree* of exertion involved in their understandings of “strenuous exercise or heavy physical work,” with one person describing it as “over-indulging” and another as anything that makes you “bust a sweat.”

While some respondents understood walking that raises the heart rate as a “strenuous exercise,” other respondents’ narratives pointed to instances in which walking is explicitly *not* considered a “strenuous exercise,” particularly “everyday walking” as a mode of transportation or “not fast” walking. The fact that the same activity is interpreted differently by different respondents points to the numerous ways respondents interpret the concepts of “strenuous exercise” and “heavy physical work.”

There were several instances researchers were able to see whether respondents’ initial interpretations of the terms “strenuous exercise” and “heavy physical work” were consistent with their interpretations of the definition provided on the survey instrument. In these instances, respondents first spoke about their interpretations of the constructs “strenuous exercise” and “heavy physical work,” and then reflected on these initial interpretations after the definition was read to them (*the definition reads: “Strenuous exercise or heavy physical work is exercise or work that causes large increases in breathing or heart rate if they are done for at least 10 minutes continuously”*). The definition was only read to respondents in instances “if needed” (as the instructions on the instrument direct survey administrators to “probe if needed”). As such, while some respondents prompted the interviewer to provide the definition, other respondents answered the question without hearing the definition. This is important to note: when the instrument is given in the field, just as when it is administered in the lab, some respondents will answer this question without hearing the intended definition. The following analysis is useful in that it offers survey designers insight into whether survey language is consistent with

respondents' immediate interpretations of the language, a particularly useful insight for those instances when respondents answer this question without hearing the intended definition of "strenuous exercise" and "heavy physical work."

In general, respondents believed that their immediate understandings of "strenuous exercise" and "heavy physical work" were overall consistent with the definition provided on the instrument. In fact, there were only two instances when respondents stated that their definitions of these constructs were different from the one provided on the instrument. One respondent initially thought the question was asking about activities like lifting, pulling, carrying or moving heavy items. Upon hearing the definition provided the respondent says, "Oh, so something like riding a bike, jogging, I gather." A second respondent, upon hearing the definition, said he was originally thinking about something different, like "busting a sweat" or something a little more intense. In both cases, respondents initially had something more strenuous in mind and, upon hearing the definition provided, determined that the question was asking about activities less strenuous than those they had originally envisioned.

In addition to gaining insight into respondents' interpretations of the constructs "strenuous exercise" and "heavy physical work," researchers also obtained information on whether respondents thought strictly about "the past three days" when answering this question or whether they thought beyond the past three days or in more general terms. While the majority of respondents seemed to confine their thinking to reference only those activities performed in the last three days, six respondents appeared to answer the question outside the context of the 3-day time frame. Notably, four of these six respondents had a physical disability or severe health problem and were therefore unable to *ever* engage in strenuous exercise or heavy physical work. For example, one respondent with pneumonia and bronchial asthma replied, "It's a no-no for me. I don't think about it, 'cause I'm not going to do it." A second respondent who is paralyzed and gets around in a manual wheelchair said, "I don't perform any strenuous activities period because of my situation."

CKQ.020: Did it make {your/SPs} muscles sore or painful?

Due to skip patterns, three respondents were asked this question. An issue that emerged from the data collected suggests at least one potential way in which this question might be interpreted by survey respondents. One respondent reported that in order for his muscles to get sore or painful, he would have to do something "beyond strenuous exercise" – here, he was thinking of "neglectful exercise." For this respondent, "neglectful exercise" includes not stretching first, not breathing properly, or not consuming the proper amount of fluids. This suggests that some respondents might believe that muscles become sore or painful only when a person is negligent in their exercise routine.

CKQ.030: In the past 3 days, did {you/SP} injure or bruise any muscles?

The fact that some people discuss bruises and skin injuries in the context of this question suggests that some respondents might consider non-muscle injuries when replying to this question, potentially contributing to response error. It appears that the term "bruised muscle"

might lead respondents to think about any bruise appearing on the skin, irrespective of whether the bruising results from a muscle injury or not. One way to address this potential for response error might be to provide a definition of a bruised muscle, distinguishing it from other types of injuries that might result in bruises.

With the exception of one respondent who replied “don’t know,” all respondents answered “no” to this question. Upon hearing the question, the respondent who replied “don’t know” said “I don’t think so. Don’t know.” This particular response may point explicitly to the fact that this respondent doesn’t know what constitutes an injured or bruised muscle.

