

RESULTS OF THE COGNITIVE INTERVIEWING STUDY TO EXAMINE QUESTIONS ON HIGH-IMPACT, CHRONIC PAIN

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This report presents findings of a cognitive interviewing study which evaluated the performance of proposed questions on high-impact, chronic pain for the National Pain Strategy (NPS) Workgroup. Publication of the 2011 report by the Institute of Medicine, *Relieving Pain in America*, has led to growing recognition of the impact of pain on the health, productivity, and well-being of the U.S. population (Institute of Medicine Committee on Advancing Pain Research, 2011). One goal of the NPS Workgroup is to lower the impact of chronic pain at the individual and population levels. However, these efforts need to be guided by population-based data. Therefore, the NPS Workgroup seeks to develop questions to measure the impact of pain on people's lives.

The pain assessment tools proposed by the NPS Workgroup use the definitions of chronic pain and high-impact chronic pain, which are based in part on the widely used definition of chronic pain recommended by the International Association for the Study of Pain, (International Association for the Study of Pain, 1986) modified to account for intermittent pain.

Chronic pain is pain on at least half the days for six months or more.

High-impact chronic pain is associated with substantial restriction of participation in work, social, and self-care activities for six months or more.

The overall goal of this cognitive testing study was to test the constructs captured by questions on chronic pain, management of pain, burden of pain and participation restrictions due to pain and to select appropriate items for inclusion on the 2017 National Health Interview Survey (NHIS). The questions that were tested are presented in Appendix A. The four questions that were ultimately selected by the NPS Workgroup and accepted for inclusion on the 2017 NHIS (based on the results of this testing) are indicated throughout this report with an asterisk. Testing took place at the National Center for Health Statistic (NCHS) in June, 2015. This report is organized into four sections. Following this initial introduction, section two discusses the methods used in this study, including the sample selection, sample characteristics, and interviewing procedure. Section two also summarizes cognitive interviewing methodology and describes how data analysis was conducted. Section three provides a summary overview of the findings. Section four presents a detailed question-by-question review of the findings.

II. Methods

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 (Willis, 2005). 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. Cognitive interviewing studies are performed by conducting in-depth, semi-structured interviews with a small, purposive sample. Respondents are not selected through a random process, but rather are selected for specific characteristics that may be relevant to the type of questions being examined. 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. 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.

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 (Miller, Willson, Chepp, & Padilla, 2014). 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. These steps 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 doing so, it is possible to understand the ways in which a question is interpreted by various groups of respondents, the processes through which respondents formulate their responses, as well as any difficulties which respondents might experience when attempting to answer the question.

HICP Interviewing Study

The NCHS Center for Questionnaire Design and Evaluation Research (CQDER) conducted a total of 40 interviews. Interviews were held in the lab at NCHS and lasted no longer than one hour. Respondents were recruited through newspaper advertisements. Recruitment was guided by the topics included in the survey questions. Since the questions under study were intended as follow-up questions to existing questions on pain, and the focus of testing was on questions about restrictions due to pain, recruitment was limited to respondents who reported having some type of pain for six months or more.

Beyond those criteria, demographic diversity was sought to the degree possible. Respondent demographics for the full sample are shown in Table 1. The sample was almost an even gender split with females comprising a slight majority over males. The sample was mostly black and non-Hispanic. Respondents between the ages of 40 and 60 comprised half the sample. While most respondents had completed some schooling beyond high school, about a third of the sample had obtained a high school diploma/GED only or less than a high school level of education.

Table 1: Demographic Profile

		n=40	Total (%)
Gender	Female	22	55%
	Male	18	45%
Age	18-29	6	15%
	30-39	7	18%
	40-49	10	25%

Hispanic/ Non-Hispanic	50-59	11	28%
	60-69	5	13%
	70-79	1	1%
Race/Ethnicity	Hispanic	3	7%
	Non-Hispanic	37	93%
Race/Ethnicity	Black	24	60%
	White	11	28%
	Other	5	12%
Education	Less than high school	2	5%
	High school diploma/GED	11	28%
	Some college	11	28%
	Associate's Degree	5	13%
	Bachelor's Degree	8	20%
	Master's Degree	1	1%
	Professional Degree or Doctorate	2	5%

Method of analysis:

Analysis of interviews was performed in the manner described briefly above, and detailed in Miller et al (2014). After each interview was conducted, summary notes were written for each question. Summary notes were based on video-recordings of interviews, which also ensured the accuracy of summaries and soundness of study conclusions. 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. After all interviews and summaries were completed, these notes and transcripts were compared to identify common patterns of interpretation and response difficulties for each question. Emergent interpretations were coded and analyzed.

A data entry and analysis software application (Q-Notes) was used to conduct analysis. Q-Notes, developed by the CQDER, 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.

III. Overall findings

General vs. domain specific limitations: A global question, without examples, proved the most effective way of asking respondents about limitations due to pain. Three approaches were taken to asking about limitations. First, two global questions on limitations to “life and work activities” were tested- one with examples of life and work activities and one without (HICP7a and HICP7b). As detailed below in Section Four, respondents were better able to answer based on a generalized concept of “life and work activities” when asked the version of the question *without* examples.

Second, after asking about limitations on general life and work activities, respondents were asked a series of questions asking about limitations on domain specific activities (HICP8-15). For example, question HICP8

focuses on limitations to work while HICP13 focuses on limitations to religious activities and HICP14 focuses on limitations to caregiving. The purpose of including these domain specific questions was to test whether the general limitation question (HICP7) was indeed general enough to capture limitations across a broad array of domains. In fact, there was no instance where a respondent answered “never” to the general question but gave a different answer to a domain specific question. Thus, respondents who indicated they had a limitation in one or more specific domain always indicated they had general limitations to life and work activities (based on the global question). Respondent narratives also support the conclusion that respondents’ domain specific limitations were captured in the general question on limitations.

Definition of “having” pain: While the concept of pain is generally understood, respondents answered questions about “having” pain in different ways.

Managing pain: Most respondents understood “having pain” to be about managing pain. That is, respondents thought not only about the sensation of pain but also about the things they must do and not do to deal with the pain. As one respondent said, “I’m always thinking about it. Even when the pain isn’t there, it’s there.” Respondents talked at length about their strategies for managing their pain and managing their time around their pain. These strategies included restricting activities, self-care activities, and doing more on days when the pain is less. Because respondents always had to make decisions keeping their pain in mind, they thought of their chronic pain as something they have to deal with much of the time.

Experiencing pain: Some respondents understood “having pain” solely in terms of the physical experience of feeling pain. As one respondent said, thinking about her ankle, “It usually hurts, but when it doesn’t, I’m free.”

Secondary effects of pain: For a few respondents, the secondary effects of pain were just as or more prominent than the pain itself. These respondents talked about the effects of taking pain medication or the effects of lack of sleep due to pain.

Note that these definitions of pain may be influenced by the composition of the sample. Only respondents who reported having chronic pain were included, so it is possible that those who don’t have chronic pain would understand pain differently.

Six-month timeframe. Testing did not establish the accuracy of the timeframe covered by the questions. Many of the questions in this set ask respondents to focus on the “past six months.” The majority of respondents did not make direct reference to this time frame. Instead, most respondents simply discussed their current pain. For example, when asked about the timeframe of his answer, one respondent said, “Every day. I’m having it right now.” A few respondents referred directly to the previous six-month period. For example, one respondent stated, “Every morning in the last six months, I get scrutinizing pain in my lower back.” When probed on the stability of their pain, most respondents indicated that their pain had remained more or less the same over the previous 6 months. Therefore, even for those respondents who answered on the basis of their current pain, no response error was seen.

