2019 EVALUATION OF OPIOID-RELATED QUESTIONS FOR FEDERAL HOUSEHOLD SURVEYS

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This document presents findings of a large nationwide cognitive interviewing study, including a companion pile sorting activity, conducted by the National Center for Health Statistics' (NCHS) Collaborating Center for Question Design and Evaluation Research (CCQDER) to examine the performance of opioid use, impairment, misuse and disorder questions intended for population-based Federal surveys. The study consisted of 180 English and Spanish-speaking interviews in eight jurisdictions of the United States, of which 152 also included the pile sorting activity. Respondents varied in demographic backgrounds and ranged in their knowledge of and experiences with opioid pain medication. Interviews focused on the ways in which respondents interpreted the various questions as well as the specific experiences included in their answers. The research serves as a validation study in that the accuracy of survey question responses were assessed through in-depth follow-up discussions with respondents. That is, interviewers were able to determine false-negative and false-positive responses as well as reasons for that error. Analysis of those interviews, specifically, identifying patterns of commonality and difference, reveals the phenomena captured by each question as well as the ways in which, and circumstances by which, they may vary across groups of respondents.

The primary goal of this work is to investigate the ways in which existing opioid questions perform on Federal household surveys. Existing sets of opioid questions, primarily those for identifying opioid use disorder among patients, were developed specifically for clinical use and were validated within the context of pain clinics among patients. Although adapted for survey use, the cognitive processes involved in formulating an answer within the question-response format of a household survey interview likely differ from that of a discussion-oriented interview within a clinical setting. Findings from a previous CCQDER study, for example, showed that, when formulating answers to opioid impairment questions, respondents' interpretations were linked to their particular personal experiences and circumstance, which were not always consistent with the questions' intent.[1] This finding suggests not only the need to examine the constructs captured by individual questions, but also the comparability across socio-economic and cultural groups.

To this end, this work examines the ways in which respondents make sense of each item as a survey question, consider those interpretations in relation to their own experience and formulate answers reflecting those considerations. Relatedly, this work seeks to understand the ways in which respondents' interpretations might vary as well as the circumstances for any variations. For example, in particular regions of the country that are especially affected by the opioid crisis, how does context impact the ways in which respondents interpret and process opioid-related questions? Ensuring that questions capture the

[1] Willson, S. (2017). Cognitive Interview Evaluation of Survey Items to Measure Substance Use and Impaired Driving. National Center for Health Statistics. Hyattsville, MD. https://wwwn.cdc.gov/QBank/Report.aspx?1186. Accessed 4/9/2018.

same construct across diverse populations makes certain that resulting data are accurate and that any discrepancies identified across various populations reflect true disparities.

Cognitive Interviewing Methodology

The methodology for this study's cognitive interviews is detailed in Miller et al. (2014). More generally, cognitive interviewing is a commonly method used within the field of survey research to investigate the ways in which respondents understand and process survey questions. 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, 3) formulate a response based on that consideration. Because they are able to identify the specific phenomena accounting for respondents' answers, cognitive interviewing studies provide in-depth understanding of the ways in which a question operates and the actual construct that it captures.

The opioid use, misuse, impairment and use disorder questions to be examined are included in Appendix 1, located at the end of this section beginning on page 47. Many of the items appeared on the 2017 National Survey on Drug Use and Health (NSDUH). The 2019 National Health Interview Survey (NHIS) opioid use question is also included. Additional questions on general health and access to care are used to frame respondents' answers to the opioid-related questions.

Sample

A purposive sample of respondents was recruited to participate in cognitive interviews. Of those, 140 English-speaking cognitive interviews were conducted in seven jurisdictions (Washington DC; Lexington, KY; Mobile, AL; Seattle, WA; Boston, MA; Wichita; KS; El Paso, TX), with 20 interviews conducted in each location. An additional 40 Spanish-speaking interviews were conducted in El Paso and Chicago, IL for a total of 180 interviews conducted for the project.

The aim of recruitment was to obtain a sample of respondents with a wide range of experiences, including those who had never used opioid pain medication, those who had used it temporarily for a specific injury or surgery, those using it currently for an ongoing condition or addiction, and those who previously had an ongoing habit of addiction. Those who never used opioid medication were recruited in-the-field by a team of interviewers using convenience sampling outside of libraries, laundromats, restaurants, and other public spaces. To reach extensive users, NCHS-based recruiters employed a combination of print and online advertisements (local newspapers, Craigslist, Facebook groups) and outreach to pain clinics and opioid addiction treatment facilities. Interviewer teams also worked to establish rapport with individuals in the community, including staff at local restaurants, to facilitate chain referral sampling of those who use opioids with and without a prescription.

As a priority, teams also worked to ensure a sample diverse in sociodemographic characteristics. This was achieved, in part, by continuously monitoring the demographic makeup of incoming interviews and prioritizing respondent characteristics when screening new respondents. To capture a broader cultural spectrum, interview teams traveled outside metropolitan areas into neighboring counties to include those living in rural areas and those with differing population compositions.

The final group consisted of respondents with relatively varied demographic backgrounds. The sample was split between men (46%) and women (54%), and included White (44%), African American (20%),

Asian (3%), American Indian (5%), and Hispanic (28%) respondents. In terms of respondents' experience with opioids, most were either temporary opioid users (42%) taking opioids briefly after a surgery or an injury, or long-term users (43%), typically taking opioids to relieve pain caused by an ongoing chronic condition. Approximately 7% reported never having an opioid, and 8% stated that, in the past, they were heavy opioid users but no longer take them. The vast majority of respondents (76%) got their opioids legally, with a doctor's prescription. Only 4% obtained opioids only through illegal means without a prescription, while 20% received a combination of legal and illegal opioids.

Interview Process

All interviews were conducted face-to-face and ranged in length (30 – 60 minutes) depending on respondents' opioid experiences. Interview location varied with most interviews taking place in a private room of an office building, hotel or library. Some interviews were conducted in semi-private locations, for example, in a park, a coffee shop or laundromat. All interviews were video-recorded using a lap top computer and camera. Prior to the start of the interview, respondents filled out several forms, including a consent form for videotaping. Once completed, the interviewer described the mission of NCHS, purpose of study, and the interview process. At the end of the interview, respondents were given $40 for their effort.

For the interview itself, respondents were asked each item and were then asked to explain their answer. Typical follow-up questions included, "How so?" and "Why do you say that?" If a respondent's answer seemed vague or unclear, the interviewer asked: "Can you give an example to describe what you are talking about?" The culminating text from the interview related how respondents understood or interpreted each question and also outlined the types of experiences and behaviors respondents considered in providing an answer. At the end of the cognitive interview, that is, after all survey questions were discussed, respondents were then asked to participate in a pile sorting activity. Description and findings of the pile sort component are detailed in a separate section at the end of this document.

Method of Analysis

Analysis of interviews consisted of a process involving data reduction and theory building, that is, drawing conclusions. First, original interview text from every interview was summarized into detailed interview notes. Summary notes specified the way in which individual respondents answered every survey question, including each respondent's interpretation of questions and key terms, activities and experiences considered by respondents, and any response difficulties and errors. Next, comparisons were made across all interviews, identifying interpretive patterns (including patterns of response errors) across interviews. Findings from this second level of analysis depict the phenomena captured by each question. Finally, thematic patterns were compared across subgroups of respondents to determine whether questions might perform differently across various groups, for example, in the different regions or languages. A CCQDER data entry and analysis software application (Q-Notes) was used to conduct analysis.[2]

Summary of Cognitive Interviewing Findings

[2] Available at https://wwwn.cdc.gov/qnotes

As will be detailed in the question-by-question findings, there are numerous, inconsistent ways in which respondents interpreted and formulated responses to the various opioid survey questions. For some respondents, questions took on unintended meanings and were sometimes seen as being 'loaded' or even accusatory. This was especially true for long-term users of opioid medication when answering questions about misuse and disorder. General-use questions (e.g., have you taken an opioid in the past 12 months?), on the other hand, were seen as relatively benign, consistent with intent and produced relatively accurate responses. Regarding impairment questions, many respondents were unable to entirely differentiate side effects of the medication from their actual pain, thus making the questions difficult to answer and resulting in data of uncertain meaning. Additionally, multiple cases of false-negative reports of misuse were identified across all types of users. While some respondents did in fact report their misuse, others did not define this behavior as such, thinking of it instead as 'not really' or 'not entirely' breaking prescription orders, and answered 'no.'

Respondents' knowledge of opioids, including the meanings or connotations they attach to the concept, is the principal, underlying factor informing the question response process. It is also the basis for varied interpretations across respondents. Significantly, respondents' knowledge of opioids is informed by their particular experience and the context of that experience. In Kentucky, for example, many respondents were vividly aware of the opioid crisis having had family members whose lives were impacted by addiction. There were regular news reports about raids on physician offices, and many recognized their community as being on 'the front line' of the opioid crisis. Those who had first-hand experience, for example, those taking opioids for many years or who had a close family member with an opioid problem, typically had a broad understanding of opioids, including knowledge of the names and classifications, as well as judgements about people addicted to opioids and doctors who they perceive as over-prescribing. On the other hand, some respondents were culturally isolated from news of the crisis, had no first-hand experience and, therefore, had no knowledge of the concept 'opioid.' For example, an older woman who had immigrated from Thailand over 20 years ago, but who is not fluent in English and maintains the traditions of her Asian upbringing (e.g., taking only Chinese medicine), expressed outright confusion when asked the question.

In terms of interpretation, there are three different aspects of respondents' understanding of opioids that inform how respondents formulate answers: 1) their general awareness of opioids, 2) the connotations they associate with opioids and, 3) their personal understanding of their own relationship with opioids. As will be illustrated throughout the report, each type of understanding frames the question response process and requires specific question design considerations.

General Awareness: Whether or not a respondent had even a general awareness of the existence of opioids is the most basic form of understanding. Does the respondent recognize the word 'opioid' when presented in a survey question? Do they understand that it implies a class of pain-relieving drugs that is different from over-the-counter pain-relievers? Although the opioid crisis seemingly appears in near constant news cycles, affecting countless peoples' lives, there still are those, like the woman from Thailand, who are untouched by the news. In another example, an older Hispanic woman questioned the meaning, saying she had never heard of opioids. When the interviewer described the opioid crisis and the impact on communities, she suggested that she may have overheard a conversation on the bus. Similarly, a young, healthy college student stated that he knew nothing of opioids and explained his only contact with the news was to catch up on sports. Basic awareness of opioids is particularly relevant for general-use questions. It cannot be assumed that all respondents are familiar with the concept, nor can it be assumed that having once been prescribed opioids in the past creates a general awareness. The section of this report discussing opioid use questions illustrates this point further, describing the ways in

which various question design strategies attempt to account for lack of general awareness and how they actually perform when presented to respondents.

Associated Connotations: Beyond respondents' basic awareness of opioids are the ways in which respondents understand the concept, specifically, the connotations they associate with the term. Some respondents, for example, thought of opioids as being dangerously addictive and should be avoided at all cost. Others, particularly those taking opioids long-term for a chronic condition, saw opioids as a 'life-saver,' allowing them to lead richer lives. Significantly, ongoing media about the opioid crisis not only promotes a general awareness of opioids, it also problematizes opioid use, creating a climate whereby some are inclined to cast judgement on opioids and those who use them. Some respondents, for example, spoke unsympathetically about unnamed 'opioid users' 'ruining their lives' or 'putting their families through hell.' Long-term users often blamed the opioid crisis on recreational users, speaking critically of those struggling with addiction, claiming it is they who 'give opioids a bad name.' Within this context, survey questions about opioids also took on connotation. Instead of seeing the questions as value-neutral, respondents typically understood them through the lens of their belief system, resulting in varied interpretations across respondents and sometimes inconsistent with question intent. While not seen in the general-use questions, this primarily occurred when answering questions pertaining to impairment, misuse and disorder.

Relationship between self and opioids: Most importantly, how respondents came to answer questions about their opioid behavior was dependent on how they have come to make sense of that behavior. As complex as the system of beliefs about opioids might be, it becomes even more complex as respondents use these beliefs to make sense of their own patterns of opioid use and how they ultimately define themselves in relationship to that use—whether they see themselves as never-users, responsible users, or addicts. For example, respondents who thought of themselves as 'not-a-pill person' were much less likely to carefully reflect upon the given time frame and simply reported 'no,' only later to recall that, in fact, they had forgotten about a previous experience with opioid use. Respondents who thought of themselves as 'responsible users' were not inclined to consider the question's definition of misuse, nor to consider whether their behavior (which they have already defined as being 'responsible') might warrant a 'yes' response. This happened for the most part for questions pertaining to misuse and disorder. Specifically, those who thought of themselves as 'not a pill person' or a 'responsible user' tended to not fully consider questions about misuse and disorder. Those who had come to understand themselves as 'addicts,' however, had no difficulty answering these questions according to their intent.

As previously indicated, a primary goal for this study was to understand how respondents' interpretations might vary as well as the circumstances for any variations. For example, we asked, how would region of the country impact the ways in which respondents interpret questions? How might race and ethnicity as well as language inform the question response process? In this study, we find that respondents' knowledge of opioids is the driver of the question response process and, to the extent that these social factors inform respondents' knowledge of opioids and the opioid crisis, they inform the question response process.

Question-LevelFindings

Opioid Use

Two questions about opioid use were examined: a question currently on the NHIS and the other on the NSDUH. For the cognitive interview, respondents were first asked the NHIS question followed by the NSDUH question. They were:

> *NHIS: During the past 12 months, have you taken any opioid pain relievers prescribed by a doctor or dentist? Examples include hydrocodone, Vicodin, Norco, Lortab, oxycodone, OxyContin, Percocet and Percodan. Yes/No*
>
> *NSDUH: Please look at the names and pictures of the pain relievers shown below. In the past 12 months, which, if any, of these pain relievers have you used? (List of 40 medications accompanying pictures of the individual pills)*

While both questions ask about opioid use within the past 12 months, they differ in key ways. Because NSDUH asks about individual drugs, it does not use, nor need to define, the word 'opioid.' The NHIS question, which does use the word 'opioid,' conveys a definition through a set of examples and indicates that they are pain relievers prescribed by a doctor. An advantage of the NSDUH question is that it captures more specific information, namely the individual medications; the NHIS, as a yes/no question, only identifies whether a respondent has taken at least one opioid within the past 12 months. The NSDUH, on the other hand, is longer to administer and requires a visual platform that would be difficult to administer over the phone.

Analysis of the cognitive interviews suggests that the two questions perform similarly, capturing the same phenomena (aside from the individual names in the NSDUH question). Although the NHIS question includes the phrase 'prescribed by a doctor or dentist,' at least some respondents did not consider this literally, and included cases where they had received the drug from illicit sources.

Among the 180 cognitive interviews, 17 errors were identified in NHIS question responses, and 10 errors were identified in NSDUH question responses. All other responses appeared accurate and were consistent with respondents' descriptions of their drug histories. The causes of error across the two questions differed and are related to the specific structure of each question.