Of the remaining nineteen, respondents described injured or bruised muscles as either something they can “feel” internally in their body or something they can “see” externally on their body. For example, one respondent said that he would “pretty much” know if he injured or bruised a muscle because “usually you can feel it”. Respondents who spoke about being able to “feel” an injured or bruised muscle discussed scenarios that might cause such an injury, such as over-extending oneself, stretching too far or not warming up before exercise, or lifting something too heavy which might specifically lead to “muscle aches.” Some respondents who understood an “injured or bruised muscle” as an “internal” pain reported experiencing such an injury first-hand in the past. For example, one man “strained” his back lifting heavy objects and another defined his “dislocated shoulder” as an injured or bruised muscle. Another respondent reported experiencing an injured or bruised muscle in the past as a result of “overdoing it with weights.”

In addition to understanding an “injured or bruised muscle” as something one feels internally, respondents also talk about injured or bruised muscles as something visible on the skin’s surface, such as a purple (bruise) mark. A total of five respondents understood injured or bruised muscles as something one can physically see on the body. For example, one woman said she would know if she had injured or bruised a muscle because she has “very sensitive skin” and she would be able to see a bruise on her skin if she injured or bruised a muscle. Another respondent talked about “injured or bruised muscles” in the context of a recent doctor’s visit, during which time she received multiple shots resulting in several bruises on both arms.

CKQ.040: Did it make {your/SP's} muscles sore or painful?

Due to skip patterns, no respondents received this question.

CKQ.060: In the last 3 days, have {you/SP} had any muscle pain or soreness?

While some respondents appeared to think exclusively in the context of muscle pain or soreness when answering this question, other respondents’ narratives point to the ways in which “muscle pain” and “muscle soreness” are more ambiguously interpreted. Sometimes respondents consider non-muscle pain when answering this question, and other times respondents appear unsure as to whether the pain in their bodies stems from a muscular or some other type of pain. Seventeen respondents received this question (two people skipped out of the question and were directed to CKQ.065, and one person should have received this question but was mistakenly administered CKQ.065).

When answering this question, several respondents appeared to restrict their thinking to exclusively consider muscle pain, versus some other type of pain. For example, one respondent who thought for a few moments before answering “no” explained that he had pain but it was not muscle pain; it was “skeletal pain” related to problems in his back and ligaments in his knees. Similarly, another respondent who suffers from daily pain as a result of his osteoarthritis replied “no” to this question, distinguishing muscle pain from arthritic pain, which he described as pain “in his bones,” not his muscles.

Yet, there was one instance in which a woman who responded “yes” went on to describe the pain she experiences from the arthritis in both of her knees. She said that she has no fluid pockets in her knees so they grind together and hurt. When she sits too long she gets stiff and her knees hurt. Given her narrative, it appears as though this respondent was thinking about a non-muscular type of pain when responding “yes” to this question, thus suggesting the potential for response error. This was the most *explicit* instance in which a respondent answered “yes” and went on to describe a non-muscular form of pain.

A few cases, however, were less explicit and more ambiguous; here, respondents either described pain but were uncertain whether it constituted a form of muscle pain or, respondents suffered from conditions that caused pain throughout their bodies and it wasn’t always clear whether the pain they experienced was located in their muscles or elsewhere. For example, one man who replied “yes” to this question described recent pain he experienced in his back from sleeping in an awkward position under the air conditioner. Probed as to whether this was a pain in his muscles specifically or a more general type of pain, the respondent said he wasn’t sure where the pain was and went on to describe it as a general pain, concluding that it was “more irritable than painful.” Two other respondents both suffering from peripheral neuropathy replied “yes” to this question, with one of the respondents explaining that peripheral neuropathy primarily results in nerve pain but it also affects the muscles and tendons. In these cases, respondents replied “yes” to the question even when the location of their pain was not exactly known or when their pain was not exclusive to just their muscles. As such, it is important to consider the more ambiguous types of pain that this question might potentially capture in survey responses, such as those cases when it is not clear whether the pain is stemming from the muscles or elsewhere in the body.

CKQ.065: In the last 3 days, have {you/SP} had any other muscle pain, aching or soreness?

Due to skip patterns, two people received this question (and it was mistakenly administered to two additional people).

Of the two people who were correctly administered this question, one replied “yes” and the other replied “no.” The respondent who answered “yes” spent the previous weekend cooking and standing on his feet a lot, saying that he “paid for that.” The person who answered “no” said: “Outside of cramps? No.” The respondent was referring to menstrual cramps. Once again, we can see the ways in which respondents might think about pain in a more general or ambiguous sense when responding to these questions, despite the fact the question explicitly asks about muscle pain.