However, this pattern may be an artifact of the sample that only included respondents with chronic pain. Respondents were recruited on the basis of having had pain that had lasted 6 months or more, and, indeed, many had had pain for several years. Therefore, it was not possible within this sample to determine whether respondents in general would evaluate their pain based on the specified timeframe.

Response categories in activity specific questions: Questions HICP8-HICP17 ask about limitations to specific activities due to pain. These questions use the response categories “never,” “most days,” “somedays,” “every day” and “this does not apply to me.” However, respondents were not consistent in their

understanding or selection of these response categories. For example, selection of “most days” could indicate that a respondent did the activity most days, was limited in their ability to do the activity most days or that most days that they did the activity, they were limited by pain. This pattern was also seen in the response categories “every day” and “some days.” Similarly, there was confusion between “never” and “this does not apply to me.” Some respondents selected “never” (instead of “this does not apply to me”) to indicated that they never do an activity, but for other respondents, “never” could mean that they are never limited in their ability to do the activity. These inconsistencies are further detailed in the question-by-question review.

IV. Question-by question Review

Three questions on chronic pain were tested. Two of the questions aim to specifically target the NPS definition of chronic pain defined as “on at least half the days for six months or more.” However, as described in more detail below, the concept of “half the days” proved confusing to respondents when presented either within the question or within the answer categories. The third question on pain frequency which does not ask specifically about “half the days” eliminates this confusion although the response categories for this question are less specific.

HICP1: During THE PAST SIX MONTHS did you have pain of any kind on at least half the days?

Answer	Cases
Yes	39
No	1

The question was asked of all 40 respondents. All but one respondent answered “yes” to this question.

Type/Source of Pain. All of the respondents thought of their pain as physical pain. There were some instances in which respondents thought about emotional pain, but only as a result of and in addition to their physical pain. The type and source of respondents’ pain varied as well as the severity of their pain (from mild to severe) and included: headaches or migraines, arthritis, lower back pain, leg pain, aching hip pain, acute knee pain, ankle pain, swollen feet pain, TMJ (jaw pain), throbbing hand pain, “Charlie horses” (muscle spasms), osteitis pubis (inflammation of the pubic bone), and nerve pain.

On at least half the days. Respondents were not always sure what was meant by “at least half the days.” Some asked for clarification while others answered despite their uncertainty. One respondent asked for clarification before answering, “What do you mean a half a day?” After the question was repeated, he said, “All day. Every day.” A different respondent also expressed confusion saying, “For the past six months? So that would be 3 months?” This respondent answered “no” because she decided she had been in pain for not quite 3 months. She said, “I calculated 3 months. That was a hard question.”

Respondents answered based on several different understandings of “half the days”:

Half of one day: Respondents who thought of “half of one day,” described their pain as occurring on at least half of one day (whether that be in the morning, evening, or spread throughout the day). For example, one respondent stated, “I assume [that means] half the day, every day or most of the day.” Another respondent explained that her ankle “hurts in the evening but not in the morning.”

Half the days of the week: Respondents who thought of “half the days of the week” described their pain as occurring on approximately half the days in one week (ranging from three to four days a week). For example, one respondent stated, “I was thinking at least weekly, a few days a week.” Another respondent stated, “I imagine half the week during that time period.”

Half of the entire six-month: Respondents who thought of “half the entire six-month timeframe,” described their pain as occurring at least half the number of days over the past six months. For example, the single respondent who answered “no” stated, “For the past 6 months?...so that would be 3 months?...I wouldn’t say that much.” Another respondent stated, “I immediately thought I have pain everyday so I answered ‘yes’, because that’s more than half the days....more than 50% of total days.”

Frequent pain: A few respondents answered based on having frequent pain- not necessarily on half the days. When asked directly about having pain on half the days, one respondent said, “Oh, half the days? That’s a good question. I wasn’t sure what that meant. I was thinking at least weekly, a few days a week. It comes and goes....let’s say I have it each week at certain times.”

Six-month timeframe. A few respondents made direct reference to the 6 month time period. For example, one respondent said, ““Yes because the past 6 months ...every day with in the past 6 months my knee hurts” Most respondents, however, did not refer directly to the time frame of their pain, but rather described their current pain. On probing, respondents indicated that their pain had been fairly stable over the previous 6 month period. Therefore, response error was not seen even in cases where respondents did not consider the 6 month timeframe that was specified in the question. However, since respondents were recruited on the basis of having had pain for 6 months or more, testing could not determine whether respondents with pain for various lengths of time (e.g. 7 months versus 2 months) would accurately answer based on the timeframe specified in the question.

HICP1a: Over the last six months, on about how many days have you had pain of any type?

Answer	Cases
I have not had pain in the last six months	0
I have had pain, but on less than half the days	1
I have had pain on more than half the days but not every day	3
I have had pain every day	8

Since respondents had difficulty understanding the phrase “on at least half the days” in question HICP1, this additional question was asked of the final 12 respondents. In this question, revised answer categories were introduced in an effort to resolve respondents’ confusion over the phrase “on at least half the days.” However, the new question and answer categories were still confusing to respondents. As the answer categories were read to the respondents, at least half of the respondents were confused with the middle answer categories and, therefore, asked to have the answer categories repeated. After several repetitions, respondents were able to select a response.

Type/Source of Pain. Respondents answered this question based on their physical pain and offered examples of their pain similar to those they mentioned in question HICP1. Respondents chose their responses based on several different interpretations of having pain:

Interpretation: In choosing their responses, some respondents distinguished between experiencing pain and managing pain while others did not. For example, one respondent who answered “I have had pain on more than half the days but not every day,” explained that she experiences “mild pain” every day, but she can sometimes manage it so that “it doesn’t set me back.” She said, “If I can go and get on the treadmill, I don’t consider that the pain is holding me back, even though it’s still hurting, but it’s not taking me away from

doing something.” In contrast, a different respondent, who chose “I have had pain every day,” said, “Mostly every day” explaining that on some days he has severe pain and on other days he has no pain because he is able to manage and deal with it. Therefore, he either has pain or has to manage pain “every day.”

***HICP2: In THE PAST SIX MONTHS how often did you have pain?**

Answer	Cases
Never	0
Some days	9
Most days	14
Every day	17

The question was asked of all 40 respondents along with HICP1.

Type/source of pain: All of the respondents thought of their pain as physical pain, mentioning sources of pain identical to those they mentioned when discussing question HICP1.

Interpretation: Respondents thought about frequency of pain when answering this question and were consistent in how they chose response categories.

Respondents who chose “some days” had intermittent pain. One respondent who answered “some days” explained, “Some days I’m in pain, some day’s I’m not.” while another stated that he was in pain “generally every week, one or more days.” Other respondents chose this response for pain that is intermittent. A respondent said that her pain only occurs in the morning. She said, “When I first get up [has pain] maybe until lunch time, then afternoon time everything is ok, like when I get out the shower it is looser and not achy or anything.” Respondents chose “most days” to indicate that they have pain most days of a week but not every day. One respondent stated, “I think because most days I think about it and know there’s a problem.” Another respondent defined “most days” as “three days out of this week” while another respondent said “four to five days a week.” Finally, respondents chose “every day” to indicate that they have some degree of pain every day. One respondent said, “I have pretty much pain all days.” Another respondent said, “Something hurts a little every day.”