For the NHIS question, most errors identified were false-negative reports, occurring from one of three error patterns related to an insufficient definition of the term 'opioid':

1) Several respondents did not realize their medication, specifically, Tylenol 3 and Tramadol, were opioids. These drugs were not included as examples, so respondents did not realize they should be counted; these respondents were surprised to discover from either the interviewer or the following NSDUH question that their medication was an opioid.
2) For a few respondents, the examples of drugs evoked a limited definition of what should be considered. For example, one respondent saw the question as asking about only opioids in pill form, so did not include a fentanyl patch. Another respondent believed the question was asking about "heavy duty" opioids and did not count Tramadol and Tylenol 3, which he saw as "borderline opioids." Another respondent did not include methadone which she was taking in

recovery; it was a medicine she was specifically taking to help her get off the drugs listed in the examples.

3) In terms of false-positive reports, only 2 cases of error were identified because respondents erroneously believed the medication they were taking, which is not listed as an example, is an opioid. For example, two respondents included Gabapentin, a drug used to treat seizures and neuropathic pain.

Finally, unrelated to the definition of the term 'opioid,' a few respondents had simply forgotten that they had taken an opioid months earlier. In several cases, respondents did not remember a previous injury or surgery that had occurred earlier in the 12-month span, and so did not think to report that opioid use. This recall error was identified when respondents were asked the NSDUH question, and their memory was prompted by various pictures and names of medication.

Because the NSDUH question lists all of the possible opioids, respondents were not required to know what counts as an opioid—only the name of their medication. Not knowing the name accounts for many of the 10 errors identified. In a few cases, for example, respondents could not remember the opioid prescribed to them after surgery. In another case, a respondent, who has an addiction problem and who has taken many kinds of opioids in the past year, could not recall everything: "When you're addicted to opiates, it doesn't really make that much of a difference … I mean, if you're dope sick, any of them are going to make you feel better." Finally, a few cases of error associated with the NSDUH question occurred because respondents reported taking Tylenol 3 when, in reality, it was regular Tylenol.

In the cognitive interview, if respondents answered 'no' to both opioid use questions, they were asked a final question about ever using a prescription pain reliever:

> *Have you ever, even once, used any prescription pain reliever? Remember, do not report your use of "over-the-counter" pain relievers such as aspirin, Tylenol, Advil, or Aleve. Yes/No*

Although it does not specify the term, all but one respondent understood the question to be asking specifically about opioids because of the context among other opioid questions. The one exception was a respondent who reported taking Lyrica and Celebrex years earlier, which are prescribed pain-relieving medicines, but not opioids.

For this 'ever in your life' question, nine cases of false-negative responses were identified, primarily because of recall difficulty and the fact that respondents did not think of themselves as opioid users. In their minds, they did not see themselves as a "pill person" or "the kind of person that uses opioids," and so did not carefully consider the question. In these cases, respondents had a surgery or an injury earlier in life that they did not think of until specifically asked.

Summary: In their overall performance, both questions about use perform similarly, capturing the same construct: opioid use in a 12-month period, with the NSDUH question also capturing information about the specific medication. The cognitive interviewing study relays a relatively clear picture of the ways in which each question produces false-negative and false-positive reports. Including the example of Tramadol in the NHIS question as well as clarifying that over-the-counter Tylenol is not Tylenol 3 in the NSDUH question, would improve the performance of each question, thereby producing more similar estimates of use.

Impairment

The impairment questions included in this study appear in the box below. The items are included for ongoing development of opioid-related items and are not associated with a particular survey. The first impairment question asks respondents to report any side effects of their opioid medication. Those who answer 'yes' to any of the symptoms receive the follow-up questions pertaining to impairment at work or while driving, and any injuries sustained due to opioid use. There were both intended and unintended interpretations of these questions, which sometimes led to response error. Each question is discussed separately below.

When taking opioids, do you feel any of the following side effects:
Drowsiness?
Dizziness?
Confusion?
Calm?
Carefree?
Lack of concentration?
Blurred vision?
Off balance?
Irrational?
Paranoid?

During the past 30 days, have you gone to work at a paid job while experiencing those side effects?
[If yes] How many times in the past 30 days, would you say this happened?

During the past 30 days, have you driven a car while experiencing those side effects?
[If yes] How many times in the past 30 days, would you say this happened?

During the past 30 days, have you had an injury or hurt yourself because of the opioids or the side effects?

When taking opioids, do you feel any of the following side effects…?

Intended interpretations

Some respondents understood the initial question about side effects as asking about unpleasant and unwanted symptoms they experienced when taking opioids. This interpretation is congruent with question intent and was common among respondents who took opioids for only a short time after medical procedures or temporary injuries. However, it was still difficult for some respondents in this group to answer the question because it was not easy to communicate the way opioids made them feel. The response strategy often employed was to answer 'yes' to many of the symptoms, even if those symptoms did not exactly match the way respondents felt.

Difficulty assessing and communicating symptoms: Respondents who had a difficult time matching their feeling states to the list of symptoms in the question often answered 'yes' to many side effects in an attempt to convey the nature of the problem. During probing, respondents were asked to describe in

their own words how they felt when taking opioids and their descriptions reveal their response difficulties. For example, one respondent said, "You don't feel…well. That's how I have to put it. There's something wrong, but you don't know what it is." Another respondent chose four side effects and made a similar comment. About taking Lortab after having a tooth pulled, he said, "I felt loopy…I felt 'off.' I wasn't myself."

The strategy of answering 'yes' to many side effects was often meant to convey the generally unpleasant feeling of being on opioids. One respondent talked about her fear of dying or having a heart attack when she took Tramadol. In trying to describe the side effects, she said she felt "weird." She went on to explain, "If I talked over the phone, I felt as if my tongue were tangled. And I might have said inconsistencies. So, people can notice when you are under the effects of a medication." She chose seven of the side effects. Another respondent took opioids for injuries sustained in a car accident and listed five side effects of his short-term use of Percocet. Some, such as dizziness and lack of balance, were especially concerning to him and his family. He said, "If I got up and walked around, it would make me really dizzy. [My wife] made me stay in bed [for safety reasons]." She was afraid he would trip and fall. Another respondent chose six side effects but admitted that she could relate to every symptom listed. She said, "When I have just taken the medication, I do feel all of those symptoms. That's why I don't take them as much. If it was up to the doctor I would always be sleeping. He tells me to take them very continuously, and I can't."

Many respondents expressed their unpleasant experiences in terms of compromised mental acuity. For example, one respondent chose four side effects from the list and explained how they were unpleasant. "Because I was really out of it. Like I would feel like I was dazed…I don't want to feel like that. I need to function. I need to know my surroundings, what's going on." Another respondent chose six side effects and also remarked how they affected his cognition in particular. "Yeah, I couldn't have a decent conversation. Because I wasn't thinking right. I'd have people call me on the phone and I'd tell them, 'Yeah, you know, I'm not up for it. Call me back in a few weeks.' Because I didn't know what I was going to say! I tried not to do any business or anything." One respondent who took them briefly after surgery listed six different side effects. She said, "That's why I hated taking it [because of all the side effects]." When asked to describe how she felt in her own words she referred to cognitive impairment and said, "First of all, I might not remember a conversation I had…and someone asks me a question, it would take me a minute to process it." She described this as "brain fog" and chose 'confusion' and 'lack of concentration' to represent that feeling. Another respondent said, "When I took the medication one after the other, I felt like I was in the clouds. I felt like I was walking but without stepping on the floor. I felt like I was not inside my body."

All the above respondents understood side effects according to the intent of the question. Their difficulty in answering stemmed from the inability to articulate the feelings and symptoms they experienced while on opioids. However, other respondents had different challenges with the question. Many who experienced the symptoms listed in this question could not always link them directly to the opioids. This made the question difficult to answer.

<u>Cause of side effects is unclear or unknown</u>: Some respondents had difficulty with this question because they could not conclusively identify the cause of the feeling states listed. In other words, feeling states can have different causes, and respondents were often unable to firmly establish a causal connection to opioids. Other causal factors identified by the respondents included age, personal characteristics or conditions, surgery, lack of sleep, chronic pain, or multiple medications.

- *Age*: Some respondents considered age when answering this question. One respondent admitted he was not sure about the extent to which it was Tylenol 3 or age that caused certain problems. He said, "Once in a while I have trouble hearing and seeing – blurred vision and like this. But I don't know if that's from, like, getting old or [the opioid]. I had cataract surgery about five years ago, so I don't know if that had anything to do with my age or the pills." He decided not to include 'blurred vision' because of his uncertainty. Another respondent who was uncertain about blurred vision did decide to include it. He said, "It happens every now and then. I guess my eyes are just getting weaker." While acknowledging that it could be due to age, he realized it also may be the opioid because he noticed it occurring sometimes after taking Lortab. One respondent listed 'confusion' but was not sure she could attribute it to the opioid. She said, "I'm having Alzheimer's. I'm getting old. It's normal."

- *Personal characteristics or other conditions*: Some respondents were not sure whether some of the side effects listed were opioid-induced or simply a personal characteristic or physical ailment. For example, one respondent chose 'calm' but said, "I'm pretty calm in general, so I don't know if that's a side effect." One respondent thought about 'off-balance' and said, "Sometimes I would be walking and I don't know if it was just me hopping along with one leg [and a cane] and being on the meds or what. But sometimes I would get kind of off-balance." Another chose 'off-balance' but expressed doubt about it being caused by opioids. She said, "Sometime I am. It *could* be because of the pain relievers." Another respondent chose 'paranoid,' however, she explained this was generally who she was. She said, "I did have a diagnosis of social agoraphobia. Because I wouldn't get out. It's a big problem. Just stay inside, paranoid." But she did not necessarily link this directly to the opioid she took. Another respondent who took Norco included 'off balance' in her answer but said, "I have been off-balance. But they say that's because of my blood pressure." Another respondent also thought of her blood pressure when she chose 'blurred vision.' She said, "I related that to my high blood pressure."

- *Surgery*: Respondents who had surgery could not always differentiate post-surgery side effects from those caused by the opioid. One respondent chose 'drowsy' and 'dizzy' but expressed doubts about their cause. He said, "I assumed those were kind of regular with after-surgery stuff. Or whether it could have been a side effect of that [opioid]? It's kind of hard to say."

- *Lack of sleep*: Some respondents thought lack of sleep (for example, due to pain or insomnia) was just as likely to cause drowsiness as the opioids they took. So, they were uncertain how to answer. For example, one respondent left it blank but explained, "I do get drowsy. But whether it's attributed to this [oxycodone] or not, I don't know. I'm sleepy a good deal of the time. Now whether it's this, I don't know." Another respondent chose 'drowsy' but expressed uncertainty of the cause. She said, "As I am always sleepy, I thought it was normal. I am always sleepy, weighed down with no energy to do things." Another respondent also marked 'drowsiness' but was not certain of the cause. She said, "Yes, but I'm not sure if it's because of the medication or because I am so tired of the pain. And when I take it, it relaxes me and I'm able to sleep."

- *Pain*: Respondents who dealt with chronic pain did not always know whether the symptoms listed in this question were caused by their experience with pain or by the pain reliever. One person chose 'confusion' but said, "I don't know if I was confused because of the pills or the pain."

- *Multiple medications*: Respondents on multiple medications often could not disentangle the side effects of each medication. One respondent who took three different medications (one of which was an opioid) talked about having blurred vision. She said, "I don't get sleepy. I don't get dizzy. But my vision is blurry a little bit." She explained that blurred vision is listed as a possible side-effect for every prescription she takes, so it was impossible to know whether blurred vision was caused by the opioid. She included it in her answer just in case.

The respondents discussed above either had difficulty expressing how opioids made them feel or they were uncertain that the way they felt was caused by opioids. Another group of respondents had difficulty with the question because they misinterpreted the concept of 'side effects' altogether.

Unintended interpretations

Side effects as positive: Not everyone understood the concept of 'side effects' as negative, in part because they had different experiences with opioids. Those who were long-term users (and possible misusers) of opioids often answered this question in terms of the feeling of normalcy they had while taking opioids. Conversely, it was when *not* taking opioids that they experienced unpleasant symptoms. As a result, some of the side effects listed in this question were perceived as positive, not negative feelings. Among respondents in this group, the feeling of 'calm' was often chosen, as was 'carefree.' For example, one respondent who was a long-term opioid user (over 10 years), chose both 'calm' and 'carefree' but said, "I just feel the way I always do. Normal." Another respondent chose 'calm' for similar reasons and said, "I just feel normal when I do it."

Other respondents acknowledged taking opioids not just to feel normal, but specifically to be able to function and be well. For example, one respondent chose 'calm' and said, "It seems like it gives me energy. It keeps me going. I can function more." Another respondent who said she struggled with addiction explained, "When you're on the hunt for it, you make yourself sick…and it gets to a point that you'll do anything to make sure you're not sick. When you have it, you're just relaxed. You're not worried about that. And you feel normal because you're not sick."

Side effects understood as therapeutic effects: The respondents above were at a point at which taking opioids had become a necessary condition for feeling normal or well. As a result, they did not understand side effects as something negative. Another group of respondents also did not understand side effects as negative, but for a different reason. This group struggled with chronic pain to such a large extent that they often understood the therapeutic effect of opioids as the side effect asked about in this question. Similar to the group above, this group often chose 'calm,' 'carefree,' and sometimes 'drowsy,' but they were specifically thinking about the relief they felt in the absence of pain. For example, one respondent who chose 'calm' and 'carefree' said, "I felt a burst of energy that actually helped me…I did not feel the pain." Another respondent said she answered calm "because the pain goes away temporarily. It calms the pain."

Suspecting that the question might be targeting abuse, some went out of their way to clarify that these feelings were not about "getting high." For example, one respondent chose all three and said, "It's not really like you're high. It's like you feel good because you're not hurting anymore. So it makes you feel good. You're calm, happy, you can do your job." Another respondent was also careful to clarify that 'calm' did not mean 'high.' She said, "I mean, I get happy, but not in what I assume they are feeling a high feeling. I just feel relief because I'm not in as much pain. Not high at all."

In fact, many respondents chose ‘calm,’ ‘carefree’ or ‘drowsy’ as a direct expression of the positive feeling associated with the (temporary) relief from chronic pain. One respondent who chose ‘drowsiness’ explained, “The pain already wore you out. And when the pain subsides because of the pain medication [exhales loudly], I’m going to take a nap. Because I’ve been struggling through all this discomfort and pain.” Another respondent had a similar perspective. He answered ‘drowsy’ and explained, “I would feel calm and was able to sleep. They would take the pain away and I used to feel relaxed.” Many respondents with chronic pain gave similar explanations:

> “You hurt and you take pain reliever – gonna give you that relief, and that makes me calm. Allows you to take a deep breath in.”
>
> “If my pain level had decreased, then I was certainly calmer. If my pain level decreased, I would potentially get drowsy because I was so tired in the first place.”
>
> “Just relaxed. Being in pain makes you tense. And when you’re out of pain it’s like a sigh.”
>
> “I would feel calm just as a result of the pain disappearing.”
>
> “It just calms me down and relaxes me. It’s a good thing if it can help me with my pain. It’s a good thing.”
>
> “Maybe a little calm. It’s calming to know when you are not in pain.”
>
> “As it alleviates pain, you sort of get calmer. More relaxed.”
>
> “As soon as the pain goes away, my mood changes. My bad temper goes away.”
>
> “Yes. Because they relieve the pain, I feel calm.”