Of the two people who mistakenly received the question, one respondent replied that he had no other muscle pain, aching or soreness aside from the peripheral neuropathy he reported in CKQ.060. The other respondent spoke of the daily pain she experiences as a result of her osteoporosis, the nerves shooting down the back of her legs and her carpal tunnel syndrome. She also spoke of the “bare bones” in her knees that constantly rub together; she’s awaiting knee replacement surgery. Probed as to whether these were muscles pains she said she has muscle and joint pains. Asked which muscles, she says mostly the muscles in the back of the legs, resulting from shattered nerves and a spinal disease. This respondent’s narrative taps into the theme previously identified, in that respondents may reply “yes” to this question should they have any experience with pain, even if this pain is not exclusive or even related to muscle pain. The fact that this theme emerges *across* questions illustrates the potential commonality of this interpretive pattern among survey respondents.

CKQ.070: For how long have {you/SP} had this pain, aching or soreness?

As illustrated in the analysis of previous CPK questions, respondents with multiple types of pain may have difficulty responding to this question, as it appears to assume the respondent is dealing with (or is able to restrict their thinking to) one type of pain.

Due to skip patterns, this question was administered to six respondents. Of these six, four respondents were able to reference a very specific time frame in which their muscle pain began; answers from the remaining two respondents suggest the potential for response error.

In the cases where respondents referenced a very specific time frame, the onset of their muscle pain was marked by a very particular event. For example, one woman was in an accident 15 years ago and has experienced pain ever since. She reported that it is very easy for her to calculate the length of time she has had this pain, aching or soreness. Similarly, a second respondent cited the date of November 29, 2007, the day when he sustained an injury at work which caused him to have three herniated disks in his back. This respondent has had a constant aching/stabbing pain ever since and is currently involved in a workman’s comp case regarding the event. A third respondent answered “24 hours,” as he was referencing back pain he incurred from sleeping in an awkward position under an air conditioning unit. It was easy for this respondent to recall that his pain lasted for the whole day on Monday and was back to normal on Tuesday. Finally, a fourth respondent calculated his response by referencing the time he officially stopped working on a full-time basis, which was in May 2000. Again, the respondent said it is easy for him to remember this date and he has been suffering from his pain for the past 10 years, ever since he stopped working full-time.

Yet, analysis of the two remaining cases suggests the potential for response error. In the first case, the respondent interpreted the question to ask about the same three days referenced in question CKQ.060, to which this is a follow-up question. Thus, question CKQ.060 asks: “In the last 3 days have you had any muscle pain or soreness?” The respondent replied “yes,” thinking about his peripheral neuropathy and myelopathy. Upon hearing the following question (CKQ.070), “For how long have you had this pain, aching or soreness,” the respondent replied

“the whole three days.” During probing, the respondent reiterates that this pain has been for the entire three days, and goes on to say he has had this pain everyday for the past 25 years. This latter statement describing the length of time he has suffered from this pain suggests a radically different answer from the one being captured in his recorded response on the instrument of “3 days;” this clearly points to the potential for response error.

The second case of potential response error occurred when the woman with osteoporosis, nerve problems, carpal tunnel syndrome and knee pain responded to this question: “One of them over a year.” Here, the respondent was thinking about the all the different types of pain she experiences. During probing, the respondent said it is her knee pain that she’s had for over a year. The shattered nerves that go down her legs have also been happening for over a year. It is not clear, however, the criteria the respondent used to decide *which* pain to reference in her response. For example, did she choose to cite the pain she has had the longest, or perhaps she cited the pain that is most severe. During probing the respondent went on to say that she has had this pain everyday for one year; it really started in 2008 but was “moderate” back then. The pain got “more severe” in 2009. This narrative suggests that the respondent was only counting her pain from the time when it got “severe,” which was a year ago; however, she has been experiencing the pain for two years. The respondent’s narrative points to the potential for response error, depending on what the question intends to capture. For instance, if the question intends to record the length of time the respondent has had *any* pain, response error has occurred. Moreover, this respondent’s narrative also points to the potential difficulty for respondents with multiple types of pain, since the question assumes the respondent is only dealing with one type of pain.