Six-month timeframe. Respondents did not refer directly to the six-month timeframe specified in the question. On probing, almost all respondents indicated that their pain had persisted for years and that it had been relatively stable over the previous 6 month period. Therefore, no response error was seen. However, since respondents were recruited on the basis of having had pain for 6 months or more, testing could not determine whether respondents with pain for various lengths of time (e.g. 7 months versus 2 months) would accurately answer based on the timeframe specified in the question.

PAIN MANAGEMENT

HICP3: To what extent have your received care and support that helps you manage your pain so that you can do the things you enjoy doing?

Answer	Cases
Not at all	4
A little	7
A lot	9
Somewhere in between a little and a lot	20

This question was asked of all 40 respondents. Quite a few respondents were initially confused by this question and asked for repetition or clarification. One respondent said, “Is that referring to physicians or family or...?” echoing several other respondents who were not sure of the intended scope of the question. All respondents were able to answer the question although several were not convinced that they fully understood the intent of the question. Another respondent explained how this confusion could impact her response:

I'm wondering if they're talking about family or friends or are they talking about the doctors and the specialists? It doesn't specify, so in my head I'm thinking about 'Who are they talking about?' because if you're talking about family and friends, they're there to help. If it's talking about doctors, I don't feel like the support is there.

This respondent ultimately chose the answer “somewhere between a little and a lot” as an average of the support she receives.

Interpretation: When thinking about *care and support*, respondents thought of care from medical professionals or medical treatments, support from family and friends, and self-care activities. Respondents often mentioned more than one of these when referring to *care and support*.

Medical: Most respondents thought of medical professionals including doctors, specialists, or physical therapists. For example, one respondent mentioned, "The physical therapy, the doctors, the back specialist that did the injection..." Another said, “When I think of care and support I think of, like, a doctor or health professional. I think of medicine...” Even respondents who did not see medical professionals understood the question in this way. For example, one respondent said, “I don’t receive any care because I am not in any doctor’s care....not currently.”

A few respondents mentioned medical treatments, such as medications, injections or support devices. This was typically mentioned while talking about care from a medical professional. For example, one respondent said “Basically the care and support for my knee...I went to the doctor and they gave me a knee brace at first for support, and prescribed Motrin for the pain....it helps a little.” Quite a few respondents mentioned cortisol injections or “pain shots” to help with their pain while others mentioned back or wrist support devices.

Family and friends: Some respondents thought of support from family and friends. Respondents mentioned family and friends giving them rides, accompanying them to doctor’s appointments and generally helping with tasks that were made difficult by pain. One respondent mentioned, "Usually my close friends and fiancé help me out because I have pain." Another respondent mentioned help from his fiancé saying, “She'll do things I don't want to do and sort of take the burden off of me, cooking, ironing, laundry, household things." Another said, “Sometimes I have help from my daughter or my granddaughter...it just depends.” They help her run errands.

Self-care: Lastly, a few respondents mentioned self-care activities, such as hot baths, soaking feet, using ice or heating pads to relieve pain or management of pain with yoga, physical activity or diet.

***HICP4: To what extent are you able to manage your pain so that you can do the things that you enjoy doing?**

Answer	Cases
Not at all	2
A little	2

A lot	12
Somewhere in between a little and a lot	22
[No data entered]	2

This question was asked of 38 respondents. Similar to the previous question, a few respondents were confused or asked for the question to be repeated although all were able to choose a response.

Interpretation: Respondents interpreted this question to be about treatments such as medication and support devices, altering their behavior or self-care strategies to manage their pain.

Treatments: Respondents mentioned medication or pain killers, muscle relaxers, creams, cooling gels, heating pads, as well as cortisol injections, back braces, knee braces, or ace bandages. One respondent said, “You know, like I said, when I go out with friends, most times I put an ace bandage on it.” Another respondent said “My heating pad is my life saver.” She explained that “Sometimes I can get the level down where I can maneuver...but there are times it’s unbearable...those are the times I break out the heating pad...” Another mentioned “I have a drawer full of all these pills, so I got to make a decision, do I want to take 600 or 800 mg of ibuprofen.” These respondents all answered “somewhere between a little and a lot.”

Altering behavior: Many respondents discussed altering their behavior, modifying or avoiding activities in order to self-manage their pain. This included things such as resting, sitting down, exercising, taking the elevator rather than the stairs, or trying to avoid certain situations that might increase their pain, such as not attending events where there is a lot of walking, lifting or standing. For example, one respondent who answered “a little” talked about how his wrist pain prevents him from taking part in neighborhood picnics:

It’s something I know is there...I tend to shy away from trying to do anything to help [set up]... It makes [the picnics] less enjoyable. Sometimes I don’t want to participate...because you never know...especially with kids [bumping into him]...it makes it uneasy for me.

Another respondent described how she altered her behavior to ease her pain because she doesn’t like to take medication. She said, “Even if I feel something, I try not to let it stop what I enjoy doing.” She still enjoys “doing hair” but will sit on a stool instead of standing to do it.

Self-care: Lastly, some respondents mentioned self-management techniques. For example, one respondent with back pain said “I do everything I can to manage it” and explain how he self-manages his pain by “bathing in hot water, putting heat on my back or lying down on a hard floor to align my back.” Another respondent talked about taking a hot bath every night with Epson salt to ease his back pain.

BURDEN

HICP5: I feel that I am a burden to my family or caregivers due to my pain...

Answer	Cases
None of the time	23
Some of the time	12
Most of the time	4
All of the time	1

This question was asked to all 40 respondents. Most respondents referred to family members, such as spouses, fiancées, children, grandchildren or siblings when answering this question. A single respondent thought about his home health aide.

Burden: The term *burden* had a negative connotation, and almost all respondents seemed to understand this as something they would not like to be. Respondents answered based on slightly different notions of *burden*.

Inconvenience: Most respondents thought about how much inconvenience they cause their family or caregivers. Many respondents answered “none of the time” either because they never ask anyone for help or because those that offer help are not inconvenienced in any way. For example, one respondent said, “I’m able to care for myself. I don’t ask a lot of people to do anything for me.” A similar respondent said, “I try to do everything without calling on somebody. Then I’d be a burden.” These and similar respondents did not want to be a burden so they avoided asking for help. Other respondents talked about how their family members were happy to help them. One respondent said, “He doesn’t feel that it’s a burden at all.” Another said talked about the ways his fiancé cares for him (rubbing his feet, getting him water) and said, “She just wants to do it. She’s got a good heart.” Thus most respondents were reluctant to think of themselves as a burden to anyone.

Some respondents did feel like a burden due to the inconvenience their pain causes their family members. For example, one respondent answered ‘some of the time’ and explained:

Yes, some of the time I feel like I’m a burden because sometimes my family will have to go out of their way to really help me...and stop what they’re doing to make sure I take care of my business.

Another respondent answered “most of the time” because he feels that he has caused financial inconvenience to his brother:

When I got put on bed rest I wasn’t making any money and my brother has to pay our mortgage and bills on his own...I know it’s taking away from him and I felt awful...he has to call out of work to pick me up because I can’t drive.

Bringing others down: Some respondents felt they were a burden to their family because their pain causes negative feelings in others (such as worry, concern or annoyance). For example, few respondents mentioned that their pain can affect the family mood or that they feel like they’re a “downer.” For example, one respondent who answered ‘Most of the time’ explained:

When the pain comes down on me. And me being around family and I have to be the one that’s moaning and groaning and it seems like I’m messing their day up, especially if we’re having a family gathering or something, and they’ve gotta look at me and I’m all in pain, I’m sure I’m messing things up, I’d much rather not be there and go through that then have them worrying about how I’m feeling.