Thinking about more than simple relief from pain, some respondents chose ‘calm’ or ‘carefree’ because the absence of pain allowed them to carry out their daily routines. One respondent said, “I don’t know. It makes me feel good. I can walk and go to the store. And I can, like, wash the dishes. I mean the pain is still there, but it [Vicodin] helps me a lot.” Another respondent chose ‘calm’ and ‘carefree’ and said, “It was being able to run with my kids and move again. Because when you are strapped in this much pain all the time, being carefree is not something you can be.” Another respondent chose ‘calm’ and said, “It keeps me going. I can function more. I can go out and do a little bit of gardening and do a little bit of things, whereas without it [codeine], I couldn’t. I can do more physical things.” Another said, “When I took the medication, the pain gradually decreased until I could not feel it. Of course, once the effect of the medication was over, I felt pain again. But I felt carefree when I was not in pain because I could walk normally again.”

Respondents who answered ‘yes’ to having any of the side effects were filtered into questions about impairment at work or while driving, and any injuries experienced as a result of taking opioids. These questions are discussed next.

During the past 30 days, have you gone to work at a paid job while experiencing those side effects?

This question and the next two were not thoroughly evaluated because they were not administered or tested on all respondents. Respondents either had not taken opioids in the past 30 days or reported having no side effects in the previous question. Additionally, some respondents were not employed. However, for those on which this question was tested, patterns emerged that were similar to the previous question. Some respondents understood the questions as intended, but others did not.

Intended interpretations

Some respondents answered according to the negative effect the opioids had on them and their ability to work. For example, one respondent answered 'no' and said, "I know that I will never take Tramadol when I have to go to work because I cannot drive feeling like that. I know what the effects of taking Tramadol are. And the other one [hydrocodone] just make me feel like throwing up." Another who answered 'yes' said:

> "I have to go to work with a headache, so I take the pills and go wherever I have to go. I have not stopped working, even if I am all drugged up and dizzy, I still have to go. Another effect that the medication has on me is that makes me very sleepy; it makes me dizzy, it blurs my sight, it knocks me down, and it makes me fall soundly asleep so, in the 10 to 15 minutes that I drive, I have fallen asleep."

Some took the medication at night in order to help mitigate these effects. One respondent explained:

> "When they gave me the headache medication, I would take it at night so the effects only last through the night, but it lasted all day. I would get up and I was still sleepy. And it wasn't just sleepiness, I used to feel disoriented, I just wanted to close my eyes and get lost. But I had to go to work, I had an office job and that didn't help either because I was always sitting down in front of a computer. So I would get up and start drinking ice cold water so I could stay awake."

Inability to determine causality: As established in the initial impairment question, some respondents could not determine causality – or at least had difficulty doing so. For example, one respondent answered 'yes' because he sometimes felt drowsy at his job. However, during probing he said he was not certain whether the drowsiness was caused by the pain reliever or by the fact that his job in landscaping was physically demanding to begin with.

Unintended interpretations

However, not all respondents understood the question as intended. Some were thinking about the effects that pain (not opioid side effects) had on their ability to do their job. For example, one respondent with mobility issues answered 'yes' but was thinking about the pain in her foot when she walks. She said, "I had to tell them [work] that I had impairment, because part of what I do [for work] involves a lot of walking." Even though the respondent reported feeling drowsy in the previous question, she was not thinking of that side effect here. Another respondent also thought of the back pain he experiences at work (lifting boxes) and answered 'yes.' However, were it not for the opioids, he would not be able to work at all.

Therapeutic opioid effect

As with the 'side effects' question, some respondents thought of the intended, therapeutic effect of the opioid and answered 'yes' because the relief from pain allowed them to work. One respondent said, "I'd do [the opioid] to stay at that level that I needed to function." Another answered 'yes' and said, "It's the only reason I'm able to go to work." Another respondent explained, "I would take this medicine and go to work every day at [company] as a technical writer. I didn't get high, I just functioned…I don't experience side effects, I just function better. I can sit down easier. I can bend my knees."

During the past 30 days, have you driven a car while experiencing those side effects?

This question was also not thoroughly evaluated because it was not administered or tested on all respondents. Respondents either had not taken opioids in the past 30 days, did not drive, or reported having no side effects in the initial impairment question. However, for those on which it was tested, patterns similar to the previous question were found; specifically, some respondents were uncertain whether the opioid caused the problematic side effect and others thought of the intended effect of the opioid.

Inability to determine causality

As with other questions, some respondents could not easily establish causality. For example, one respondent sometimes had difficulty driving but was unsure whether it was due to her cataracts or to the opioid. She answered 'yes' and said, "I was driving to go to a meeting and it's not far from home…and I felt like is it the pill [hydrocodone] or is it the cataracts? It wasn't completely dark yet…I was feeling strange." Another respondent thought about it and decided to answer 'no.' She said, "No…I was trying to remember. I mean, I have been drowsy and drove, but not because of the medication…It's just lack of sleep. Because I've taken them and I've never had any accidents or anything like that."

Therapeutic opioid effect

Similar to the question on work, some respondents thought of the intended effect of the opioid and answered 'yes' because the relief from pain allowed them to function and drive a car. In other words, these respondents answered 'yes' because they were on opioids daily for pain management and would not otherwise be able to function normally. In essence they interpreted the question as whether or not they took opioids and then drove normally (not impaired). For example, one respondent answered 'yes' because she was thinking about being on the opioid and driving – but this was not about side effects. She explained, "It's not like I'm going to work because I'm high…or I can't drive or can't focus or anything like that – blurred vision while I'm driving, no." She takes opioids daily in order to manage chronic pain. This allows her to drive and go to work. Similarly, another respondent answered 'yes' because she is on opioids while driving. However, during probing she clarified, "No, I don't experience any side effects." Another respondent discussed how the opioids help her to drive every day because they control her pain. "Throughout the entire month my pain has been either mild or very strong so, sometimes I take one Vicodin sometimes I take two." She answered 'yes' not because she experiences negative side effects, but because she can drive only when not in pain.

During the past 30 days, have you had an injury or hurt yourself because of the opioids or the side effects?

This question was also not adequately evaluated because it was not administered or tested on all respondents. Respondents either had not taken opioids in the past 30 days or reported having no side effects in the initial impairment question. However, for those on which it was tested, some understood the intent and were thinking about mishaps caused specifically by the opioid. For example, one respondent answered 'yes' and explained, "It was one day in the evening, I took the medication but had not eaten anything before, so I needed to use the restroom and when I got there I hit my head with the wall, I got dizzy, it was as if the floor had shifted." Even those who answered 'no' demonstrated a similar understanding. When one respondent was asked the intent of that question he said, "That if I had gotten hurt because I felt dizzy or something and I got hurt. They don't have many side effects. They take the pain away but they don't have side effects. Perhaps because I have taken pills my whole life, I am immune."

However, as with the previous questions, causation is still a potential problem. Some respondents were uncertain whether the opioid caused the problematic side effect. For example, one respondent leaned toward answering 'yes' but ultimately could not decide. He thought of a bathroom fall he experienced but attributed it more to his condition and pain than to the opioid. He said, "It was not because of the medicine but because of what I would take them for." He found it too confusing to provide an answer. Another respondent with opioid disorder issues answered 'no' but had to think it through. Because the injury was caused literally by using a dirty needle to inject opioids, he did not attribute it directly to the opioids.

Opioid Misuse

The NSDUH opioid misuse question was examined in this study appears and appears in the box below.

> *The next question asks about using prescription pain relievers in any way a doctor did not direct you to use them. When you answer these questions, please think only about your use of the drug in any way a doctor did not direct you to use it, including:*
>
> - *Using it without a prescription of your own*
> - *Using it in greater amounts, more often, or longer than you were told to take it*
> - *Using it in any other way a doctor did not direct you to use it*
>
> *Have you ever, even once, used any prescription pain reliever in any way a doctor did not direct you to use it? Yes/No*

Its length and multiple components made the question challenging to administer in the face-to-face interview; many respondents asked for the question to be repeated. In the end, respondents approached the question in one of two ways: 1) by addressing individual components of the question or, 2) as a single question, specifically asking "Do you abuse opioids?"

Multiple-Part Question

In formulating their answers, approximately half of the respondents processed the question in its multiple parts, considering their own behavior as it relates to the actions in question. For these respondents, the question captures the following aspects of misuse:

Taking more pills than prescribed*:* When answering the question, some respondents reported taking more pills or within a shorter time period than was prescribed. For example, one respondent answered 'yes' because, in 2017, when prescribed Percocet for wisdom teeth extraction, he took the medication every two hours as opposed to the three to four hours; since he used more frequently, he also took more pills than was prescribed.

Taking someone else's medication*:* Some respondents also reported using others' opioid medication. Typically, this involved taking a spouse's or friend's leftover prescribed medication.

Taking medication for another purpose*:* In some cases, respondents reported using their own leftover medication for another reason. Primarily, respondents described using the remaining medication for another pain episode. In one case, however, a respondent described a time when she took leftover opioid medication for sleep:

> When I was in the hospital the nurse would tell me 'This is for the pain and for you to be able to sleep.' So, I knew it would make me fall asleep and I took it. I took at least twice.

Purchasing opioids off the street: Finally, a number or respondents reported answering 'yes' because they had bought opioids off the street, without a prescription and outside the medical system:

> "Yes, I have because I've bought them off the street before."
> "When he [the doctor] quit prescribing it, I started buying illegally."

Of note, there were two cases in which respondents answered 'yes' outside of these primary reasons: One respondent answered 'yes' because she was forced by an ex-boyfriend to take 4 tablets of Percocet as a date-rape drug. Another respondent answered 'yes,' not because she had misused opioids herself, but because she once sold her left-over Percocet prescribed for a broken collar bone.

There were a few people who answered 'yes' to the question because they had taken less medicine than was prescribed; they had taken the question literally as it states '*in any way a doctor did not direct you to use it*. For example, one respondent answered yes, explaining, "I took less then he [the dentist] said to take." Even after the interviewer repeated the question to insure there was no misunderstanding, he reasserted, "I would say yes, because I didn't take it every 8 hours or whatever it says."

Single Question: 'Do you abuse opioids?'

Rather than considering its various parts, many other respondents understood the question holistically, as a single yes/no question, specifically, 'do you abuse opioids?' As a result, these respondents based their answer on a single characteristic: whether or not they saw themselves as opioid abusers. "I never abused anything pharmaceutical!" one respondent answered. Similarly, when asked the point of the question, another respondent explained, "I guess they want to know if you're a drug addict…just to get yourself high…" For these respondents, providing an answer required little recall or calculation. Their answer was simply based on a pre-existing understanding, solidified by their knowledge of the opioid crisis, the problems of opioid addiction and their relationship to the epidemic.

Those answering 'yes,' invariably understood themselves as abusers or addicts—past or present. For some, the question served as an invitation to relay their history of addiction. For example, one respondent answered:

> I've done all those things…. I was my own pharmacist…. I don't recommend it…. I just had a drug and alcohol filled lifestyle at the time…alcohol, cocaine, prescription drugs… [When I was first prescribed valium and codeine 40 years ago, I thought] this is really wonderful…an unrealistic euphoria… [The doctor] was naïve and just kept giving me prescriptions when I asked.

In contrast, those who did not see themselves as abusers often followed up with evidence to support their answer of 'no.' For example, one woman explained:

> Because I don't like feeling under the influence of anything. And I've been prescribed opioids many times. But because I don't like the way they feel, I usually cut the use before it's even time. I may have 10, 12 days' worth and I might go 2 days.

Importantly, unlike the previous group, these respondents did not base their answer on whether or not they 1) took more pills than prescribed, 2) took someone else's medication, 3) used their opioids for another purpose, or 4) bought opioids off the street. Their answer was solely based on their understanding of self as abusing. For example, immediately after being read the question, one respondent asked, "Have I ever abused it? No."—and then, moments later when discussing his actual experiences, described occasionally taking his wife's Tylenol 3 for headaches.

In fact, of the 97 'no' responses, 7 were identified as false-negative reports. That is, although they answered 'no' to the question, when discussing their experiences in the follow-up conversation, respondents described engaging in misuse. When asked about this contradiction, respondents provided various justifications or rationalizations as to why this behavior would not count. For example, one respondent explained that she did not count "doubling up on the medication" because it was not "any time recently." Another respondent, who is a rock climber and typically keeps left over pills for future injuries, explained that this is not really 'misuse' because "I used them in a way a doctor directed me to use it." Even though he is not using the pills for the reason they were prescribed, he uses them in a "similar manner" to the prescription. Another respondent explained that, although it was not his true doctor, his daughter—who happens to be a nurse practitioner—told him he could take tramadol for back pain even though it was prescribed to him months earlier for a hematoma. Yet another respondent explained that he manages his overuse by taking less the next day. Because he is "in control," he answered 'no.'

Many respondents who dismissed the question as one about abuse were long-term opioid users under a doctor's care. These respondents saw themselves as 'responsible opioid users,' succinctly disassociating themselves from 'reckless opioid users' who "give opioids a bad name." Such an understanding prompted respondents to answer 'no' with little hesitation. However, when asked directly if they have ever taken more pills than what was prescribed, multiple respondents acknowledged that indeed they had done so because their pain had become so intolerable. These conversations invariably turned into discussions of the difficulty respondents have in managing their pain with the number of pills they have for the month, that is, until their next prescription comes through. After discussing the problem of running out, some respondents divulged even more incidents of misuse. For example, when asked if

there was ever a time that he ran out of pills, one respondent exclaimed, "Go a day without them?! I can't go a day without them!" Then, when asked how he knew that he could not go without and, again, asked if he has ever run out, he admitted, "Okay, it just so happens that my wife is taking the same kind. So, I'll borrow one from her if I do run out." As was the case of this respondent, the below excerpt of a transcript illustrates how, with just a change in the line of questioning, a respondent can abruptly shift from describing themselves as a 'responsible opioid user' to the acknowledgment of misuse behavior:

Respondent:	No. I just take them the way he [the doctor] prescribed them.
Interviewer:	Have you ever been in a situation when the pain was really bad, and you needed to take a pill sooner than was prescribed?
Respondent:	Yes.
Interviewer:	So, was there ever a time, even once, that if the pain was really bad that you would take more?
Respondent:	Sometimes I would.
Interviewer:	So how does that work out?
Respondent:	I just need to take it sooner if it is bad.
Interviewer:	So, if the prescription was to take one every 6 hours, was there a time that you would take it every 4 hours?
Respondent:	[nods to indicated 'yes']
Interviewer:	So, what would happen at the end of the day? Would you run out?
Respondent:	One time I did.
Interviewer:	So, what happened with that?
Respondent:	I took too many. (He chuckles.)
Interviewer:	OK.
Respondent:	So, then I went out on the street to get it.
Interviewer:	Oh really? You had to go out onto the street?
Respondent:	Yes. I had to purchase about 5. They were expensive.

It should be noted, as these examples suggest, that while some respondents might initially dismiss the question, when asked direct questions about their experiences, they do acknowledge misusing. That is, when the question is understood as asking about specific experiences as opposed to a general question easily understood as one about abuse, respondents may candidly reflect and report misuse. This is not to say that this type of question design will solve the problem of false-negative reports of misuse, though it will likely mediate the problem. It is very possible that there were more cases of false-negative responses among the cognitive interviews that were not identified—after all, these revelations only came about with careful interviewing, by pointing out contradictions and making respondents feel safe enough to reveal their inconsistencies. It is not clear if this can be entirely recreated in the format of a survey interview.