B. Medical Conditions (MCQ)

The MCQ section of NHANES is intended to assess the association between lifestyle changes to control high blood pressure and diabetes, high cholesterol, other chronic diseases and obesity. The first set of four questions asks whether or not respondents have been told by a healthcare professional to engage in particular health behaviors which include controlling or losing weight, increasing physical activity or exercise, reducing sodium in one’s diet, and reducing the amount of fat or calories in one’s diet. The second set of questions investigates whether or not respondents are currently engaging in these behaviors. In the following question-by-question analysis, researchers assess how respondents interpret MCQ questions and what respondents were thinking about when answering these questions. Researchers also point out instances that may lead to potential response error when applicable. (*Note: Due to the lack of skip patterns in this section, each MCQ question was asked of all twenty respondents.*)

MCQ.new1_a: To lower risk for certain diseases, during the past 12 months have you ever been told by a doctor or health professional to control weight or lose weight?

Six respondents answered “yes” to this question and fourteen answered “no.” Despite the fact the question asks explicitly about “controlling or losing weight,” respondents appeared to interpret this question as asking exclusively about weight loss, as no respondent reported a doctor’s order to “control weight” even though subsequent narrative data suggested otherwise.

Respondents who answered “yes” to this question often mentioned the number of pounds a doctor recommended they lose, once again pointing to the way in which respondents understood this question as one about weight *loss*.

Some respondents who had not been told to control or lose weight stated that they are an appropriate weight for their height. Others acknowledged that they have already complied with weight loss recommendations prior to 12 months ago. A few respondents reported that their doctor has recommended that they *gain*, not lose weight.

In addition to gleaning insight into the ways respondents interpreted this question, researchers also evaluated whether respondents answered this question within the 12-month timeframe referenced in the question. It appeared as though the majority of respondents contained their responses to the past 12 months. Several respondents had happened to see a doctor in the past month and were thus able to easily recall recent advice given to them by their doctor. Other respondents *routinely* see a doctor every 1-3 months due to chronic health problems; again, in these cases, respondents appeared to easily be able to recall advice given to them in the past 12 months.

However, respondents did not always reference a particular timeframe when they talked about their answer to this question. In one instance, a respondent noted that he has not seen a doctor or other healthcare professional in the past 12 months. Nonetheless, this respondent goes on to speculate as to whether or not the doctor would tell him to control or lose weight if he *had* seen a doctor in the past year. This respondent believed that his doctor would tell him to lose weight but, since he has not seen a doctor in the past 12 months, he answers “no” to this question. This case is significant in that, although the respondent restricts his thinking to only include advice received in the past 12 months, his “no” response might be misleading since it could suggest the respondent’s weight is at a healthy level when, according to the respondent himself, it’s likely not (since he thinks a doctor would tell him to lose weight). Thus, it is important to keep in mind that a “no” response to this question might be capturing at least two potentially very different types of people: (1) people who maintain a healthy weight or, (2) people who are at an unhealthy weight but haven’t been to the doctor in the past year. In other words, researchers should be mindful that unless respondents who have not seen a doctor are screened out of this question then a false assumption can be made.

Respondents’ overall tendency to answer this question within the context of the past 12-months is a consistent finding across the next three questions and therefore will not be restated in each case.

When responding to this question, almost every respondent appears to consider advice received from a doctor or health professional (versus advice received from a non-health professional). A few respondents spoke specifically about the type of doctor who told them to lose weight. For example, one respondent mentioned that her orthopedic doctor told her to lose weight. Another respondent recalled that his primary care doctor recommended he gain weight. Although this particular respondent answered “no” to this question since he was not told to “lose or control weight,” he was thinking of advice given by a doctor. Still another respondent provided the

name of her doctor who told her to lose weight. Two respondents lost weight on their own, without the instructions from a doctor. Despite having lost weight in the past 12 months, these two respondents answered “no” to the question since they were thinking specifically about advice received from a doctor or health professional. As such, it appears respondents consider advice received from a doctor when answering this question.

MCQ.new1_b: To lower risk for certain diseases, during the past 12 months have you ever been told by a doctor or health professional to increase physical activity or exercise?

Seven respondents have been told to increase physical activity or exercise, thirteen have not. Two of the respondents who have not been told to increase physical activity or exercise explained that either they are in good health or their current exercise level is appropriate. Two other respondents, one who recently had a hip replacement, said they are unable to increase exercise and therefore their doctor has not suggested that they increase physical activity. Another respondent stated that the doctor has told him to decrease (instead of increase) exercise because of his orthopedic problems.