Similarly, another respondent mentioned:

Sometimes I can’t do the activities that they do, you know, we go on picnics, kids like to play [games]. I can’t do that, and it really interferes with...our family time.

Another respondent simply said, “Sometimes when I’m in pain, I feel that I can be annoying.”

Needing care: A few respondents thought about whether or not they need care. One respondent answered “all of the time” because he was anticipating needing a home health aide post-surgery and he believed he would need her “all of the time.” Other respondents answered “never” because they never need care (not just that they don’t ask for help as the respondents above). One respondent said, “I’m independent and self-sufficient” while a few others described how they take care of others rather than others caring for them.

HICP6: How often does pain affect your family or significant others?

Answer	Cases
Never	9
Some days	20
Most days	4
Every day	3
[No Data Entered]	4

Thirty-six respondents were asked this question. Many respondents interpreted this question similarly to the previous question on burden (HICP5) and referenced their previous answer.

Effect on activities or interaction: Many respondents felt their pain affected their family because they cannot participate in activities. For example, one respondent answered ‘Some days’ and explained that she is family oriented and her family always wants to go out to the park or walk around, but she can’t because of her knee pain. Another respondent who also answered “some days” explained, “In terms of mobility, if it’s a weekend, and I’m in bed, and they want to do something, I just stay home.”

Respondents also thought about how their pain affected their interactions with others. One respondent described the effect of her pain on her fiancé, “He has to deal with me and my pain and my attitude to the pain.” This respondent answered “most days” but also said that there are some days she keeps her pain from him so he doesn’t realize how much pain she’s in. Similarly, another respondent also answered “most days” and described how his pain causes him to be in a “bad mood” which “rubs off on [others].”

A few respondents described how their pain keeps them from doing activities with their children. “My son might want to play and I can’t,” said a respondent who answered “some days.” In addition, two respondents who answered “some days” discussed the affect pain has on their intimate relationships. One respondents specifically said that she can’t be intimate with her husband when she is in pain, “If it’s (the pain) really, really bad, I can’t be intimate with my husband.” Another mentioned that he and his wife sleep in separate beds so he can move around when he is sleeping and in pain.

Needing help: Some respondents thought about help they receive from family friends to do things, such as household chores, that they have a hard time doing because of their pain. One respondent answered “some days” because she is reluctant to ask for help, “Even though I don’t want their help or assistance, I will ask because it’s out of my control and they know if I ask, it’s real because I try not to.” Similarly, another respondent said, “I try to keep involvement of others at a minimum.” However, he answered “some days” because there are days when he needs his wife’s help to put on his socks.

Concern: A few respondents discussed concern that their pain causes others. One respondent answered “most days” and described how his mom “thinks about it all the time.” On the other hand, another respondent answered “never” because she feels her family doesn’t care about her pain. She said, “They don’t give a damn.”

Others' pain: A few respondents interpreted the question as asking about others' physical pain. One respondent answered 'Every day' and discussed his fiancé's neck pain and his dad's back pain. Another respondent answered 'Some days' and was thinking about how often family or significant others experience pain. "I interpreted that to mean how often my family or others experience pain." Another respondent was confused with the point of this question. He answered 'Never' and explained, "No because my pain is my pain...They don't feel it. Why would they?"

Based on the results of this testing, the NPS workgroup revised this question to emphasize that the question refers to the respondent's pain:

***HICP6 (revised): How often does YOUR pain affect your family or significant others?**

LIMITATIONS

As described in Section Three, respondents were asked two global questions about limitations due to pain (one with examples, one without) and eight domain specific questions. Since the desired goal was to develop a single, global question targeting limitations due to pain, the sole purpose of testing the domain specific questions was to verify whether or not a global question would accurately capture limitations across domains.

***HICP7a and HICP7b: Over the past six months, how often did pain limit your life or work activities [HICP7b: including household chores, leisure and social activities]?**

	HICP7a	HICP7b
Answer	Cases	Cases
Never	2	0
Some days	16	17
Most days	17	12
Every day	5	2
[No Data Entered]	0	9

All 40 respondents were asked this question without the examples and 31 respondents were also asked the same question with the examples.

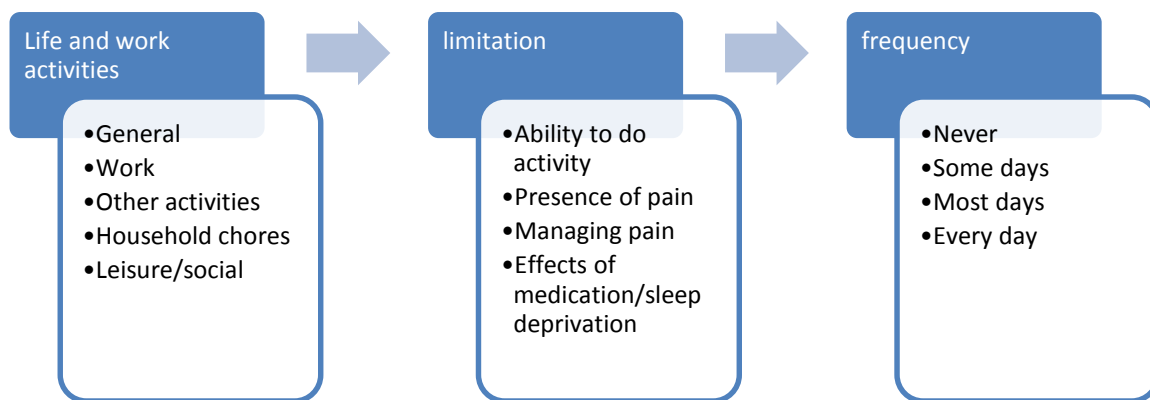


Figure 1. Decision points for responses to questions HICP7a and 7b.

As depicted in Figure 1, respondents had three decision points to consider.

Life and work activities (without examples): When asked the question without examples, respondents focused on general activities of everyday life, work activities or other specific activities.

General activities: Most respondents answered based on a generalization of their daily activities. When asked what type of activities they were thinking of, these respondents said things like “Life. Period.”, “I would say everything.” and “Overall everything. No particular thing.”

Work activities: Other respondents focused mostly on their work activities. For example, one respondent who answered “most days” described how he used to work as a walking security guard. Now, due to his pain, he can only work as desk security. When asked what she was thinking about when she answered “every day,” another respondent said, “I’m just thinking, I don’t do no work, actually, I can’t do no work.”

Other specific activities: A few respondents thought of other activities such as hobbies or exercise or a combination of several activities together. For example, one respondent said, “I can hardly ever play piano even though I’d like to” while another respondent was thinking of difficulties she has doing online school.

With examples: When asked the question with examples, some respondents thought about the same life and work activities as they had referenced in the previous version of the question (HICP7a). However, most respondents focused specifically on the examples listed in this version of the question- household chores, leisure and social activities.

Household chores: Most respondents focused on household chores when answering this version of the question. When asked which activities she was thinking about when she answered “some days,” one respondent with severe hand pain said, “Household chores; pushing a vacuum. It’s something I don’t like to do anymore. Obviously you have to use two hands to push and maneuver a vacuum.” Another respondent also answered “some days” because some days he needs to clean under the bed and he can’t move it by himself due to his pain. A third respondent who answered “most days” said he was “thinking primarily of household chores...like cutting the lawn or some aspect of house cleaning.”