Opioid Disorder

Questions pertaining to opioid use disorder are taken from the NSDUH. They are adaptations of the Diagnostic and Statistical Manual, 4th edition (DSM-IV) definition of substance abuse and dependence. The NSDUH disorder survey questions have been validated against the Structured Clinical Interview for

DSM-IV among respondents recruited from substance abuse treatment programs.[3] To our knowledge, this is the first time that such questions have been examined within the context of a population-based survey interview. This is an extensive battery of questions that includes the following:

1. *During the past 12 months, was there a month or more when you spent a lot of your time getting or using prescription pain relievers?*

2. *During the past 12 months, was there a month or more when you spent a lot of your time getting over the effects of the prescription pain relievers you used?*

3. *During the past 12 months, did you try to set limits on how often or how much prescription pain relievers you would use?*
   [If yes] Were you able to keep to the limits you set, or did you often use prescription pain relievers more than you intended to?

4. *During the past 12 months, did you need to use more prescription pain relievers than you used to in order to get the effect you wanted?*

5. *During the past 12 months, did you notice that using the same amount of prescription pain relievers had less effect on you than it used to?*

6. *During the past 12 months, did you want to or try to cut down or stop using prescription pain relievers?*

7. *During the past 12 months, were you able to cut down or stop using prescription pain relievers every time you wanted to or tried to?*

8. *During the past 12 months, did you cut down or stop using prescription pain relievers at least one time?*

9. *Please look at the symptoms listed below:*
   [Feeling kind of blue or down • Vomiting or feeling nauseous • Having cramps or muscle aches • Having teary eyes or a runny nose • Feeling sweaty, having enlarged eye pupils, or having body hair standing up on your skin • Having diarrhea • Yawning • Having a fever • Having trouble sleeping]
   During the past 12 months, did you have 3 or more of these symptoms after you cut back or stopped using prescription pain relievers?

10. *During the past 12 months, did you have 3 or more of these symptoms at the same time that lasted for longer than a day after you cut back or stopped using prescription pain relievers?*

11. *During the past 12 months, did you have any problems with your emotions, nerves, or mental health that were probably caused or made worse by your use of prescription pain relievers?*

[3] Jordan, K., Karg, R., Batts, K., Epstein, J., and Wiesen, C. (2008) "A Clinical Validation of the National Survey on Drug Use and Health Assessment of Substance Use Disorders." *Addictive Behaviors*, 33; 782-798.

[If yes] Did you continue to use prescription pain relievers even though you thought this was causing you to have problems with your emotions, nerves, or mental health?

12. *During the past 12 months, did you have any physical health problems that were probably caused or made worse by your use of prescription pain relievers?*
    [If yes] Did you continue to use prescription pain relievers even though you thought this was causing you to have physical problems?

13. *This question is about important activities such as working, going to school, taking care of children, doing fun things such as hobbies and sports, and spending time with friends and family. During the past 12 months, did using prescription pain relievers cause you to give up or spend less time doing these types of important activities?*

14. *Sometimes people who use prescription pain relievers have serious problems at home, work or school — such as: • neglecting their children • missing work or school • doing a poor job at work or school • losing a job or dropping out of school. During the past 12 months, did using prescription pain relievers cause you to have serious problems like this either at home, work, or school?*

15. *During the past 12 months, did you regularly use prescription pain relievers and then do something where using prescription pain relievers might have put you in physical danger?*

16. *During the past 12 months, did using prescription pain relievers cause you to do things that repeatedly got you in trouble with the law?*

17. *During the past 12 months, did you have any problems with family or friends that were probably caused by your use of prescription pain relievers?*
    [If yes] Did you continue to use prescription pain relievers even though you thought this caused problems with family or friends?

Everyone who reported using opioids received the disorder items. Personal experience with opioids framed respondents' understandings of these questions. This often resulted in respondent difficulty, confusion over question intent, or outright response error. A pervasive theme among this set of questions was the extent to which respondents came to understand them as attempting to assess whether they were addicted to opioids. In these cases, respondents did not necessarily consider each question as a unique item, but rather as another way of asking whether they had any problems with addiction. Moreover, these patterns tended to emerge and solidify as the questions proceeded. In other words, there was a strong context effect such that each additional question in the disorder series contributed to the notion that addiction was the underlying construct for all the questions. While the first few questions were often taken and evaluated at "face value" by respondents, this was less likely to be the case for questions that came later.

Though interpretations converged on the singular concept of addiction, responses to the questions differed according to respondents' experiences with opioids and understandings of their own behavior vis-à-vis opioid use. For example, respondents who recognized themselves as addicted easily and without hesitation answered 'yes' to many of the disorder questions, as the topics directly resonated with

and reflected their personal experiences. In explaining their answers, they typically described the downsides of addiction and struggles to overcome it.

On the other hand, respondents who were long-term opioid users but who did *not* identify themselves as having an addiction problem often answered 'no' to many of the disorder questions. This group had what they described as doctor-prescribed opioids which they used for legitimate purposes, usually incurable chronic pain. To them, addiction was seen as either drug abuse or recreational use (such as "getting high"), and while they may have literally experienced some of the factors in the disorder questions, they did not see their experience as aligning with the intent of the disorder questions. Often this meant that long-term users answered 'no' to many of the questions, even when the literal answer was 'yes.' Some did answer 'yes,' but indicated reluctance with that answer and sought clarification because they did not want to incorrectly imply that they were addicted.

In sum, long-term opioid users classified themselves as either 1) addicted or 2) legitimate, non-addicted users, and both groups interpreted the disorder questions as assessing addiction. However, answers between these two groups varied because how they understood and defined their behavior varied. That is, even when the disorder questions were interpreted in a consistent manner, answers had inconsistent meanings, depending upon personal experience.

Finally, some respondents with only short-term, finite experiences with opioids (for example, after an injury or surgery) on occasion answered 'yes' to many of the disorder questions. These were respondents who had heard of the opioid epidemic and had a great deal of worry about addiction, even when their exposure to opioids was minimal and short-lived. To this extent, these are cases of false-positive responses.

These patterns have implications for how the disorder questions may function and the information they may capture in household surveys. In this study, the questions performed best among those who already thought of themselves as having opioid use disorder; there was little difficulty, confusion, or response error demonstrated by this group. This finding aligns with results from a NSDUH clinical validation study conducted among respondents who were recruited from community and outpatient substance abuse treatment programs (Jordan et al., 2008). However, the questions did *not* elicit the intended responses from long-term opioid users who defined their use of opioids as legitimate and did not see themselves as addicted. Nor did the questions elicit intended responses from short-term opioid users who were inordinately worried about becoming addicted. These findings suggest that the disorder questions tested here will not perform on general population household surveys in a manner similar to that of samples drawn from substance abuse treatment programs.

> *During the past 12 months, was there a month or more when you spent a lot of your time getting or using prescription pain relievers?*

As the first question in the disorder series, respondents were more likely to evaluate this question on its own terms rather than to immediately assume it was about opioid addiction. This produced various interpretations and difficulties. One difficulty was the double-barreled nature of the question. Because it incorporates two activities (time spent getting and time spent using) and requires only one answer, this created some difficulties. A second difficulty related to what substances/medications to include.

However, despite the fact that many respondents did not yet perceive addiction as part of the underlying construct in this series of questions, there were respondents who absolutely did. Rationales for their answers were clear indications of whether they judged themselves to have any addiction problems.

Problems Associated with the Double-Barreled Phrasing

Focus on Only One Activity (Getting vs. Using): Because time spent getting and time spent using are different activities, some respondents focused on one or the other. Respondents often focused on the activity that applied directly to them but pointed out the difficulty in responding to two questions with only one answer. For example, one respondent, upon hearing the question said, "I haven't been trying to get them, but I've been using them." When pressed for how he might respond to the survey question, he had difficulty committing to an answer. He said the problem was that the question was "like asking two separate questions. Did I have a lot of trouble getting them? No. As far as using them? Yes. It's like two different questions." He decided to answer on the basis of the concept that applied to him (using) and chose 'yes.' Another respondent who decided to answer 'yes' also expressed difficulty with the two concepts. She said, "Getting or using. I would say the using part. Yeah. I mean, I didn't spend a whole lot of time getting them because the doctor gave them to me before I left the hospital. But I DID spend time using them. Because I was in pain. And I had major brain surgery." Another respondent who answered 'yes' said, "Time getting? No. I'd get a decent amount so I wouldn't have to worry about getting them…Time using? Yes."

- *Time Spent Getting*: Some respondents focused on the word "getting" and answered on that basis. However, opioids can be "gotten" legally and illegally, and respondents thought of both.

  Legal Acquisition: Some respondents thought the question referred to time spent picking up prescriptions. For example, a respondent who answered 'no' explained, "Did I spend a lot of time or an excessive amount of time trying to get my prescription? No, I just went to Walmart to pick my prescription up." Another respondent who answered 'no' was also thinking about his time spent getting opioids. He said, "Well, when you say 'a lot,' I just get it once a month. So, I'm thinking did I make any extra trips?" He had not, and answered 'no.' Others had similar interpretations:

  > "They are asking if I struggled to get the medication, and no. When the doctor prescribed it I got it right away. And since there were no refills, if I needed more I just had to go back and ask him."
  >
  > "At that time I only had Medicaid, which is Welfare and sometimes I wouldn't get the card and I would have trouble getting my refill, but not so much, so no."
  >
  > "I just went to the drug counter [at the pharmacy] and got it. There were no issues."

  Illegal Acquisition: Other respondents thought the question was about the amount of time they spent acquiring opioids illegally. One respondent answered 'yes' and said, "Sometimes. Whenever I run out [of the prescription], I have to go out and look for some to buy on the street." Another answered 'yes' and said, "When they have run out, I have had to go find someone to sell me some. Sometimes there isn't someone close by and I have to be up and down looking for someone."

  Other respondents answered 'no' because even though they understood the question to be asking about illegal acquisition, they got their opioids legally. One respondent said, "It says 'getting,' meaning that I was self-medicating, and I wasn't." Another said, "I think they are asking if I try to get the medication on my own in an inappropriate way." Another answered 'no' and said he

thought the question was asking "If I bought the medication without a prescription, secretly, and if I struggled to get them." Another respondent explained:

> "I understand that maybe if I don't have the prescription and I need to buy more, I want them, or my body needs to take something to feel good... That is how I understand the question. And no, because I have not taken the medication other than when the doctor has prescribed them, and I haven't had the need to look for more."

- *Time Spent Using*: Other respondents focused on the word "using" and answered on that basis. For example, one respondent thought about how often he used opioids in relation to the frequency of his pain. He said, "It would depend on my pain level at the time. How long I had the pain level. If I had more pain, I would spend more time [using]." Another respondent said, "Yes, because of the medication I was prescribed for my dental. That's how I understood it [the question]. Was there any time that I was using prescription pain medication…because the doctor kind of left it like, you take it when you need it."

  One respondent who answered on the basis of "using" wondered if the question was trying to get at addiction. Even though he did not see himself as addicted, he answered yes, thinking about his daily use of opioids to avoid chronic pain. He felt the need to clarify his response and said, "I'd say 'yes' because I take them all the time. I can't live without them. I don't know if that's addiction. I'm 'addicted' because I want to keep from getting in extreme pain!" While this respondent hinted at the fact that the question could be getting at addiction (which he did not identify with) he ultimately chose to answer on the basis of how frequently he used opioids. Others, however, did think the question was designed specifically to capture addiction. This group answered differently and is discussed next.

Question Interpretation: Pain Relievers in General or Any Prescription Medication

While not a dominant pattern, several respondents who had not yet associated opioid addiction with this series of questions included a variety of substances (not just opioids) in their answers. A few respondents lost sight of the phrase 'prescription pain relivers' and answered for either pain relievers in general (including over-the-counter (OTC) pain medication, such as Ibuprofen and Acetaminophen), or prescription medication in general. For example, upon probing one respondent commented, "I thought that it was asking about my regular meds [for various ailments]."

Question is about Addiction: For some respondents the question was not double-barreled or confusing because they immediately saw it as asking about opioid addiction. In these cases, their answers reflected whether or not they judged themselves to have this kind of problem with opioids. One respondent who was a long-term opioid user was at first unsure how to answer. When asked what she thought it meant, she said, "Someone without a prescription. Someone who is spending a lot of time figuring out how to get their next pills." Even though she had been on opioids for 12 years, she answered 'no' because she had a prescription, used opioids "legitimately" for chronic pain, and did not see herself as addicted. In fact, unlike the respondent discussed above, many people who used opioids daily, but did not see themselves as addicted, answered 'no' to this question. The following are examples of their initial reactions:

> "I never do nothing more than what I'm prescribed."
> "I did use it as prescribed."

"I just take them the way I'm supposed to."

"No. Like I said, I don't do anything illegal, you know what I'm saying?"

Other respondents who answered 'no' explained their answer in terms of defining what question was asking:

"Have I been using prescription drugs for the past 12 months – or over-using. Going out of my way to get them."

"If someone is getting out of control and using it more than they used to."

"If I'm getting more pills just for a kick or getting high or something like that. So, no. I don't abuse pills."

"Have you used a lot of pills in the past 12 months that you shouldn't have or in a different way."

"As if you were addicted to the medication. As if you cannot be without the medication, you cannot put up with the pain. I have heard of people that do suffer from that; they need their medication, but it is not my case."

"I understand that maybe if I don't have the prescription and I need to buy more, I want them, or my body needs to take something to feel good... That is how I understand the question. And no, because I have not taken the medication other than when the doctor has prescribed them, and I haven't had the need to look for more."

Some respondents acknowledged contradictions between their answer and their behavior and offered explanations for this inconsistency. For example, one respondent did not see himself as having an addiction but did acknowledge that he needed opioids (by prescription) every day. He answered 'yes' but wanted to clarify that he was not an abuser of opioids. He said, "It wasn't because I was trying to get high. I'm not buying them off the street from friends. I don't do that at all. I've seen too much bad stuff happens to friends to mess around with that stuff." Another respondent answered 'no' even though she bought and used opioids illegally for some portion of the past 12 months before she went into treatment for addiction. She explained, "Not for the methadone, but I did for everything else. Like every day was a hunt-and-find. If I made $100, I spent $90 on pills. It was bad." She answered 'no' because she was currently taking methadone as a way to combat opioid addiction and was no longer engaging in illegal behavior because of it.

During the past 12 months, was there a month or more when you spent a lot of your time getting over the effects of the prescription pain relievers you used?

For respondents who did not immediately draw the conclusion that the questions were asking about addiction, the intent of this question was not clear. This was demonstrated largely through the term 'effects.' Respondents were often confused by it or had different understandings of it. However, some respondents did begin to intuit a pattern and understood this to be asking about addiction. And finally, the question was difficult for some long-term users because it assumes they stopped opioids for a month or more.