In this sample, many respondents had disabilities or chronic health problems, thus the term “physical exercise” is interpreted among many respondents within the context of disability or limited ability. Physical disabilities and chronic illness may shape the way in which some respondents interpret this question. Those with physical limitations may find it difficult to answer this question or see it as an inapplicable question because they may be unable to or extremely limited in the physical activity they can do. For example, a respondent who uses a scooter to get around and has rheumaty arthritis exercise for her includes sitting in a chair doing arm rolls and stretching out her legs. Another respondent who uses a cane and leg braces remarked that simply getting out of the house and looking for a job has increased her activity. The respondent who recently had a hip replacement, however, did not see her leg exercises as an appropriate type of exercise for this question, though she was told to do leg exercises after her surgery. Instead, this respondent thought of jogging or bicycling as the types of exercises to which this question is asking about. Other respondents pointed out that the doctor recommended that they swim, take an exercise class, bike, or walk.

When answering this question, most respondents did not make reference to a disease risk that could be lowered with increased physical activity and exercise. This might suggest that respondents are not thinking about increased activity and exercise in the context of disease prevention; rather, they may simply respond according to whether a doctor has told them to increase their activity *for any reason*. The few respondents who did mention a specific disease talked about diabetes, cancer, cardiovascular diseases, cholesterol, and hypertension.

Our analysis shows that either respondents do not realize or do not believe physical activity or exercise lowers the risk for certain diseases. For example, one respondent said he would like to exercise more if he could. He said it would be just for “general well-being” and to “reduce stress.” One interviewer asked a respondent what diseases this question might be referring to and the respondent replied, “It could be anything.” Another respondent said she did not know what the interviewer means by “to lower diseases.” She understood that exercising can improve

overall health, but she did not see how exercise was associated with specific diseases. Because the question asks if a doctor has told her to increase exercise to lower her risk for certain diseases, the respondent answered “no” to this question. Narrative data points to the potential for response error in that respondents might not report being told to increase physical activity or exercise if they have not explicitly been instructed to do so for the purpose of disease prevention.

The potential for response error might also occur if respondents report being asked to increase physical exercise, but *not* for the purpose of disease prevention. For example, one respondent who is in a wheelchair said the doctor told him to increase physical activity in order to maintain his upper body strength. This advice to increase activity appears *not* to have been given for the purposes of disease prevention, but rather for the purposes of strength training. Nonetheless, the respondent answered “yes” to this question. Similarly, we considered the case of the woman who received a hip replacement and who was instructed by her doctor to increase her exercise after the surgery. This woman’s experience might be another instance where we can see how respondents might understand any instruction by a doctor to increase exercise when answering this question, including advice given for strength training or rehabilitative purposes, and not just disease prevention purposes.

MCQ.new1_c: To lower risk for certain diseases, during the past 12 months have you ever been told by a doctor or health professional to reduce the amount of sodium in your diet?

Eight respondents answered “yes” to this question; twelve replied “no.” Almost every respondent mentions the word “salt” in their narrative, suggesting that respondents associate sodium with salt.

In total, eight respondents said that sodium can lead to high blood pressure, and two mentioned diabetes and high cholesterol. One respondent speculated that sodium might be associated with heart disease. Another respondent who answered “no” said that she did not know why someone would reduce the sodium in their diet, nor did she know what effect sodium had on her health. This response is noteworthy given that the respondent mentioned having a family history of high blood pressure and heart attacks. A different respondent said that the doctor did not tell her to reduce her sodium intake because she already knew the importance of doing so. Some respondents who reported not using salt said they either do not add it to their food or they use alternatives such as “sea salt or Mrs. Dash.”

MCQ.new1_d: To lower risk for certain diseases, during the past 12 months have you ever been told by a doctor or health professional to reduce the amount of fat or calories in your diet?

Five respondents answered “yes” to this question and fifteen responded “no.” Two respondents understood this question in the context of the risk carbohydrates pose to diabetics. The same respondent who did not see a connection between sodium and disease also did not associate fat and/or calories with disease risk. During the interview she said:

“I’m not thinking about reducing the amount of fat or calories for lowering disease because that’s not what [doctors] tell you.

Here, the respondent did not connect fat/calorie intake with the risk of disease. As with the previous question, response error may occur if respondents do not report being told to decrease fat or calories if they have not explicitly been told to do so (or do not remember they have been told to do so) by a doctor for the purpose of disease prevention.