Leisure and social activities: A few respondents focused on the part of the question that mentions leisure and social activities. One respondent answered “some days,” saying that when she is not in pain, she can “go visit a friend and play cards.” Another respondent was thinking that pain prevents him from enjoying “going out to eat, playing cards and being social” when he answered “most days.”

Limitations: Respondents then had to think about their limitations due to pain. Most respondents thought about how their pain limits their ability to do activities, but some respondents thought about having pain (in general), time spent managing pain or the secondary impact of having pain.

Ability to do activities: Most respondents thought about how pain limited their ability to do activities. Some thought about activities they could not do at all any more. For example, several respondents were no longer able to work, and a few could no longer go out with friends or have sex. Respondents who answered “some days” thought about activities they couldn’t do as much as they used to. One respondent doesn’t go to the gym as much as she used to while another said, “I still do my job, but I don’t do as much strenuous stuff as I used to.”

Presence of pain (in general): For other respondents, just having pain was a limitation. One respondent answered “most days” and said, “Most days it’s painful to do everything, but I don’t allow it to limit me from doing them.” Another respondent with severe leg pain answered “every day” but went on to describe the many activities he does. He said, “I’m in pain all the time no matter what I’m doing.” Therefore, these respondents were not limited in their ability to do activities, but considered the presence of pain itself to be a limitation.

Time spent managing/avoiding pain: Some respondents thought about how much time they spend managing their pain or taking steps to avoid pain. One respondent with lower back pain answered “some days” and said, “I have to manage my time. I do what I can when I can.” Another respondent with fibromyalgia answered “every day” and said, “I’m always thinking about it. Even when the pain isn’t there, it’s there.” Similarly, another respondent said having arthritis “makes you think about what you’re doing; you have to think before you do something.” For these respondents, managing the pain significantly limited their activities.

Impact of sleep deprivation/medication: A few respondents were limited by the secondary effects of pain. That is, they at times felt sleepy or foggy due to pain medication or lack of sleep. One respondent with knee pain answered “most days” and said, “The medication makes me sleepy. I feel distracted.” Meanwhile, another respondent answered, “some days” and said, “If I don’t sleep at night [due to pain], I will sleep in the day and that cuts down on available time to do things.”

Table 2. Comparison of responses to HICP7a and 7b

		With examples (HICP7a)			
		Every day	Most days	Some days	never
Without examples (HICP7b)	Every day	2		1*	
	Most days		13	5*	
	Some days		2*	13	
	never			1*	1

*discordant responses

With examples vs. Without examples: As seen in Table 2, most respondents answered similarly for the version of the question with examples and the version without examples (HICP7a and HICP7b). In cases where respondents’ answers were discordant, respondents answered HICP7a focusing on their limitations at work while they answered HICP7b focusing on limitations doing household chores. One respondent summed up the difference between these two domains, “At home, I’m the boss. I don’t have to do it [chores] if I don’t want to. At work, you have to work to get a pay check.” Therefore, in almost all cases, respondents reported greater limitations when they were thinking about work than when they were thinking about household

chores. Further, it was seen that respondents were able to focus on a more general concept of “life and work activities” when they were presented the question without examples. Indeed, the examples distracted respondents from the generalizable concept and caused them to focus narrowly on the listed examples.

HICP8: Over the past six months, how often did pain limit your ability to do work such as an income-earning job or volunteer work?

Answer	Cases
Never	5
Some days	21
Most days	8
Every day	3
This does not apply to me	3

Two respondents had difficulty providing an accurate or coherent answer for this question. One of these respondents answered “this does not apply to me” but later wanted to change his response. When asked why, he said, “Maybe I didn’t understand or was thinking of something else.” The other respondent asked for repeated repetitions of the question. When she was asked to clarify her response she said she didn’t remember. It’s worth noting that this respondent, in particular, was on pain medication that made her drowsy during the course of the interview.

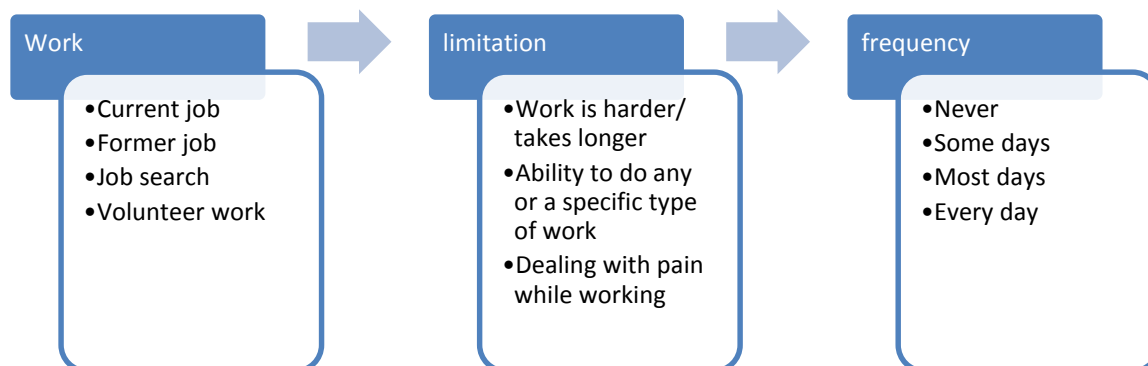


Figure 2. Decision points for question on limitations on work due to pain (HICP8).

As depicted in Figure 2, respondents had three decision points to consider when answering this question: 1) definition of work, 2) Type of limitation and 3) frequency.

Work: Respondents first had to consider what was meant by “work.” Many respondents thought about their current, paid employment status. This was true even for some respondents who had changed jobs due to pain. For example, a former unarmed security guard who had switched to a desk job because he could no longer walk answered based on the current desk job. Another respondent answered “this does not apply to me” because she does not currently have paid employment even though she does volunteer extensively at an animal shelter. Therefore, this respondent answered based on her current job status rather than on her volunteer work.

However, quite a few respondents who were not working, thought about their previous jobs. Some had quit their previous jobs due to pain, but others had stopped working for other reasons such as retirement or desire for a career change. Other respondents without jobs answered based on their ability to search for jobs. Only one other respondent without a job answered “this does not apply to me.”

While those *with* jobs primarily considered paid employment, some without jobs considered volunteer work such as providing food for homeless people, tutoring or working with animals.

Limitation: Respondents next had to consider the types of limitations their pain imposed.

Most respondents said that while pain did not prevent them from working, it did, at times, make it harder to work well or efficiently. Some respondents said they needed to take more frequent breaks or that they worked more slowly, like the respondent who said, “...my job day to day involves walking which I have to take frequent breaks, so it can take longer.” This respondent answered “most days.” Similarly, another respondent answered “some days” and said her pain, “...just slows me down, makes a lot of days longer.” Others described how they had to manage their time differently, doing harder tasks on days that they had less pain and saving easier tasks for days when their pain flared up. This was exemplified by the respondent who answered “some days,” describing how his part-time schedule enables him to work when he feels able and rest when he’s in pain.

A different interpretation of *limitation* was seen in respondents who answered based on their ability to have a job. Some respondents described how their pain prevented them from doing any work at all. One respondent answered “most days” and described his experience:

I don't know how to do anything else except IT work and working at the warehouse. Since those are my two skills, I can't do either one. I had to walk out on four [warehouse] jobs.

A different respondent indicated that she is limited by pain “every day” because she would like to do volunteer work but fears that she would not be dependable. She said, “I don’t know when I could go. I would let them down if I can’t get out of bed.” Therefore, she doesn’t do any work at all.