The Term 'Effects' is Unclear

Some expressed outright confusion about the meaning of the term, "effects." For example, one respondent asked for clarification on this point. She said, "I don't know. Do you mean did I have a bad reaction or something to it? No." Other expressions of confusion included: "You mean after-effects, like that?" and "Like side effects? I don't get side effects." One respondent initially answered 'no' but during probing revealed some confusion. He asked, "Does that mean getting better? Or any side effects? If the effects of the pain reliever is relieving my pain and if that's what they mean, then 'yes.' But if it meant any bad effects, 'no.'" Another respondent who was not certain how to answer explained, "I don't feel weird. When I take it, I don't feel nervous or nothing. I feel the same way – I feel normal, watching TV, talking to my grandson or daughter."

However, some respondents had no trouble interpreting the question as asking about side effects they experienced while taking opioids, such as feeling calm, drowsy, or feeling a rush. For example, one respondent answered 'no' and said, "They don't have too many side effects."
On the other end of the continuum, some thought of the therapeutic effect of the opioids. When asked what he thought the question was asking, one respondent said, "If the medicine I'm taking takes long to help me recover. Generally, when I'm taking meds it takes me three to four days, a maximum of a week to get better. It's asking if it takes me very long to feel better."

Question is about Addiction or Withdrawal. Some respondents saw this question as asking if they had been (or were) addicted to prescription pain relievers. Respondents who said they had an addiction understood 'effects' as withdrawal symptoms and answered 'yes.' One respondent said, "The first week [after stopping] really sucked…Everything was spinning." Another respondent also interpreted 'effects' as withdrawal symptoms. She described the process of quitting opioids. "It was like a week I tried to ween myself off, and I would have a nauseous feeling and a fever and night sweats."

Some respondents answered on the basis of the withdrawal symptoms they experienced, not from attempts at quitting opioids, but when they ran out of their prescription early. One respondent said, "Every month when I…run out or quit for a day or so…well [the effects] are physical. It's just kind of like you don't have any energy. You're sleepy. You're just tired." Another said, "Oh, yeah. When you're out – take them all early. Like I said, I get them a 30-day supply. And if I take them in the first two weeks, then I'm two weeks going through hot and cold sweats, waking up in the middle of the night soaking wet, you know what I mean?"

Respondents who did not identify as having any addiction problems also saw this question as asking about misuse, addiction, or withdrawal. One respondent explained what she thought the question was asking. "If I am an addict, if I use it to self-medicate." One respondent said, "They don't get me high other than relieve my pain, that makes me feel better." One respondent answered 'no' and explained his experience after his morphine prescription ran out. He said, "Not once did I ever feel…I don't know what withdrawals are like. Not once did I feel anything except an increase in pain." Other respondents drew similar conclusions about question intent and addiction. One respondent answered 'no' and said the question was asking "whether or not I was having side effects or withdrawal symptoms." Another said, "I wouldn't say that. I wasn't hooked." One respondent said, "No, I didn't take them that long. Just a couple days." When asked what he thought the question was about, he said, "Someone who is taking them regularly. Withdrawal or something." This is similar to another respondent who answered

'no' and said, "This is like for people who are drug addicts. I don't think of myself as a drug addict. I think of myself as an old lady in a lot of pain [laugh]."

Question Makes a False Assumption. For some long-term opioid users, this question made the false assumption that they had stopped using prescription pain relievers at some point in the past 12 months. They answered 'no' to convey that they had never stopped taking the opioid. In other words, 'no' did not mean that they stopped and had no effects to get over; it meant that they never stopped. For example, when asked why one respondent answered 'no' he said, "Because it's an everyday thing." There was never a time he had to get over the effects of opioids because he had never stopped taking them.

Significantly, there were some respondents who described themselves as having an opioid addiction but still answered 'no' because they never stopped using opioids. One person said, "No. I was always afraid to do without them. Because I knew I'd be sick. I didn't feel good. My muscles would ache. So, I was always trying to keep one step ahead so I didn't go through that." Another respondent said, "No, because I have always been able to find the pills. I haven't been more than one night without the pills, so I never get sick because I always find them." This is an important distinction between types of experiences. An answer of 'no' because of on-going, consistent use means something very different from an answer of 'no' because use was brief and consequently without after-effects.

> *During the past 12 months, did you try to set limits on how often or how much prescription pain relievers you would use?*

The intent of this question is unclear because reasons for setting limits are integral for deciding how to answer. Respondents answered with different rationales. For some, the theme of addiction began to coalesce in this question. However, others did not yet connect question intent to addiction assessment. This group had different (potentially problematic) understandings of the question. Both patterns are discussed next.

Setting Limits to Minimize Addiction

Many respondents saw this as a question about addiction. Those who understood the question as asking whether they were addicted and who did not see themselves as addicted answered 'no.' This included both short-term and long-term users. One respondent said, "No, I didn't have no addiction problems, praise the Lord." Another said, "I don't have no issue. I don't have no problem. I take it for what I need it." Another said, "I don't…I just use it like the doctor tells me." Another respondent gave a similar answer. "No, I take only what the doctor said. I follow the instructions to the very detail." One respondent described the question as asking whether she "set a schedule to not get an addiction." Some long-term users answered 'no' because their chronic pain made opioid use necessary. Many described needing prescription pain relievers in order to function. One respondent said, "I take it for what I need it. It's just like with any drug. I don't see how it gets to the point of abuse." Another answered 'no' and explained, "If I take them regularly, I don't get extreme pain." Similarly, another said, "I usually make sure I take one a day. It does relieve the pain."

On the other hand, those who saw themselves as addicted often answered 'yes.' One respondent said, "Yes, a thousand times. But it don't work." Another said, "I tried that, but it didn't work." And another said, "I have always tried it but I cannot make it, my addiction is stronger." One respondent explained

the process of coming up short when trying to set limits. “I’m always trying to use every six hours. But I count and I think, ‘I got plenty, I can just take one now.’ Another four hours goes by, ‘I got enough, I’ll take another one.’ I guess it’s psychological.” This respondent often ran out early of the 30-day supply. Another respondent discussed a similar process with his addiction struggles. “I try to monitor it, you know what I mean? Tell myself I’m not gonna…take this or I’m not gonna take that. I’m going to take three instead of six. And it works for a minute, but you still go back to the same thing. You know, your addictive personality comes out in you, and it is what it is.” Another with a similar experience said, “I would break the pill in half and I would take only half, but I would take the other half 15 to 30 minutes later. It just didn’t work.”

Set Limits to Avoid Addiction

Not all answers of ‘yes’ reflect attempts to control actual addiction or disorder. Reasons for setting limits were often out of concern over the *possibility* of addiction. This was demonstrated among both short-term and long-term users. They answered ‘yes’ because they worried about becoming addicted and were trying to avoid that problem by setting limits. For example, one respondent with chronic pain was worried about addiction. He said he cut back “knowing that pain killers are addictive. I wanted to safeguard myself a little bit. I don’t think there’s any chance I’m addicted to it.” Because he was on opioids for 10 years, the interviewer asked how he knew he wasn’t addicted. He related it to tolerance. “I would not be getting as much relief as I have been with the same medicine – or working as well. If I was tempted to have another one to make up for it, I know that’s a warning sign.” Another said, "When I told you that I wanted to take less medication than they were giving me because I was feeling like I was becoming codependent on the medication. Instead of taking it every eight hours, I only take them at night."

Worry over the possibility of addiction for short-term users was often precipitated by what respondents had seen or heard about the opioid epidemic. For example, one short-term user answered ‘yes.’ When asked why she said, “I wanted to make sure I didn’t get addicted. Just because when it comes to opiates, you hear about the epidemic everywhere and basically everyone has the slightest chance, with taking extra milligrams or whatever, and stuff like that.” One respondent had significant pain but avoided taking his Tramadol as much as possible. He said, “I would quit taking them regularly and try to skip the regular [dose].” When asked why he did that he explained it was from “reading in the newspaper the effects of opioids and such as that.” Others heard about concerns from family. One respondent with knee problems was taking as little Hydrocodone as possible. When asked why she said, “Basically after my mom told me you cannot drive with being on these meds. And she was afraid I would become addicted to it. So, she was like, ‘You’re doing good [with pain], let’s try to cut back.’ Because I’ve heard so much about the opioid epidemic, I’m not trying to be hooked on anything.” Another respondent was careful due to information from her healthcare providers. When asked why she answered ‘yes’ she said, “Because I learned from the nurses that Tylenol is dangerous in certain doses. So, I always was mindful of how much I was taking every day. And in terms of the oxy [OxyContin], you can only take it every so many hours, so I was mindful of that.” Another respondent had worries because of her physician’s warnings. She answered ‘yes’ and said, “The doctor explained to us the potential side effects of the medication, including becoming addicted to the medication. It scared us, so as soon as I did not feel the pain anymore, I stopped taking the painkillers.”

Some respondents had seen others struggle with opioid addiction. This prompted them to be cautious about their own use. One respondent with one, no-refill prescription said that he “yes, absolutely” set limits by taking less than what the prescription indicated. He explained that opioid abuse was prevalent

in his senior, assisted-living community. He said, "There's a lot of pill-seeking there. Hardcore. I thought old people were supposed to be straight [law-abiding], but no. Not really." Another respondent had one, no-refill prescription after a car accident. He took only a half a pill at a time instead of a full pill as indicated. When asked why he said, "Because I have three nephews addicted to opioids – one of them sitting in jail right now. One of them just lost his family over it. Another one survived a car wreck when he should have been killed on this stuff."

Avoiding Side Effects

When respondents did not connect this question to the concept of addiction, other (possibly unintended) interpretations occurred. For example, some respondents associated it with opioid side effects. They said 'yes' to setting limits, not because they were worried about addiction, but because they did not like the way opioid side effects made them feel. For example, one respondent said she set limits because the side effects were too unpleasant for her, particularly with regard to what she called "brain fog." She said, "You can't function on that stuff." Another respondent who answered 'yes' described similar problematic side effects. "You just feel like you're in a fog. You're drowsy all the time. Tired. Lack of energy. Stuff like that. And concentration. You just can't concentrate." Another respondent said the same for Tylenol 3 and Lortab. "I just took less because I don't like feeling that [lethargic]." After a C-Section, one respondent said she set limits for similar reasons. "When I was on Oxycodone, it made me drowsy and hard to function with a brand-new baby." Another respondent said, "After feeling the side effects, I decided to cut down the dose, I was afraid of having an accident."

Other respondents thought about the effect opioids had on them physically. One respondent said, "One thing about Lortab, they would tear my stomach up. Give me diarrhea a lot…I'd rather not even go through that." Another respondent said she set limits because, "I was really more concerned about not getting my stomach upset."

Avoiding Pills in General

Another unintended interpretation centered on personal aversion to taking pills. Some respondents who were short-term users answered 'yes' because they set limits not just with opioids, but with pills in general. For example, one respondent said, "Yes, I always do that…that's my problem. I wait too long before I take anything…I always try to take the least amount I need to." Similarly, another respondent answered 'yes' and said, "Some nights I skip. I don't take any if it's not necessary. I feel like the less meds I'm on, the better." Others who were long-term users had the same rationale for limiting what they took. One respondent said, "If I'm in pain, I don't like to take more, or more powerful, of a drug than I need to. I try to do natural things." Another explained, "It depends on how I was feeling. The days I am okay I do not take them, but when I feel like I am dying, as my husband says, then I take them. The medication is not going to control me. I was not born sick." One respondent was taking many different kinds of medication including opioids. She described her attempts to take fewer pills in general. "Sometimes I do not take all the pills because it is too much. For example, if it says three times a day I take them only twice. Sometimes I do not take them at night, just in the morning." These answers of 'yes' reflected more of a personal aversion to pills and medication in general than concerns about the effects of opioids in particular.

Limits are Related to Experiences with Pain, Not Opioids

Finally, long-term users with chronic pain were often thinking about their experience with pain, which often prohibited their ability or desire to cut back on opioid use. As one respondent said, "I didn't try to set those limits. The amount of pain I was experiencing set those limits." He answered 'no' to the question.

Experience with pain sometimes created confusion on how to answer the question. For example, one respondent said, "That was kind of hard to answer." When asked why he said, "Well, when I take them, I only take them when I feel pain." In other words, his decision making was based on his level of pain, not any other factors such as those described above (worry about addiction, side effects, or pill avoidance). Another answered 'yes,' and also thought about it in terms of pain management. He had spinal stenosis and managed his chronic pain through alternating steroids and opioids. He said he cut back on the use of opioids when the steroids were used. He said, "Because when I get these steroid shots, there's no need for [opioids]." When the effects of the shot wear off, he used opioids until the next injection (about every three months). In essence, the experience of chronic pain for some dictates the quantity of pain relievers used, so the concept of setting limits is seen as not applicable.

> *During the past 12 months, did you need to use more prescription pain relievers than you used to in order to get the effect you wanted?*

Some respondents understood this question as asking about addiction, drug abuse, or recreational use, such as 'getting high.' Others thought it was asking about building drug tolerance. Their understandings were shaped by the phrase, 'the effect you wanted,' which was often understood in relation to their experience.

Question is About Addiction or Drug Abuse

Some long-term users heard 'the effect you wanted' as asking about drug abuse or getting high. Because their experience with opioids was driven by pain, not by recreational use, they often answered 'no.' For example, one respondent who did not see herself as abusing opioids answered 'no,' commenting that "that's bordering on addiction." Another respondent who had at times taken more than his prescription called for also answered 'no.' When asked what he thought this question was asking he replied, "Am I overtaking my pain medicine, and I'm not." He said he took the opioid in response to pain, not because he was addicted or wanted to get high. Others had similar interpretations. One respondent answered "I'm not a junkie, no." She said she did not use Lortab and Norco to "get high" or "feel good." She used it only for pain. Another respondent also answered 'no' even though she sometimes did take more than the prescription indicated. Her rationale was that she did not use them to "get high" and thought that's what the question was asking.

However, a few long-term users understood 'the effect' to be the therapeutic effect of relief from pain. One respondent clarified that his use was only to reduce pain. He answered 'yes' but explained, "The only effect I wanted was trying to get the pain to go away. So, yes, I got the effect I wanted." Another respondent also focused on pain relief as 'the effect.' She answered 'yes' because "Sometimes the pain was so bad I wouldn't take one [pill], I would take two at a time."

Question is about Building Tolerance

Others thought it was asking about drug tolerance not necessarily caused by abuse. One respondent answered 'no' and explained that "just like everything else, when you get used to it, it doesn't give you the same effect." Another respondent answered 'no' and explained his understanding of the question:

> "Sometimes you are used to taking a certain amount of milligrams, your body gets used to it, so you feel like your regular doses are no longer effective. So, you decide to double the doses; instead of taking a pill you take one and a half or two because your body is already used to the medication and it no longer takes the pain away."

Other respondents answered 'yes' and also described how tolerance naturally increases over time. One respondent explained, "I started taking opioids in 1989. And gradually over the years I've built up a tolerance. So, I know that I could take more than I take, but I don't. But I know that I'm not getting the same relief that I did when I first started." Another respondent also described how the therapeutic effect diminishes over time. She said, "Yes, sometimes. Sometimes the pain wouldn't go away with just one pill. Sometimes I would take it at night, and I would wake up early in the morning with pain." Another respondent also answered 'yes' and said, "Because I started taking them, one here and one there. And then I was taking a couple here and a couple there. And then by the end of it I was taking five, ten, fifteen a day." Another respondent said, "Yes, sometimes the doctor would tell me to take only one of the medications for migraines and it wouldn't work, I had to take a double dose to be able to function." Another respondent also answered 'yes' because, "It is not enough, you do not feel the same (effect)."