Similar to respondent interpretations in the previous question, most people seemed to think about advice given by a doctor when answering this question, as they often explicitly mentioned their doctor. A few respondents reported lowering their calorie intake without or before a doctor’s recommendation, suggesting that they are still thinking about doctors or health professionals in the context of this question. However, one respondent who answered “yes” was not thinking about advice from her doctor; instead, she was thinking about the diet her granddaughter, “who is in the culinary arts,” recently put her on. During probing this respondent said:

“Yes, my granddaughter has me on this special diet now, thank the Lord. My granddaughter before she left for high school, she’s in culinary arts. She said grandma I’m going to have to think of some little dietary things. I know you like to eat. She got me on yogurt...cottage cheese, which I never liked. She’s a tiny thing, she’s healthy so she wants me to be healthy. So she gave me a good start.”

This respondent’s narrative reveals instances in which respondents might answer “yes” to this question outside the context of advice given by doctors or health professionals. In this instance, this woman replied “yes,” thinking about the new diet her granddaughter has recommended for her. Depending on what the question intends to capture, this analysis points to the potential for response error.

MCQ.new2_a: To lower your risk for certain diseases, are you now controlling your weight or losing weight?

Eight respondents answered “yes” to this question, nine responded “no” and three were unable to answer whether or not they are controlling weight or losing weight. Some respondents made no distinction between losing and gaining weight, stating that they are both controlling and losing weight. Other respondents saw a distinction between the two terms (i.e., “controlling” and “losing”) and acknowledged they have lost weight in the past and are now currently controlling their weight. Controlling weight, however, was open to interpretation. For some respondents their actions fell into the category of controlling weight if they were making a conscious effort to keep their weight stable. Controlling weight meant something different for those whose weight was stable but not a result of active attempts. The following paragraphs provide examples of these varying interpretations of the term.

Some respondents who answered “no” described their weight as “stable” or constant. One respondent said, “No. My weight has been stable for years.” Another respondent said, “No I’m not worried about my weight. I’m going to stay in the weight range that I’m in.” Here,

respondents see their stable weight over time as different from “controlling” weight, perhaps because their weight remains stable without a concerted effort.

Although some respondents appeared to easily answer this question, the question seemed to be more difficult for other respondents. Particularly, this question appeared difficult and sometimes impossible for respondents who did not need to lose weight or, who have been told to gain weight. One respondent who replied “don’t know” explained, “Neither. I don’t know. [The doctors] can’t ask me to lose weight because I’m a normal weight. I’ve been maintaining this weight for some time.” In another instance the interviewer had to repeat the question. It appeared difficult for the respondent to answer because she felt that she didn’t need to lose weight. She stated, “I don’t do either because I don’t have to.”

Overall, this question appeared to prove difficult to respondents when they felt that the question did not map onto their own experience. In such instances, there might be the potential for response error or, at a minimum, respondent confusion.

MCQ.new2_b: To lower your risk for certain diseases, are you now increasing your physical activity or exercise?

Nine respondents answered “yes” to this question, ten responded “no,” and one refused to answer. Our analysis of this question suggests that respondents appeared to interpret the term “increase” in various ways. Respondents appear to have varying interpretation of what it means to increase physical activity or exercise. Simply engaging in physical activity or exercise makes some respondents answer affirmatively to this question. For other respondents simply engaging in physical activity is not enough to answer this question as “yes” because they are exercising but not increasing their level of activity. The following examples affirm this observation.

One respondent who walks occasionally said that he would not consider his walks to be an effort to increase physical activity. Another respondent who walks regularly said she is not increasing her current level of physical activity answered “yes” to this question. Conversely, a respondent who rides a recumbent bike several times a week but cannot increase his level of exercise because of orthopedic problems answered, “No, I can’t increase exercise.” Similarly, the respondent in the manual wheelchair who believes he does “more than enough exercise on a daily basis” does not report increasing physical activity because he said he already exercises.

Indeed, respondents already engaged in some sort of exercise routine particularly appear to have varied interpretations of this question. For example, one respondent who replied “yes” to this question said, “Yes. Not more than usual.” The interviewer then probed this respondent on the term “increasing.” She said, “Increasing? I’m level with that. It’s become second nature.” Here, given her “yes” response, the respondent appears to conceptualize “maintaining” her current exercise regime as the same as “increasing” her level of exercise. Alternatively, a second respondent interpreted this question differently, suggesting that his current exercise routine did *not* count as “increasing” his level of activity. Specifically, this respondent said, “No, because I can’t. Again the physical problems, my orthopedic problems. I can’t increase what I can do because of my orthopedic problems; I’m restricted by my orthopedic problems.” This

respondent exercises regularly but answers “no” to this question because he is unable to increase his exercise level due to health problems.