In contrast, another respondent answered “never” because she has a job despite her pain. She said, “I still do my job, but I don’t do too much strenuous stuff. I just do what I’m comfortable doing.” This respondent answered based on her ability to be at work and to keep her job even though she has to limit the work she does on the days she’s in pain. Several respondents answered in this way, describing their need to work. One respondent answered “never” because “I force myself to work.”

Some respondents answered based on the mere presence of pain during their work. These respondents said that pain did not prevent them from doing their jobs but that they felt significant pain while working. One respondent answered “some days” and described how he keeps working on days he feels pain, “Even though you’re still in pain, you force yourself to keep working.” Another respondent said, “I’m working in pain pretty much because I have to work.” This respondent answered “some days” because “...some days I’m 100% and other days I just want to be in bed.” For these respondents the presence of pain was itself a limitation.

Frequency: Finally, respondents had to consider the frequency with which they experienced these work limitations due to their pain. These frequencies were represented by the response categories. However, choices at the previous two decision points influenced how respondents ultimately chose a response category, at times leading respondents with quite similar experiences of work and pain to choose very *different* response categories. For example, as described above, one respondent answered “everyday”

because she feels pain while working every day, and a different respondent answered “never” because he shows up at work every day despite his pain.

Further, respondents with very different experiences of employment and pain sometimes chose the *same* answer category, depending on their choices at the previous two decision points. For example, one respondent who was unemployed due to her pain answered “most days” because she frequently had to call in sick at her previous job due to migraine pain while another respondent answered “most days” because his pain makes him work a little bit slower than he’d like to.

HICP9: Over the past six months, how often did pain limit your ability to go to school or achieve your educational goals?

Four respondents changed their responses to “this does not apply to me.” Two of these respondents initially answered “never” because they are not in school, so their pain “never” interferes with school. Two other respondents initially answered “some days,” describing how often they experience pain. They later changed their responses when they realized the question focused specifically on school.

Answer	Cases
Never	6
Some days	8
Most days	2
Every day	0
This does not apply to me	25

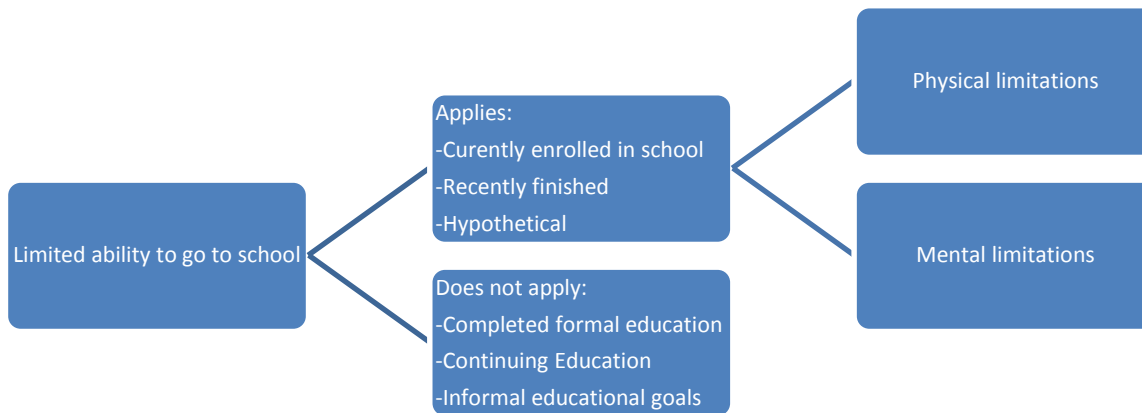


Figure 3. Response schema for question on school (HICP9)

As seen in Figure 3, respondents first considered whether the question applied to them and if so, then considered the limitations imposed by pain.

School: When answering this question, respondents first had to consider whether this question applied to them by evaluating their school status and their educational goals. All respondents who were currently in

school or had very recently finished school considered this question to be relevant to them. Inconsistency was seen in two respondents who were not currently enrolled due to their pain. One respondent said, “I want to take an online college course, but with my pain, the way it is, I don’t think I would really want to waste their time or mine.” Rather than “this does not apply to me” this respondent answered “some days.” In contrast, another respondent had considered going back to school but decided not to because of his pain. This respondent answered “this does not apply to me” since he is not in school. Respondents only considered *formal* schooling rather than continuing education or informal classes when answering this question.

Limitations: Respondents for whom this question applied, then considered whether and how they were limited by their pain. Some respondents cited physical limitations such as limits on their ability to sit or stand for long periods or their ability to walk into school. For example, one respondent answered “some days” because there are days he can’t get out of bed to go to school due to his pain. Other respondents thought about mental limitations. One respondent who recently took some online classes said, “The pain would come and go and that really does interfere with me focusing on the deadline of getting work done and it wasn’t easy.” This respondent answered “some days” because she did not feel pain all the time and she was able to successfully complete the classes despite the interference of the pain.

One respondent answered “never” thinking about physical limitations but noted that if she had thought about mental limitations, she would have answered “some days” because there are days that pain interferes with her ability to concentrate.

HICP10: Over the past six months, how often did pain limit your ability to participate in enjoyable activities such as hobbies, going to the movies or fun with friends and family?

Answer	Cases
Never	4
Some days	25
Most days	8
Every day	1
This does not apply to me	2

Most respondents were readily able to think of things they enjoy doing such as dancing, going to movies, playing sports, and spending time with friends and family. A single respondent answered “this does not apply to me” because she doesn’t do any enjoyable activities. “I don’t really do much,” she said.

Limitations: Most respondents considered several types of limitations that pain imposes on their ability to do enjoyable activities. Many respondents described having to limit the frequency, intensity or duration of the activities they do. One respondent said, “I’ve gotten away from [going to family gatherings] for now. If I do go, I don’t stay very long.” He answered “some days.” Another respondent said, “Most of what I like doing, I’m not doing as often anymore.” Because he can’t play sports very often any more he answered “most days.” A third respondent described how hard it is for him to exercise. He answered “most days” and said, “There’s not too much I can do anymore. If I work out, it will only last about 10 minutes.” Finally, another respondent discussed how infrequently she and her husband do fun things together any more. She answered “every day” and said, “Even it’s sunny, we don’t go on no picnics.”

Three respondents were reluctant to say that they were limited by their pain even though they indicated that they experienced pain while doing activities. These respondents answered “never” to indicate that, like one

of the respondents said, “I don’t let my pain stop me.” These respondents mentioned, “Pushing through” and “doing it anyway.” For other respondents, however, the mere presence of pain was a limitation.

Several respondents answered based on how often they DO enjoyable activities. For example, one respondent explained that she doesn’t go out as often as she used to because of her hand pain. She explained that she answered “some days” rather than “most days” or “everyday” saying, “Some days I fight it and go anyway if I really want to go.” Another respondent also answered “some days” because he does enjoyable activities “about one day a week.” A third respondents answered “never” and said, “I can’t say that I have done any of that -in the past six months, right? No. I can’t say that I have.”

Other factors: A few respondents answered based not only on limitations due to pain, but also on other factors, such as money, time, responsibilities and age, that limit their ability to do enjoyable activities. One respondent described his busy schedule and said, “I do relax and engage in leisure activities, but that happens about once a week.” Another example is the respondent who indicated that she would go out a lot more if she had more money and access to transportation. Finally, one respondent said she didn’t like to visit her husband’s family very often because it’s harder to feed and care for her infant at her in-laws’ house. These respondents all acknowledged that pain was also a factor in limiting their activities. However, clearly, for these respondents and perhaps for others, it was difficult to separate limitations due to pain and those due to other factors.