> *During the past 12 months, did you notice that using the same amount of prescription pain relievers had less effect on you than it used to?*

There were two main interpretations of this question. Respondents either thought it was asking about the extent to which they had developed a tolerance to opioids *or* that it was asking about their level of pain. Those with chronic pain who were long-term users of opioids were more likely to have the latter interpretation.

Question is about Building Tolerance

Like the previous question, many respondents answered according to whether they believed they were building any tolerance to opioids. However, *unlike* the previous question, it was less likely to be seen as asking about addiction or misuse, as respondents attempted to differentiate it from the previous question (which otherwise possessed the illogical appearance of asking exactly the same thing). For example, one respondent said, "Any time you take something, you'll build a tolerance to it." Another respondent said, "You get immune I guess." When asked for details he said, "When you first start taking it you feel better…it gets rid of the pain. But after taking it – [I've] been on it for a while [a year] – it just seems like aspirin. Your body's just so used to it, you don't feel no difference." Another respondent answered 'yes' and said, "I can tell a little bit of difference. Because I feel like I need three [Percocet] a day." When she first started prescription pain relievers, she needed only one pill a day. Another respondent explained, "I'm just getting used to the medicine…it takes more and more and more." Another respondent described his rationale for answering 'yes.' "It takes away I'd say 50% [of the pain], whereas before it used to take away more." Another explained, "It's like any other drug. Once you do it or you drink so much, one day then it becomes a habit. It's like you're immune to it." Another respondent gave a similar explanation. "When you keep using them, it feels like they don't… As I told you, I am immune. So, for them to have the effect, I have to take more."

There was not necessarily a difference between how short-term and long-term opioid users understood this question. Respondents who had been taking opioids for different lengths of time expressed similar experiences with tolerance and answered the question in a similar manner. For example, one respondent explained how she had to keep switching the type of opioid she took in order to feel any relief. She said, "I had been taking that Dilaudid for a whole year. And after a while it doesn't work anymore. You have to change it to something else because your body becomes immune to it." Another respondent who had taken opioids for six months also discussed tolerance in relation to this question. She said, "I guess my body began to build up a tolerance. It worked for a shorter period of time." And finally, a respondent who used opioids for only six weeks also answered 'yes' because she thought she was building a tolerance to it. She said, "I think towards the end of that…I think I did start feeling like it [oxycodone] worked better when I first took it because my body wasn't used to it. So as time went by, it seemed like, I don't know, it seemed like things were getting dull. You know, like it wasn't as sharp, the effect. I think my body had acclimated to it."

Even though many understood this question as asking only about tolerance, some did connect the intent more directly to addiction. For example, one person who discussed his addiction answered 'yes' and said, "Because you get used to them. You definitely have to find something different…Your body got used to the pills, so now you have to find a substitute. Either you're going to take more or find something else." Another respondent who did *not* see himself as having an addiction problem, noted how tolerance can affect those with this problem. He answered 'no' and said, "I don't build a tolerance. When I see addicts for opioids, they stopped feeling the effects of getting high. I just want relief from pain. It's what I want them for." Others who also saw themselves as using opioids responsibly for pain management answered 'no' to the question. One respondent expressed his concern about becoming addicted and said, "No, I don't. Because I never over [used]…I took the least amount. Sometimes I wouldn't even take it every four hours [as prescribed]."

Question is Asking about Level of Pain

A few respondents answered this question on the basis of their level of pain – in other words the opioid was less effective when *pain* increased, not when *tolerance* increased. One respondent answered 'yes' because sometimes her pain came from multiple places – back, knee, and tooth. The more sources of pain, the less effective the Norco. She said, "Because it just seems like it don't hold up…because sometimes you have your normal pain [back and knee] and sometimes you have mouth pain…It don't hold from the first dose to the second…Your back might be at ease, but your mouth still be hurting." Other respondents also answered 'no' because they perceived the pain to be worse, not the pills to be less effective. For example, one respondent described increased pain after knee surgery and believed she had to take more pills because it "hurt more" – not because she had otherwise been on opioids for five years prior. Another respondent also answered 'no' because he attributed taking more pills to an increase in pain. He said he "wasn't aware" of the pills having less effect but did describe how he took the prescription more frequently (every two hours instead of every four) because the pain increased.

> *During the past 12 months, did you want to or try to cut down or stop using prescription pain relievers?*

This question was often interpreted as assessing addiction, and this presented problems for some respondents.

What Does an Answer of 'Yes' Mean?

Respondents who believed the question was assessing addiction thought that answering 'yes' might imply a level of difficulty associated with having an addiction problem that they did not see themselves as having – even though they *did* cut down or stop taking opioids. For example, one respondent who had stopped using opioids said, "I'm going to answer 'no' to all of that because there wasn't a process." He explained that he did not have to 'try' to stop, he just did. Another respondent had a similar reaction. He decided to answer 'yes,' but clarified, "Cut down is not what I did. It was stop."

Other respondents specifically pointed out that the question might be trying to assess whether they had issues with addiction and were trying to "kick the habit." This caused difficulty for some who argued that while answering 'yes' might be technically correct, it could also suggest something about them that was not true. For example, one respondent heard the question and said, "I don't know if the answer is 'yes.' But the Tramadol…I guess, yes. [But] that would be misleading." The interviewer asked why. "That it may sound like you realize you're a dope addict and you're trying to have self-control, but you're afraid of losing control." He did not want an answer of 'yes' to imply he had addiction issues. Another respondent hesitated before answering and was asked why. "Because it wasn't like an addicting habit. It was just, I was doing this for my pain…One day when the pain went away. Oh, okay, I'm done. I didn't even think about it." Another respondent heard the question and asked, "Did I want to? Against my will?" He decided to answer 'yes' and explained that it was not a difficult process for him. He simply stopped taking pain medicine shortly after having teeth pulled. He said, "I figured once the pain subsided from my wisdom tooth surgery, I feel like I don't need it and if I still had pill remaining, then I would just kinda discard the pills." The interviewer asked what he meant earlier by 'against my will.' He said, "I feel like some people are addicted…they kinda quit cold turkey. In fact, I wasn't addicted." Finally, another respondent decided to answer 'yes' because it was technically true but added that she was not addicted. She said, "Yes, stop using them. I only take them when I feel sick. I am not addicted to any medication."

Other respondents answered 'yes' to this question because they feared opioid addiction, even when not taking opioids extensively or for long periods of time. An older respondent had been given a limited number of opioids for pain and stopped taking them as soon as he felt able. He answered 'yes' to this question. When asked why, he said, "Well, again, it's just that I knew there was a limit [to the refills]. And let's say I did get to like it, with no refills. What would I do? Plus I just wouldn't be able to function. I didn't want to lose any ground in my life…what would I do if I got hooked? I don't want that." Another respondent had a post-surgery prescription and stopped taking opioids after several weeks. He said he was motivated to stop over fear of what he knew from "reading in the newspaper – events about opioids." Another respondent answered 'yes' and explained, "For example the Tramadol I try not to use it at all because of the secondary effects. Also, the Hydrocodone, because I don't want to get addicted...Until I cannot longer take the pain, is when I take it. Sometimes even when the pain is very strong, I try to take an Advil or some other type of medication, like an 800mg pill before taking one of those [Hydrocodone]."

Other Problematic Interpretations

Attempts to differentiate this question from the previous three questions (which otherwise appeared strikingly similar) resulted in other problematic interpretations. First, some respondents tended to understand it through the lens of pain. For short-term users, this often meant that both the level of pain

and the frequency of opioid use decreased after surgery or temporary injury. For long-term users, chronic pain made cutting back undesirable, impossible, or both. Second, short-term users had trouble with the assumption that they had a regular pattern of use to begin with, or thought about their pattern with pills in general, not just opioids.

Cutting Back Depends of Level of Pain: Some respondents thought the question was asking whether they cut down in response to a decrease in pain. This was especially true of short-term users who had conditions that improved over time. For example, one respondent answered 'yes' and said, "I wasn't feeling sick anymore so I spoke to the doctor. I told him that I wasn't in pain anymore and if I could stop taking them, and I did not use them anymore." Another respondent also answered 'yes' because his pain started to decrease, rendering pain relievers unnecessary. He said, "Once I noticed that my pain was decreasing, I started to take only one capsule." However, another respondent with the same interpretation answered 'no' because the decision to cut back was contextual – it was contingent on pain. "I did not decide it; it is just that I do not need them anymore. It has to do with having pain or not. If my symptoms decrease, I decrease the amount of medication."

While some respondents answered 'yes' because their pain subsided, others had on-going pain that made cutting back difficult. These respondents answered 'yes' because they wanted to stop but could not because pain prevented them from doing so. One respondent said, "Oh, yeah, I wanted to, but of course…I'm constantly in pain. Like now – I'm having to readjust my seat from sitting [too long]." Another respondent answered 'yes' even though she did not succeed. She said, "I was trying to ween myself off of them. But it didn't work. When I did that, it lasted for about a week or two. Then that's when the pain started getting more intense." Another respondent answered 'yes' and said, "I'd like to, but like I said, the pain. You know what I mean? It's too [intense to] deal with, like Advil – it doesn't work."

Other respondents had no desire to cut back or stop because they knew their pain was too intense or incurable. One respondent answered, "No, not really." When asked why he said, "Because I know that the pain is going to be there. It's inoperable. It's not like a strained back or I just had two teeth pulled. There is no way my back is going to heal itself." Another respondent who answered 'no' said, "Because if I did, I'd be miserable [because of chronic pain]." Another respondent said, "If I want to live pain free, I need to stay on a regular routine." And another respondent said, "No, because it helps me."

Assumes a Regular Pattern of Opioid Use: For some short-term users, the question was awkward because they did not take enough pain medicine to have to cut down or stop to begin with. This was either because they did not have a regular pattern of taking opioids or took opioids for only a brief time with no plans for future use. Several respondents who took opioids sporadically and without a set schedule were uncertain how to answer because the question implies the existence of a reason to cut back or stop. One respondent said, "I'm not sure how to answer that because I'm not on them steady…I do not take any daily pain medicine. Just case-by-case. Just a few days here and I might be fine for the next few months." This respondent had a chronic condition that required periodic medical procedures which created temporary pain. Another said, "It's short-term dosage, so I don't know what you mean?" Another said, "No, I've only been taking them a few months now…so that question kind of flies right by me. It doesn't mesh with my situation…it doesn't apply to me." Another simply stated, "No, because I don't use it frequently."

Resist Taking Pills in General: Other respondents resist taking pills in general. Even though they had no experience with opioid misuse, they still answered in the affirmative because they *always* try to cut back

or stop using pills – not just with opioids, but with everything. One respondent answered 'yes' even though she had taken only one Dilaudid pill after outpatient surgery. She said, "I didn't want to continue to take the Dilaudid if I don't need to. I can manage this level of pain with the [OTC] Ibuprofen." Another respondent answered 'yes' and said, "I just didn't want to rely on taking pain pills all the time. I just want to stop. Didn't want to be part of the opioid epidemic or whatever. I'm not really a pill-taker if I don't have to. Only if necessary." Another respondent who answered 'yes' gave a similar explanation. "I don't like taking medication. I think that's one of the reasons I won't take [OTC pain relievers] if I can help it. Positive attitude, just try to stay healthy other ways without meds."

> *During the past 12 months, did you cut down or stop using prescription pain relievers at least one time?*

The reasons why respondents cut down or stopped using opioids varied, and this formed the rationale on which they based their answers. At root of many interpretations was the extent to which 1) the behavior was a conscious, active decision versus a decision that was essentially made for them (due to circumstances such as the prescription running out or the pain ending), 2) they believed the question applied to those who misuse opioids, or 3) they worried about the addiction risks associated with using opioids.

Active vs. Passive Decision to "Cut Down or Stop Using"

Prescription Ran Out: Some respondents answered 'yes' to this question to indicate that they stopped using opioids because their prescription ran out. They did not cut back or stop because of any personal or active decision to do so. For example, one respondent had monthly refills, however, each script was for 28 pills – not 30 or 31. He answered 'yes' because there are always a couple days each month that he does not have pills to take. He said, "I'd say about 12 times in the last 12 months. It's usually when I run out monthly, every 28 days." This occurred among both long-term and short-term users. Another respondent answered 'yes' because he had a one-week prescription with no refills that he completed. One respondent answered 'yes' but was concerned it was sending the wrong message. He said, "But I feel like that question is trying to ask…asking if I had an addiction. Maybe I'm misinterpreting that." But when the interviewer repeated the question, he chose to answer literally. "Yes. I stopped because I ran out."

However, other respondents did *not* include the completion of a prescription in their answer. They saw the question as asking about a conscious decision to cut back or stop. One respondent answered 'no' because he did not cut down "on purpose." Instead, he reported that he runs out of pills at the end of each month and goes a few days without taking opioids as a result.

Pain Ended: Respondents answered 'yes' to this question when they stopped taking opioids because their pain subsided. For example, one respondent said, "Once the excruciating pain became tolerable, I started cutting down the dose." Similarly, another respondent explained, "I didn't need it. I wasn't in pain – the pain was manageable. It wasn't affecting my activities." Another respondent said, "Yeah, I cut down a little bit." By this he meant he would sometimes skip doses if he felt the pain would be tolerable. "It was like up and down like a seesaw. Sometimes it goes away for a long time. And I take it when I feel the pain." Another respondent said, "Yes, I stopped and didn't need it anymore. My pain stopped and I didn't depend on it for medical care." Another respondent with a similar experience answered 'yes' but wasn't sure that was the intent of the question. He said, "Yes, I guess. Because I

took the codeine for three days and stopped." He used less than prescribed and did not take the full week prescription, but that was due more to the pain disappearing than it was to any concerted effort to avoid opioids.

Question is about Addiction

Some respondents saw the question as targeted towards those with misuse or addiction issues and answered 'no.' This included respondents who were short-term users and consequently did not see themselves as having misuse or addiction problems. For example, one respondent who had used opioids only briefly and stopped answered 'no' because he saw this question as asking about "someone who takes them regularly." Another had a similar rationale and said, "No, because I don't use it frequently." Another said, "No. I don't take that many. To cut down from one is hard to do."
Respondents who struggled with misuse or addiction interpreted the question in a manner similar to the short-term users. That is, they saw the question as asking about dealing with addiction. Some tried to reduce their addiction by decreasing their frequency of use. For example, one respondent answered 'yes' and said, "I was trying to ween myself off of them. But it didn't work. When I did that, it lasted about a week or two." Another respondent answered 'yes' even though it was for only one day. He said, "Yes, because you try to go a whole day, but the effects when you don't have the pain relievers are really bad and very strong, mentally and physically. I was not able to do it." A respondent who was in treatment said, "I wanted to decrease my dosage of Suboxone and eventually stop." Another respondent had a similar goal. He said, "One time I was at work. Instead of bringing it with me I left it in the truck. I set out wanting to stop and wanted to. But I got very sick. Throwing up, running nose. Mostly this mucus thing where it was just coming out of me." Another respondent answered 'yes' and said, "They changed me. Trying to get the same effect, but it would change. When I went to the pain doctor [four months ago] he took me away from the opioids…By June I was done."