One respondent appeared to really struggle to come up with an answer to this question. After taking a moment to think he shrugged his shoulders and said, “I’ll say ‘yes.’” (*He appears frustrated by his response options.*) “I’m gonna have to say...I don’t even want to say ‘don’t know’ cause there’s no answer that applies, so I won’t answer that one. It’s because it’s ‘yes,’ but ‘yes moderately.’ And that’s actually what [the doctors] told me to do.” Here, the doctors advised the respondent to engage in “moderate” exercise given his severe health problems, yet the respondent was unsure whether this constituted a “yes” or “no” response to the question; as such, he refused to answer. As in *MCQ.new1_b*, physical disabilities and chronic illness may shape the way in which some respondents interpret this question. Those with physical limitations may find it difficult to answer this question or see it as an inapplicable question because they may be unable to or extremely limited in the physical activity they can do.

Another respondent answered “yes” to this question, though she admitted that she can’t exercise. This respondent has bronchial asthma and only one lung. Since she exercises “when she can” she responded “yes.” Overall, respondents provided different answers depending on the way they interpreted the question and, in particular, depending on their interpretation of the term “increase.” In these cases, respondents’ varied interpretations of the term “increase” could potentially lead to response error, depending on what type of experiences the question intends to capture.

MCQ.new2_c: To lower your risk for certain diseases, are you now doing reducing the amount of sodium in your diet?

Thirteen respondents answered “yes” to this question, six responded “no” and one refused to answer. Our analysis of this question suggests that respondents interpret this question differently, particularly the phrase “are you now reducing.” Some respondents answered “no” to this question because they have always done things to reduce the sodium in their diet. Yet, using the same logic, other respondents answered “yes” because, as one explicitly said, “this is something I’ve always done.” The following quotes represent the differences in interpretation for this question.

“Yes. I use very little salt and always have, so I will have to answer yes. Reducing salt started out as an active choice, but I don’t really think about it anymore. It’s not a conscious choice. It’s a habit.”

“No. I haven’t been to McDonalds, Burger King or KFC or anyplace like that in 15 years. [I] don’t eat fast foods period. On occasion I’ll eat a sub. So I control my sodium in that way and I also do all the cooking at home so I control the amount of sodium I put in my food. And we try to eat, we eat as few processed foods as we can. We eat as much natural or organic foods, just the healthier foods. The only place I shop for groceries is Whole Foods.”

Given these varied interpretation, these narratives point to the potential for response error, depending on what the question intends to capture. Specifically, respondents appear to have different interpretations of what it means to “reduce” versus “maintain” one’s sodium intake.

MCQ.new2_d: To lower your risk for certain diseases, are you now reducing the amount of fat or calories in your diet?

Nine respondents answered “yes” to this question, ten responded “no” and one refused to answer. Respondents who answered “no” said that they eat whatever they desire and/or are at their desired weight. Respondents reported doing a number of things in order to reduce fat or calories: they read labels for the calorie content in foods, they choose low fat products or whole grains, and/or they decrease their intake of specific foods.

Notably, respondents do not always understand some of their particular modifications in health behavior in the context of fat or calorie reduction. For example, one respondent said “no” to this question and went on to describe her recent decision to cut snacks out of her diet since she quit smoking. Here, the respondent does not consider cutting snacks as a behavior that reduces fat or calories. In another instance, a respondent said, “Can I make a comment now or afterwards?” He went on to say that the survey is “missing him on the calories or sodium.” Instead, the respondent said that he more closely monitors his carbohydrate intake, presumably due to his diabetes. This respondent also said he controls his weight by “not eating too much.” Such statements point to the ways in which this respondent does not understand his limited carbohydrate intake or overall food consumption in the context of fat or calorie reduction. Such an interpretation of the question could potentially lead to response error if the question is designed to capture respondents who limit their carbohydrate and overall food consumption.

Response error may also potentially occur because respondents may or may not see a distinction between maintaining a certain fat or caloric intake and decreasing intake. For example, one respondent said, “It’s something I automatically watch.” This question was difficult for this respondent and he ultimately refused to answer it. The respondent said that watching caloric intake is something he has always done without anyone telling him to do so. Essentially, the respondent interpreted the question to ask whether he is refraining from or reducing something with which he has never had a problem.