HICP11: Over the past six months, how often did pain limit your ability to do household chores such as cooking, cleaning or yard work?

Answer	Cases
Never	4
Some days	25
Most days	7
Every day	2
This does not apply to me	2

Most respondents described doing household chores such as laundry, cooking, child care and mowing the lawn. A few respondents answered “this does not apply to me” because their living situations don’t require them to do chores. For instance, one man lives with his wife who does all the household chores and another respondent lives in community housing where all the chores are done communally.

Limitations: Most respondents described physical conditions that limit their ability to do chores. For example, quite a few respondents had difficulty bending or standing for long periods which limited their ability to cook or do other chores.

Some respondents indicated that they don’t let pain stop them from getting their chores done. These respondents answered “never” and several of them described how they “push through” the pain. One respondent described the chores she had done the previous day, “I vacuumed, watered the plants and even though I wasn’t feeling up to it, I pushed myself- some days I have to push.” Another of these respondents said, “I always do what needs to be done.”

A different respondent contrasted paid work, which he viewed as mandatory, and chores, which he felt were optional. “I’m the boss here. You have to work to get a pay check, but in the house if I don’t want to do it... I don’t.” This respondent answered “most days” since he often puts off doing chores.

Other respondents described strategies for managing their chores and their pain. These respondents described how they do more around the house on days when they have less pain. One respondent described it in this way:

I’m always doing a balancing act because it depends like how I feel even though I know it needs to be done. When I have the most energy and the least amount of pain then I can do the strenuous stuff. When it’s worst, then I do the easier stuff.

These respondents answered “some days” since there are some days they can get things done and other days that they can’t.

HICP12: Over the past six months, how often did pain limit your ability to do errands outside of the house such as grocery shopping?

Answer	Cases
Never	5
Some days	27
Most days	7
Every day	0
This does not apply to me	1

In answering this question, respondents thought primarily about grocery shopping, the example mentioned in the question, but also thought about picking up and dropping off packages and doing errands, in general.

Limitations: Most respondents thought about the physical limits that pain imposes on their ability to do errands. Respondents mentioned sore knees, difficulty walking and the inability to carry heavy loads as conditions that limit their ability to do errands. Some respondents considered exhaustion due to pain as the primary factor that limits their ability to do errands. A few other respondents mentioned that doing errands exacerbates their pain. Therefore, they limit the amount of errands they do in order to minimize their pain.

Respondents who thought about these physical limitations talked about how their pain either keeps them from doing errands or limits the errands they can do. For example, one respondent said, “Sometimes I don’t even go any more. Too much walking and my legs be hurting.” This respondent answered “some days” as did another respondent who said, “I can do most of that stuff, but it just takes a lot longer.”

Several factors influenced respondents’ estimations of how often pain limits their ability to do errands. First, respondents who felt that doing errands, especially grocery shopping, was essential, tended to answer “never.” For instance, one of these respondents said, “That’s mandatory, so even with pain, I gotta go get it.” Another of these respondents said, “I have to eat!”

However, other respondents did not consider doing errands to be essential. Most of these respondents had friends and family they could ask for help or who routinely did the errands for them. For example, one respondent said his fiancé usually does the shopping since he can’t. This respondent answered “some days.”

Access to transportation also influenced how a few respondents answered this question. As one of these respondents said, “It’s all about economics.” She answered “some days” and noted that her limits due to pain are related to whether she has the money for bus fare. Another respondent also answered “some days” and said it depends on whether he can get a ride. A different respondent answered “most days”, and said, “Carrying 4-5 grocery bags when you don’t have a car is not easy and then I have to pay extra for a cab or ride.”

Finally, some respondents talked about their strategies for getting errands done despite their pain. These strategies included, reducing the number or length of errands and doing errands on days when their pain is less. One respondent talked about how she and her boyfriend write all their errands down on post-it notes. Some days they can’t do any errands but other days they have less pain. “On those days when we’re fine, we just get everything done,” she said. Respondents who strategized to get errands done answered either “some days” or “most days” depending on how often they had to juggle their schedules.

HICP13: Over the past six months, how often did pain limit your ability to participate in religious activities?

Answer	Cases
Never	15
Some days	12
Most days	2
Every day	1
This does not apply to me	10

Religious Activities: In considering their participation in religious activities, respondents thought not only about attending religious services but also about other expressions of spirituality. Some of these spiritual activities, such as spiritual outreach and prayer group, occurred out of the home while others, such as personal prayer, bible reading and watching TV, could occur in the home.

Limitations: Respondents answered based physical and mental limitations imposed by their pain. Physical limitations included difficulty getting to religious activities that occur out of the house as in the respondent who answered “some days,” saying, “I’m very religious. I go to church every Sunday if I can, but sometimes, if my knee hurts, I won’t be able to make it to church.” Other respondents had physical difficulties performing religious activities. For example, several respondents mentioned difficulty standing at appropriate times during religious services. Another respondent answered “every day” because his pain prevented him from praying seven times a day which is required by his faith. Finally, one respondent answered “some days” and described her difficulty participating in church because pain prevents her from clapping frequently which is expected in her religious tradition. She said, “When the preacher says something I agree with...sometimes when I clap, it feels like my hand about to snap off.”

Mental limitations kept some respondents from participating in religious activities. For these respondents, dealing with pain reduced their energy and desire to participate in religious activities. For example, one respondent, who answered “some days” said, “It feels like too much energy to get it together sometimes.”

Never vs. Does not apply: To a greater extent than seen in other questions in this set, there was no consistent pattern for respondents who answered “never” versus respondents who answered “this does not apply to me.” Some respondents answered “never” because they participate in religious activities despite their pain. For example, one respondent said, “I always gotta serve the lord. I go no matter what.” Another

respondent said, “I’m going to church in pain. I’m going. I won’t let my physical ailment come between me and my God.” Others answered “never” because their pain is not great enough to interfere with their participation in whatever religious activities they choose to participate in. One respondent said, “I’m always going to pray and read the bible or watch TV and see the evangelists. I don’t need to go outside.”

Additionally, several respondents answered “never” to indicate that they do not participate in religious activities. For example, one respondent said she doesn’t go to church because she’s “lazy” and another said, “That was in the past. I don’t do that no more.” This could be considered response error because these respondents should have answered “this does not apply to me” since their non-participation was not related to their pain.

On the other hand, “this does not apply to me” was equally variable in interpretation. Most respondents chose this answer because they are “not religious” or “not into the spiritual world.” However, others used this response to indicate that they stopped participating in religious activities due to pain. Also, at least one respondent chose this answer because she would never let pain interfere with her religious beliefs. Therefore, she believed that the question did not apply to her situation.

HICP14: Over the past six months, how often did pain limit your ability to provide care to family or friends (for example to care for a child or elderly relative)?

Answer	Cases
Never	10
Some days	16
Most days	1
Every day	1
This does not apply to me	12

Caregiving: Respondents thought about care they provide for family members and friends. While some respondents provide constant care for elderly parents or young children, other respondents provide occasional care for grandchildren, friends or sick relatives. Respondents who live alone and don’t provide care to others answered “this does not apply to me.”

Limitations: Respondents thought about how pain impacts their ability to provide care. Most respondents who have children and elderly parents that require daily care answered “never” to indicate that they can’t let pain stop them from providing care. As one respondent said, “I can’t deny the baby... I’m in pain or not, I’m going to do what I can to assist.” Other respondents also answered “never” to signify their commitment to helping those who depend on them. One respondent talked about how she takes care of her fiancé when he is also in pain. She said, “Even if I have to limp my way to the freezer to get him an ice bag, I don’t mind. I’ll deal with my pain to do something for him.”