Worry about Addiction: There were also respondents who answered 'yes' not because they struggled with addiction but because they were simply worried about addiction, sometimes even when taking only small amounts of opioids for short amounts of time. These respondents tried to take less than the prescribed amount. One respondent said, "At least once I did." She tried to take less than the two-per-day she was prescribed and sometimes had pills left at the end of the 30-day supply. Another respondent also answered 'yes' and described how she was trying to take as little hydrocodone as possible. "I've had maybe one pill in the past two to three weeks. I'm trying to cut it out completely, but I still have those moments [of pain]." Another respondent also described not taking the hydrocodone he received upon release from the hospital. He said, "When I got out of the hospital they gave me the medication…they gave me some but I didn't use it."

> *Please look at the symptoms listed below. During the past 12 months, did you have three or more of these symptoms after you cut back or stopped using prescription pain relievers?*

This was a difficult question. Respondents did not (or could not) always connect the symptoms to their use of opioids. The causes could have been from other factors in their life or other drugs they were taking in addition to opioids – and often they did not know which was the cause. As a result, respondents answered 'yes' to this question if they merely experienced any of the symptoms shown on the hand card, irrespective of the cause or the timeframe. In other words, side-effects experienced while taking opioids were included along with symptoms occurring once opioid use was discontinued.

Additionally, some respondents interpreted the question as asking about addiction. Those who did not think of themselves as having an addiction answered 'no' regardless of their actual experience with the listed symptoms.

Cause of Symptoms is Unclear or Unknown

Many respondents reported experiencing symptoms but did not always know what gave rise to them. For example, one respondent answered 'no' but admitted she was not sure. She said, "I have teary eyes and runny nose, but I don't know if that had anything to do with it." Another respondent answered 'yes' and discussed his symptoms. He said, "Cramps and muscle aches. I want to even say vomiting. But that might have been just from sinuses. Teary eyes, runny nose." He also included trouble sleeping but said, "That's probably from the mattress I had. The cramps are from when I was working in the warehouse. My muscles would cramp up." Another respondent included yawning but said, "I'm always tired though." He did not necessarily trace it back to the opioid. Another respondent thought her symptoms could be related to the opioid but described how she was not sure. "It was like a week I tried to ween myself off and I would have a nauseous feeling and a fever and night sweats…made me think if it's not related. If something else is going on. Makes me analyze further beyond the meds…When I was trying to get off [hydrocodone] and switch to Motrin or just go without them, period, I would have some of these symptoms. Other times I would be okay." Another respondent also demonstrated lack of knowledge about the cause of his symptoms. He said, "I feel tired. That's not on there. Like no motivation." The interviewer asked if this was because he cut back. "I don't really know…or I'm just getting old. I just get so tired. I get drowsiness. It could be I'm slowing down, whatever. Or maybe it's still in my system [the hydrocodone from the night before]. How long does it take to totally get out of your system, I don't know." Another respondent admitted having some cognitive symptoms but not knowing whether they were from the opioid or the concussion he suffered from a car accident. One respondent decided to answer 'no' but really was not sure. He said, "And yes, I have felt depressed and blue but I cannot tell you that it was because I have stopped taking the medication."

Respondents taking multiple types of medications also did not always know which ones gave rise to the symptoms on the hand card. One respondent answered 'yes' and said, "They weren't all at the same time, but all within a week or so. Or within days of each other. I definitely had the diarrhea. And I said feeling sweaty, but I'm not sure if that's because of that [the opioid] or my anti-depressant." Another answered 'yes' but also was not sure which drug was the cause. She said, "Some of those probably had to do with the meth. Like I was blue or down [also vomiting, sweaty, feverish and diarrhea], but I don't know if that was the opiate or the meth."

Finally, some respondents thought of their pain (not the opioids) as the cause of these symptoms. One respondent answered 'yes' to this question and said, "Well, what happened is I ran out and at one point I was in a lot of pain waiting until my doctor renewed the prescription. So, if that's the case, I can answer that [yes]." When asked which symptoms he was thinking of he said, "I would mark 'feeling kind of blue or down' because you know you're in such pain…I'd say maybe 'yawning' and 'trouble sleeping' because the pain was [intense]." Another respondent also answered 'yes' but was thinking of the pain not the opioid and said, "Because of the muscle pain I couldn't sleep. Just those two. I think the medication used to help me relax, it would take the pain away but it would also relax my body. I think that is why I would get (muscle pain)."

Side-Effects Reported

Some respondents were not focused on symptoms that occurred once they stopped taking opioids, but rather were thinking of the side effects they experienced while on them. For example, one respondent chose 'no' but said, "I don't know if this counts or if it's just me generally being tired because I work too much…the yawning is in there…feeling kind of blue or down…My mood seems to be all over the place sometimes, but I do question whether it's from some of the medication I take. I don't know the side effects of the muscle relaxer I take." Another respondent answered 'yes' but was thinking of those symptoms while taking opioids. He said, "While I was taking it sometimes. I would feel nauseous. Even the water tasted weird." One respondent answered 'yes' but during probing clarified that these symptoms occurred while taking opioids. She said, "I think that's when I have used them. Not when I have stopped using them."

Question is about Addiction

Some respondents understood this question as asking about withdrawal symptoms due to addiction. Those who did not think they were addicted answered 'no,' regardless of their actual experience with these symptoms. For example, one respondent answered 'no' and clarified that she "has never been addicted." She explained, "A lot of days I only take morphine [and not the hydrocodone] and I have never felt those, that withdrawal." This respondent has had a prescription for morphine for the past 12 years and also has hydrocodone (for "breakthrough pain"). She answered 'yes' to the previous question because it was the hydrocodone she sometimes cuts back on – but not the morphine. Another respondent answered 'no,' making certain to convey that she was not addicted. Although some of the symptoms did apply to her, she said, "I wasn't in DT's. I didn't have any of that [expletive]. I just hurt." In explaining her situation of taking opioids for the past four years, she said, "I had a prescription. I followed the prescription. I took it and I went to work…No, I wasn't an addict…. If I were an addict I would have been missing work and getting fired." Another respondent answered 'no' and said, "No, but I know people like that. They can only control themselves with Vicodin, and it has to be 500mg."

Respondents who identified with addiction struggles saw this as a question about experience with withdrawal and answered 'yes.' For example, one respondent said, "Yes, all of them. It happened when I stopped using them, or when I don't have enough." Another respondent talked about his addiction and said, "These are withdrawal symptoms. [I've had] basically all of them." Another answered 'yes' and said, "I call it withdrawal." Another respondent answered 'yes' and said, "These are all symptoms of withdrawal." And another said, "Yeah, most of them…By the time you get another script, you can't wait to get them. You're taking them in the parking lot when you get out of the pharmacy. Bad as that sounds."

> *During the past 12 months, did you have any problems with your emotions, nerves, or mental health that were probably caused by your use of prescription pain relievers?*

As with other questions that ask respondents to assess causality, this was difficult for some respondents to answer. Even if respondents had problems with different aspects of mental health, they could not always see an association between the problem and the opioids they took. Moreover, respondents often understood this question to be assessing addiction.

Difficulty with Causality

Many respondents answered 'yes' while acknowledging that multiple factors probably contributed to their mental health challenges. For example, one respondent discussed a life with many stressors. She answered 'yes' but admitted that factors outside of opioids played a role. "I know my fibromyalgia kicks up under stress. And I'm under stress and my anxiety is up. And I can't take my anxiety medicine until I get home [from work] because it makes me lethargic." Another respondent answered 'yes' but specified, "I don't think it was directly the Percocet." He thought his problems with mental health were also caused by the mix of emotions he felt from coping with his physical withdrawal symptoms. Another respondent said, "Maybe. Probably emotions." When asked what he meant he replied, "Well, your emotions, you just don't feel personable. You don't want to be around people. Friends invite you out and you just don't feel like going out." But he wasn't sure if this was due to the opioid. "I can't say it's from the prescription medicine for sure. I just know I had all this energy and had no problems [prior to taking the opioid]." Another said, "Yeah, they probably are. Probably my moods. They'll change." Another respondent also answered 'probably.' He said, "It's just restlessness. Waking up in my sleep. Talking in my sleep. Fighting in my sleep." When pressed, he said he would answer 'yes' to the question. Another respondent who was diagnosed with schizophrenia answered 'yes' not because he thought the opioid caused the condition, but because he thought it was a contributing factor in making it worse. He said, "Sometimes I hear voices, too." The interviewer asked if this was caused by the opioid. "Yeah. I don't know for sure. But…I'll tell you what, when I use opioids it increases it. It's partially [responsible], you know what I mean? It doesn't help." Another respondent also linked the opioid to her worsening mental health but chose to answer the question 'no' because her depression predated her opioid use. She said, "Yes, I get depressed but it is because I get drowsy. I suffer from depression, I have that problem, so when I feel down or sick I get more depressed…If I take the medication I do feel that at the moment it worsens, that is why I try not to take them."

In fact, respondents who were unsure of causality would sometimes answer 'no.' For example, one respondent ultimately answered 'no' but said, "I am not sure how to answer this question because I have had trouble with depression symptoms, but I don't think those were caused by the pain relievers." One respondent associated his disrupted sleep pattern with opioids and mood. But he ultimately answered 'no' because he couldn't link the bad moods directly to the opioid. He said, "They are going to upset your metabolism and sleeping pattern. And when your sleeping pattern is disrupted, you get up in the morning nagging and whining. You're going to have problems with your family or your children." One respondent unsure of causality could not answer. He was on opioids after a serious head-on car collision during which he suffered a concussion and broken bones. He said, "I don't know. A head-on collision is very traumatic." He knew he had anxiety but was not sure whether it came from the experience with the car accident or from the opioid.

Question is about Addiction

Finally, as with other questions in this section, this one was interpreted as asking about addiction. The question resonated with the experiences of those who identified with having an addiction problem. One respondent was in a long-term pain management program that included opioids. She connected this question to that experience and discussed how her mental health, among other things, was periodically evaluated. "About once a year or so they give you, you meet with a shrink to evaluate your mental health. And never once have they said I'm depressed or anything." Other respondents also associated their long-term opioid use (or misuse) with deteriorating mental health. They said:

> "I don't know why; you just don't feel like yourself. You get sad, you think about how low you are in life, all the things that have happened to you, all the bad things, all the time you waste

looking for medications, putting yourself in bad situations, at night, with people you don't know... It is ugly."

"That medication kind of affects you emotionally you said, right? All that plus the time that you are inside the house, you take the medication, you have to stay at home because you cannot be active all the time, yes, it makes you feel unwell. Your emotions sometimes because you get depressed, and I think it's because of the medication; I never felt any anxiety or depression before."

"Yes, because if I don't have the medications, I get desperate: 'I don't have anything for the pain; I don't have anything for the pain!' You become dependent on that certain medication. 'That is the only one that works for me!' So, if someone gives me a different type of medication, a lower dose, it won't work. And I get desperate."

During the past 12 months, did you have any physical health problems that were probably caused or made worse by your use of prescription pain relievers?

Two problems manifested in this question. First, as with other questions asking about causality, respondents could not always provide an accurate answer. Second, physical health problems were often interpreted exclusively as pain among those suffering with chronic pain. This was at the exclusion of thinking of other possible health problems they may have experienced.

Difficulty with Causality

Like other questions asking about causality, respondents often did not know, at least not definitively whether opioids were the root of the problem. One respondent answered 'no' and said, "I don't know. I don't think so. I just got to not over-do work because that'll cause more pain." Another answered 'yes' but also was not sure. "Maybe I'm speculating." He did not know if his nausea and headaches were due to the concussion from a car accident or a side-effect of the hydrocodone (which he was taking because of the car accident). Another respondent answered 'no' but had to think about how to answer. When asked why he said, "I got an infection from using IV drugs. And that led me to having heart surgery. It wasn't the actual [opioid] drug. It was the way I did it. It was a dirty needle." While there was a link between his opioid use and heart problems, the respondent did not include it because he reasoned it to be an indirect link.

'Physical Health Problem' Equals Pain

Respondents who were using opioids to manage chronic pain thought about their pain when answering this question, equating 'physical health problems' with pain. They would answer 'no' because opioids had done just the opposite of what the question was suggesting. As one respondent said, "No. It's made my life better. I'd be an absolute mess if I didn't have these [Duragesic patch and Percocet]." Another respondent also answered 'no' because the opioid helped with pain – which he saw as the physical health problem this question was asking about. To explain his answer he said, "My pain. When I quit taking it [the opioid] …my pain comes back." One respondent with a similar interpretation was confused. He said, "No, they don't CAUSE the pain." In his mind, the oxycodone did just the opposite – it made his physical health problems better. One respondent was so confused he thought the question was asking whether he was physically limited because of his health condition. He answered 'yes' and

explained, “Because I like to exercise and [I have] difficulty with exercises – not having the use of my leg. That’s where it [spinal stenosis] affects me most. My leg. I can’t walk. That’s all part of exercise.” If anything, the opioid brings pain relief that allows him to do these things.

> *This question is about important activities such as working, going to school, taking care of children, doing fun things such as hobbies and sports, and spending time with friends and family. During the past 12 months, did using prescription pain relievers cause you to give up or spend less time doing these types of important activities?*

Similar to the previous questions, respondents often thought this was asking about addiction. Second, the question was often interpreted through the experience of pain among those long-term users suffering with chronic pain.

Question is about Addiction

Respondents who talked about having addiction problems understood that taking opioids impacted their ability to engage in important life activities and this is how they interpreted the question. One respondent answered ‘yes’ and said, “I isolate a lot.” When asked to explain he said, “I don’t go anywhere…I’m just not comfortable around people. They know I’m on pain meds.” Another said ‘yes’ because “my family, coworkers, don’t really like being around me when I’m putting needles in my arm. When I first started using, it was at least this sort of progression. But now if I go at it, I go ALL at it. So all of my intentions are focusing on getting high and continuing to stay high. So, it’s probably more that I don’t care about anything else.” Another respondent answered ‘no’ because she has been going to a “detox clinic” and was on methadone. She also understood this question as getting at addiction. She explained that during her struggles “You spend your entire day that you’re awake figuring out how to get money so that you can find a way to get some drugs and get high. That’s no life. You can’t hold down a job. You spend 15 hours a day just trying to get well – not even get high, but get well, so that you’re not sick.” Others who struggled with addiction also answered ‘yes’ and told similar stories:

> “Just spending less time with my family, with my kids because I have been trying to get the pills.”
>
> “Not completely abandon them, but it does take your time away from everything you like. Do you want to be with your family? With your girlfriend? Do you like to play PlayStation? Do like to go out with friends? Yes, it is going to take time away from that because you spend your life trying to find the pills.”
>
> “I used to like going out to the park, go shopping, do a lot of things, now I do not like to even go out. My friend used to call me all the time and she would take me everywhere. Not anymore because I do not like it. I do things because I have to, not because I want to.”
>
> “There are things like... I no longer go see my family when they get together, to eat, at parties, because I am always chasing the pills.”