Additionally, the effort of some respondents to reduce fat or calories is sporadic rather than consistent; this might explain why, at least in part, some respondents say they are not reducing the fat or calories in their diet despite suggesting they periodically try. For example, one respondent replied, “No, I’m still working on that,” and goes on to talk about his weakness for KFC. Thus, even though this respondent has been told to reduce the fat and calories in his diet, he does not always comply, but he sometimes tries to comply. This example suggests that respondents may watch what they eat intermittently yet, since it is not a constant or consistent behavior, they do not report it in their response to this question. As such, it is important to consider the various ways people interpret their current health behaviors when determining what types of information and experiences this and other MCQ questions are capturing.

Appendix A – Creatinine Phospho-Kinase Questionnaire

CKQ.010. In the **past 3 days**, did {you/SP} do any strenuous exercise or heavy physical work?

PROBE IF NEEDED: Strenuous exercise or heavy physical work is exercise or work that causes large increases in breathing or heart rate if they are done for at least 10 minutes continuously.

- YES 1
- NO..... 2 (CKQ.030)
- REFUSED 7 (CKQ.030)
- DON'T KNOW 9 (CKQ.030)

CKQ.020. Did it make {your/SPs} muscles sore or painful?

- YES 1
- NO..... 2
- REFUSED 7
- DON'T KNOW 9

CKQ.030. In the **past 3 days**, did {you/SP} injure or bruise any muscles?

- YES 1
- NO..... 2 (CKQ.050)
- REFUSED 7 (CKQ.050)
- DON'T KNOW 9 (CKQ.050)

CKQ.040. Did it make {your/SP's} muscles sore or painful?

- YES 1
- NO..... 2
- REFUSED 7
- DON'T KNOW 9

<p>BOX 1</p> <p>CHECK ITEM CKQ.050: IF CKQ.020=1 or CKQ.040=1, GO TO CKQ.065 OTHERWISE, CONTINUE</p>

CKQ060. In the last 3 days, have {you/SP} had any muscle pain or soreness?

- YES 1 (CKQ.070)
- NO..... 2 (END SECTION)
- REFUSED 7 (END SECTION)
- DON'T KNOW 9 (END SECTION)

CKQ065. In the last 3 days, have {you/SP} had any **other** muscle pain, aching or soreness?

- YES 1 (CKQ.070)
- NO..... 2 (END SECTION)
- REFUSED 7 (END SECTION)

CKQ.070. For how long have {you/SP} had this pain, aching or soreness?

____|____|____|____| ENTER NUMBER (OF DAYS,
WEEKS, MONTHS OR YEARS)

- REFUSED 777
 - DON'T KNOW 999
 - ENTER UNIT
 - DAYS..... 1
 - WEEKS 2
 - MONTHS..... 3
 - YEARS 4
-

Appendix B – Medical Conditions Questionnaire

MCQ.new1

To lower {your/his/her} risk for certain diseases, during the past 12 months {have you/has s/he} ever been told by a doctor or health professional to:

CAPI INSTRUCTION:

HELP SCREEN: CONTROLLING YOUR WEIGHT MIGHT BE RECOMMENDED TO HELP PREVENT HIGH BLOOD PRESSURE, DIABETES, HIGH CHOLESTEROL AND OTHER CONDITIONS.

RESPONSES: YES = 1, NO = 2, REFUSED = 7, DON'T KNOW = 9

- a. control {your/his/her} weight or lose weight? _____
- b. increase {your/his/her} physical activity or exercise? _____
- c. reduce the amount of sodium in {your/his/her} diet? _____
- d. reduce the amount of fat or calories in {your/his/her} diet? _____

MCQ.new2

To lower {your/his/her} risk for certain diseases, {are you/is s/he} now doing any of the following:

CAPI INSTRUCTION:

HELP SCREEN: CONTROLLING YOUR WEIGHT MIGHT BE RECOMMENDED TO HELP PREVENT HIGH BLOOD PRESSURE, DIABETES, HIGH CHOLESTEROL AND OTHER CONDITIONS.

RESPONSES: YES = 1, NO = 2, REFUSED = 7, DON'T KNOW = 9

- a. controlling {your/his/her} weight or losing weight? _____
- b. increasing {your/his/her} physical activity or exercise? _____
- c. reduce the amount of sodium in {your/his/her} diet? _____
- d. reduce the amount of fat or calories in {your/his/her} diet? _____