Respondents who provide as-needed care for friends and family answered “some days” because they are usually able to help when needed but sometimes they can’t provide the level of care they would like to. For example, one respondent who babysits for her nieces and nephews said, “Sometimes I have to say ‘no’ because [the children] are too active, and if my pain levels are too high I won’t be able to function and I don’t want to ruin their day.”

A few respondents answered based on the presence of pain while they provide care for others. For example, one respondent who often cares for his elderly mother does not want his mother to know how much pain he is in. This respondent answered “most days” describing the walks he and his mother often take and how he will have to stop and rest frequently due to the pain in his legs, all the while not letting her know that he’s hurting.

One respondent answered based on how often she is called on to provide care. This respondent answered “every day” because she has to take care of her children every day.

HICP15: Over the past six months, how often did pain limit your ability to have close, personal relationships?

Answer	Cases
Never	11
Some days	20
Most days	5
Every day	0
This does not apply to me	4

Respondents were often unsure of what was meant by “close personal relationship” and asked for clarification before answering. Respondents often opened with questions like, “You mean like with friends and family?” or “Does that mean like having sex?”

Close, personal relationships: Ultimately, respondents thought about a variety of relationships that fit this description. Some respondents thought about friends and family, in general, while others thought specifically about romantic relationships or about sex. Respondents who thought specifically about romantic relationships but who were not dating anyone answered “this does not apply to me.”

Limitations: Respondents considered both physical and mental limitations to their ability to have close, personal relationships. Mental limitations included pain’s impact on their energy and desire. As one respondent, who answered “most days” put it, “When you don’t feel well, you don’t really want to be around people.” Another said, “The pain takes up a lot of my mental energy.” This respondent answered “some days” thinking about the impact his pain has on his ability to be close to his partner.

Physical limitations impacted respondents’ ability to do social activities with friends and family and their ability to have sex. One respondent who answered “some days” described how pain impacts her ability to date:

Some days within the last couple months, I got asked out on a couple of dates. Some of them I went to, but some of them I could not go to because of the pain in my knee.... And then it would make me and the person kind of grow distant.

Regarding sex, one respondent, who answered “some days,” said, “Some days I just want to snuggle up and have close time, but I can’t.” Another respondent, who also answered “some days” was more graphic in her depiction saying, “The difficulty is the positions or the activity part. We couldn’t get so active because I don’t feel like moving. I just want to lay there because my legs are in pain.”

A few respondents answered “never” based on the nature of their relationships. Several respondents brought up the idea of “real friends” (who remain friends despite the limitations imposed by pain). One respondent said, “I can’t always do the activities they want to do but I can still spend valuable time with them.” Another said, “If you have a close personal relationship, if they care about you, the pain won’t interfere.”

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Appendix A

Pain		Answer categories
HICP1	During THE PAST SIX MONTHS did you have pain of any kind on at least half the days?	<ul style="list-style-type: none"> <input type="radio"/> Yes <input type="radio"/> No
HICP1a	Over the last six months, on about how many days have you had pain of any type?	<ul style="list-style-type: none"> <input type="radio"/> I have not had pain in the last six months <input type="radio"/> I have had pain, but on less than half the days <input type="radio"/> I have had pain on more than half the days but not every day <input type="radio"/> I have had pain every day
Chronic		
*HICP2	In THE PAST SIX MONTHS how often did you have pain?	<ul style="list-style-type: none"> <input type="radio"/> Never <input type="radio"/> some days <input type="radio"/> most days <input type="radio"/> every day
Pain Management		
HICP3	To what extent have you received care and support that helps you manage your pain so that you can do the things you enjoy doing?	<ul style="list-style-type: none"> <input type="radio"/> Not at all <input type="radio"/> A little <input type="radio"/> A lot <input type="radio"/> Somewhere in between a little and a lot
*HICP4	To what extent are you able to manage your pain so that you can do the things that you enjoy doing?	<ul style="list-style-type: none"> <input type="radio"/> Not at all <input type="radio"/> A little <input type="radio"/> A lot <input type="radio"/> Somewhere in between a little and a lot
Burden		
HICP5	I feel that I am a burden to my family or caregivers due to my pain....	<ul style="list-style-type: none"> <input type="radio"/> None of the time <input type="radio"/> Some of the time <input type="radio"/> Most of the time <input type="radio"/> All of the time
*HICP6	How often does pain affect your family or significant others?	<ul style="list-style-type: none"> <input type="radio"/> Never <input type="radio"/> some days <input type="radio"/> most days <input type="radio"/> every day
Participation Restrictions		
*HICP7a	Over THE PAST SIX MONTHS, how often did pain limit your life or work activities?	<ul style="list-style-type: none"> <input type="radio"/> Never <input type="radio"/> some days <input type="radio"/> most days <input type="radio"/> every day
HICP7b	Over THE PAST SIX MONTHS, how often did pain limit your life or work activities (including household chores, leisure and social activities)?	<ul style="list-style-type: none"> <input type="radio"/> Never <input type="radio"/> some days <input type="radio"/> most days <input type="radio"/> every day

HICP8 work	Over THE PAST SIX MONTHS, how often did pain limit your ability to do work such as an income-earning job or volunteer work?	<input type="radio"/> Never <input type="radio"/> some days <input type="radio"/> most days <input type="radio"/> every day <input type="radio"/> This does not apply to me
HICP9 Education	Over THE PAST SIX MONTHS, how often did pain limit your ability to go to school or achieve your educational goals?	<input type="radio"/> Never <input type="radio"/> some days <input type="radio"/> most days <input type="radio"/> every day <input type="radio"/> This does not apply to me
HICP10 Leisure and Social Activities	Over THE PAST SIX MONTHS, how often did pain limit your ability to participate in enjoyable activities such as hobbies, going to the movies or fun with friends and family?	<input type="radio"/> Never <input type="radio"/> some days <input type="radio"/> most days <input type="radio"/> every day <input type="radio"/> This does not apply to me
HICP11 Household Chores	Over THE PAST SIX MONTHS, how often did pain limit your ability to do household chores such as cooking, cleaning or yard work?	<input type="radio"/> Never <input type="radio"/> some days <input type="radio"/> most days <input type="radio"/> every day <input type="radio"/> This does not apply to me
HICP12 Errands	Over THE PAST SIX MONTHS, how often did pain limit your ability to do errands outside of the house such as grocery shopping?	<input type="radio"/> Never <input type="radio"/> some days <input type="radio"/> most days <input type="radio"/> every day <input type="radio"/> This does not apply to me
HICP13 Religious Activities	Over THE PAST SIX MONTHS, how often did pain limit your ability to participate in religious activities?	<input type="radio"/> Never <input type="radio"/> some days <input type="radio"/> most days <input type="radio"/> every day <input type="radio"/> This does not apply to me
HICP14 Care-giving	Over THE PAST SIX MONTHS, how often did pain limit your ability to provide care to family or friends (for example to care for a child or elderly relative)?	<input type="radio"/> Never <input type="radio"/> some days <input type="radio"/> most days <input type="radio"/> every day <input type="radio"/> This does not apply to me
HICP15 Intimacy	Over THE PAST SIX MONTHS, how often did pain limit your ability to have close personal relationships?	<input type="radio"/> Never <input type="radio"/> some days <input type="radio"/> most days <input type="radio"/> every day <input type="radio"/> This does not apply to me

*Selected by NPS Workgroup.