Question is about Pain

Many respondents who were managing chronic pain with opioids answered 'no' to this question because the opposite of what the question suggests was true. Opioids allowed them to manage their pain, which in turn allowed them to participate in important activities. For example, one respondent answered 'no' and remarked, "Not the medicine. The surgery. The medicine actually helped so I could cope and go about how I would like to go about it…It helped me manage the pain a little bit better so I can still enjoy the things I like." Other respondents had similar reactions:

> "Not the pain reliever, but the pain. Without the pain reliever I don't know where I'd be."
>
> "No. The pills don't slow me down or keep me from doing anything. They just help me to get up and be normal."
>
> "Without them [the opioids] I couldn't participate."
>
> "No, they actually helped me. The first four or five months with the sciatic pain, there were times that in order to be able to go to a gathering I had to take Norco, to be able to move a little, to be able to sit down. Otherwise, I wasn't able to."

This experience was so overriding that some respondents were initially confused by the question and asked to clarify the meaning. One respondent asked, "Meaning I can't because of these [pointing to the bottle of oxycodone]? No! It would be that way if I DON'T take them." One person heard the question and said, "Did the medicine cause it? No!" The interviewer asked what he was thinking. "That NOT having the medicine causes it!"

In fact, many respondents were so focused on their pain or condition – not the opioid – as the factor preventing them from engaging in the kind of activities in this question, that they missed the reference to 'prescription pain relievers' altogether. This caused them to answer incorrectly. For example, during probing one respondent was asked to explain his answer of 'yes.' He said he was thinking of "as far as working, exercise – some of the things I used to like as far as hobbies and sports." When asked to confirm that opioids were preventing him from doing those things he said, "It's not because of the opioids, it's because of the pain." Another respondent answered 'yes' and said she answered this way because she could no longer do "fun things" with her family, like going to the water park, because of her pain. Another was also thinking of family events that he misses because "Sometimes I don't feel good and I just don't want to go." He explained that it hurts to walk and he has to use a cane. Another respondent said, "For the same reason, because of my legs I cannot be up and down. I cannot work either, so it would stop me from running as they do. I can't. They would say 'hurry up.' I can't." When asked if this was caused by the pain relievers she said, "No, because of my illness." Similarly, another respondent answered 'yes' and said, "Whenever I get sick, I have bad headaches, and I don't feel like doing anything, so I just lie down in bed." When asked if the opioids prevent his participation in these activities he said, "No, it's the pain. It's the other way around, the painkillers help me." Pain was such a prominent factor in their life, none of the above respondents were thinking of the effects of taking opioids when they answered 'yes' to this question.

Similarly, some respondents who missed the reference to 'prescription pain relievers' were thinking of their condition (not their pain, per se) as limiting their physical exercise in particular. One respondent answered 'yes' because his back injury limited his ability to play golf, and another answered 'yes' because she was thinking of her osteoarthritis. She said it made it difficult for "walking and running, and some nights I was not able to go to yoga because of stiffness in my lower back." One respondent

answered ‘yes’ because the pain stopped him from going to the gym. He said, “Going to the gym is something that I gave up. I signed up for a free gym program, but I gave it up [because of the pain]. Standing up and lifting weights, I couldn’t do it.”

Some respondents thought about how their pain caused them to limit or quit work and answered ‘yes.’ Others answered ‘yes’ because their condition and pain prevented them from doing much of anything at all. One respondent answered ‘yes’ because she spends most of her time on the couch. She said, “I just lie there and watch TV…because of the pain.” Another respondent who answered ‘yes’ said, “When I had the attack [from spinal stenosis], yes. I couldn’t go to work because I couldn’t walk. And the pain is so bad, not only can you not walk, even when you lay down it’s painful. You can’t sit, you can’t…it’s hard to describe. It’s just one of those pains that won’t go away.”

Finally, the question was difficult when respondents could not disentangle the effects of the opioids and effects of the pain in terms of missing important activities. One respondent answered ‘yes’ but specified, “Both, but probably more the pain…because I couldn’t do anything.” Another respondent articulated well the difficulty with this question. She answered ‘no’ but said:

> “I think I could say yes AND no to that question. The use of drugs didn’t cause me to miss out on all that stuff. But I think that because I had an operation and was recovering from it AND the use of drugs, that combination caused me to be home. So really, I couldn’t go out and do all those things because I was recovering. And the recovery did include the drugs. So, I could put yes or no to that. I would say both are true. But I wouldn’t say the drugs alone caused me to miss out on these things. It was the drugs AND the recovery from the operation.”

> *Sometimes people who use prescription pain relievers have serious problems at home, work, or school – such as neglecting their children, missing work or school, doing a poor job at work or school, losing a job or dropping out of school. During the past 12 months, did using prescription pain relievers cause you to have serious problems like this either at home, work, or school?*

Many respondents were not asked this question and most were not directly probed because the relevant discussion occurred in the previous question. However, those who did receive the question understood it largely as a question about troubles stemming from addiction. For example, one respondent answered ‘yes’ and explained difficulties with both work and family. He said, "Yes, I used to get to work late, tired, because you feel very tired [while taking opioids]." When asked about any effects on family life he said, "Yes, I had problems because it is like you are never home. If you are there, your body is there, but not your mind. The only time you are actually there is when you take the pills and feel good." Problems at work were identified among several respondents. One said, “Mostly at work. I arrive later, sometimes I want to leave early and I just leave [without permission].” Another respondent answered ‘yes’ and also described problems that taking opioids created for her work:

> “Basically, at work. I used to work on my own cleaning houses. I used to work at the same company with my husband. He works on construction and I used to clean the houses, but for some time now it has affected me because I cannot drive. Because of the medication, I could not risk driving anywhere I had to go. I couldn’t concentrate on the cleaning, I was always sleepy, and I couldn’t be cleaning for many hours. Because of all that I had to leave my job.”

Even those who answered 'no' understood this question as asking about serious (often work-related) problems stemming from abuse. One respondent who answered 'no' explained the questions asking, "If I had a crisis, or that I could not control my behavior." Another who took opioids but did not define herself as having a problem said, "Other people I have seen that they get very sleepy, they don't get up to go to work, they are dizzy, but not me."

> *During the past 12 months, did you regularly use prescription pain relievers and then do something where using prescription pain relievers might have put you in physical danger?*

In making sense of this question respondents often understood it to be asking about side effects associated with opioids, and the outcome of those side effects on daily activities. Others understood it to be asking about dangers associated with addiction more generally.

Question is about Side Effects

Many respondents thought of their experience with side effects – mostly drowsiness – when they heard this question. For example, one respondent said, "I might have…I get drowsy. Where I work. It's one of the side effects of codeine and the muscle relaxant. You can get a little too loose!" Another respondent answered 'no.' Because he knew drowsiness was a side effect, he only took the opioid at night. He said, "No, I don't put myself in that kind of position. Mostly, when I take that pain medicine, I'm home and getting ready to go to bed. So, when I'm up, I try not to be on it." Another respondent answered 'no' for the same reason. He said, "I have only taken them in the hospital or at night. When the doctor gave me the medication, he told me, 'If you are in a lot of pain try to take them at night.' And not during the day in case I had to go out and drive." In fact, driving was frequently thought of as the activity most affected by opioid side effects.

- Driving on Opioids: Danger associated with driving was often what respondents thought of when they heard 'physical danger.' For example, one respondent answered 'no' and said, "I don't think so…I was fine driving. Being slightly tired [from the pain reliever] is the same as being slightly tired from work." Another respondent also thought of the impact that side effects have on driving. He answered 'no' because he drove before the onset of any side effects. However, he acknowledged "You're not supposed to drive on Tramadol, and in April I did. But I'll say that I took it 30 minutes before…and it typically takes that long to kick in. But if I wasn't able to drive, I would have Ubered." One respondent stopped to consider before answering 'no.' When asked what he was pondering he said, "They say you're not supposed to drive sometimes. Or operate machinery. So maybe I used the lawnmower or the weed thing [associated with his lawn maintenance job], but it could've been, you know, not good to do it. But I didn't have a problem." Another said, "Yes. Driving…riding my motorcycle…or working on cars and stuff like that. I shouldn't have been doing that." When asked why he said, "I fell over a couple of times on my bike…I didn't keep my balance." Another respondent answered 'no' and also thought of driving. He said, "I had to go to work, I had to drive. Perhaps driving I could harm someone else." Another respondent shared a similar rationale:

  > "Yes, for example driving. All my medications instruct me not to drive. But who is going to do it? I have no choice. That is a big risk because those medications cause vertigo, dizziness. I was putting myself at risk, I could have fallen asleep, I could have had an accident."

Respondents who took opioids after surgery used the recovery period to avoid traffic accidents. For example, one respondent said, "No, because I couldn't walk, I was using crutches so I was always sitting. If I wanted to go out and drive, I don't think I would have been able to because of the effects of the medicine. I was taking them at the time that I was just at home, sitting down."

- Use of Machinery or Physical Labor: Impaired or drowsy driving was not the only physical danger respondents thought of. Other examples included the need to work with machinery or perform physical labor while taking opioids. The following are two examples.

  > "When I was working, at the beginning I used to work with sewing machines, so I could have... Many times I was able to pull out my finger in time because I almost poked it. I would be sewing, and I had to work fast, and I would get very sleepy and I would feel that I had smashed my fingers with the machine. One day I poke myself right in the middle of the finger."
  > "About two times I have taken the medicine without eating, and I have been up high on a ladder, very sleepy and tired. One time I felt like I had dozed off while on the ladder, and it felt almost like when you feel you are going to fall off the bed."

- Injury Resulting from Overuse in the Absence of Pain: Some respondents interpreted this question as asking whether after taking a pain reliever they physically over-exerted themselves and exacerbated their underlying condition. For example, one respondent answered 'yes' and explained, "I wouldn't say physical danger, but I would say it like this. If I took a medicine and then felt good enough to, like, shoot some hoops or something like that, then yeah, it probably made it worse afterwards." Another respondent thought of his physical job. He takes opioids to dull the pain, making it possible to do the work. But the physical activity aggravates his physical condition. He said, "I would have to say 'yes' because my job…we lift boxes and sometimes if there's no volunteer I have to be the one to do that. So, yes…. I go home in more pain."

Physical Danger Because of Addiction

Respondents who identified as having an addiction saw this question as asking about their experiences in this regard. One respondent answered 'yes' and talked about the dangerous behavior she previously engaged in, such as driving while high (on any substance, including opioids). She said, "Driving a car, having kids in the car with me. Getting too high [and] dropping cigarettes, burning holes in couches, burning holes in the bedding…Be sitting at a red light and just nod out." Another respondent also thought of multiple substances that create impairment. He said, "Oh, yeah. Driving. Lost my license for two years. Got it suspended…drinking and opioids." One respondent described experiences of being high," "tripping", falling, and "busting up" his face. Another answered 'yes' and said, "Just going to work high. Doing anything when you're high can get you hurt." When asked for examples he said, "Falling asleep at the wheel happens a lot. A lot of black-outs too, when I'm on opiates…From an hour to several hours. I used to have three friends in this town that died from opiates." Another person who struggled with addiction said, "Yeah, every time. I was doing 50 to 60 mg of Dilaudid in a shot. You're in danger of OD-ing every time. You push it to the limit every time."

During the past 12 months, did using prescription pain relievers cause you to do things that repeatedly got you in trouble with the law?

Follow-up probing on this question (and the next) did not occur for every respondent on which it was administered. Because the battery of questions was so extensive, many respondents began to express frustration with the discussion. This was especially the case for those who understood each question in this series as asking essentially the same thing – are you addicted? As a result, probing became redundant. Interviewers picked up on this cue and probed less extensively (or not at all).

Probing that did occur on this question tended to take place with those who identified themselves as addicted, and centered on understandings of the phrase "trouble with the law." Respondents understood this as asking predominately about jail time or related issues such as trouble with probation officers. One respondent answered 'yes' and said, "I was on probation and I was using other drugs. And I was afraid to report to my probation officer and take the drug test. And she violated me because I didn't report." He spent 30 days in jail as a result. He explained the experience:

> "Yes, constantly…I was on pills and so was my girlfriend. She's a paranoid schizophrenic and she'd been driving on her medication and opiates. And I tried to keep her…tell her not to buy more alcohol. She outweighs me by 100 pounds, so she shoved me down and started to choke me, so I hit her with my cane to get her off me. And she told the police what happened and they came and arrested me. I had to go to a six-month domestic violence class for that. And I'm [currently] on probation for it."

He attributed the cause of the fights essentially to the opioids both he and his girlfriend took. One respondent did not have personal experience with this but interpreted the question similarly because she knew someone who did. She said, "My son's father is in jail for larceny, stealing money, and assault…trying to feed the addiction." Another respondent answered 'yes' because while on opioids, "What I did was steal at the stores." She was arrested as a result.

While most understood the question as trouble with the criminal justice system, some saw it as trouble with authority more generally. For example, one respondent described the question as asking about trouble "with an authority figure in any capacity" and gave examples such as police, work supervisors, and even parents.

> *During the past 12 months, did you have any problems with family or friends that were probably caused by your use of prescription pain relievers?*

Similar to reasons discussed in the previous question, follow-up probing did not occur for every respondent. In many cases probing was simply too redundant, causing interviewers to curtail extensive probing. Those respondents for which meaningful probing did occur were those who already identified themselves as having some level of addiction difficulties. However, even so, some respondents had difficulty answering because they could not establish a firm causal connection between opioid use and problems with loved ones.

Question is about Addiction

Many respondents understood this question as asking about relationship problems that arise due to addiction. One respondent answered 'yes' because his girlfriend said in "no uncertain terms" that she "wouldn't be with someone who uses." Another respondent answered 'yes' because of stresses related to addiction. She and her husband had to file bankruptcy, to which she attributes opioid use as the cause.

Other respondents discussed fighting and violence with family that resulted from addiction. One respondent answered 'yes' because he would constantly fight with his mother as a result of his addiction. He said, "I can't blame them [family], because I'm making an excuse for what I did." Another said, "Yeah, when they put a restraining order on me, I couldn't go home. I was staying at my brother's house. Staying there for, like, eight months. And then I couldn't [get along with] his wife. Because she knew I was [on pills] …she was telling me it was all my fault, stuff like that. And she was probably right, but I'm just saying it's the wrong time to say that." Another respondent also thought of "arguments and irrational fights, taking pills and not telling people. I guess I was high and not being myself." One respondent also understood the question as asking about arguments but was not sure of the point at which "normal" arguing becomes "problematic" arguing. She had arguments with family but said, "I would say no because a problem would be something serious. Perhaps an argument but not a serious problem."

Other respondents thought not of fighting, but of lack of interest in relationships or a desire for isolation. One respondent answered 'yes' and said, "At least for me, [when] getting high other relationships weren't really possible to maintain." Another respondent had a similar experience. She said, "Made me unsociable. I had more fun doing things by myself. I'd go off to a casino by myself." Another respondent said he "doesn't want to be in contact with them [family]…just want to be alone, by myself." However, he answered 'no' because this was not frequent enough to qualify as a problem. To him a problem is on-going, not occasional.

Difficulty Establishing Causality

Some respondents had problems with family or friends but were uncertain of the cause. One respondent hesitated before answering 'no.' When asked why he said, "I don't think it was the pain killers that caused it. It was the relationship was already going down the drain. It had nothing to do with drugs or her drinking. It was over…I think I did the drugs just to forget how miserable I was." Another described problems with his son, which he attributed to both personality differences and the use of opioids. He said, "My son, he takes pain medicine too. So, we don't always get along. He's a real tough person to get along with. Impossible. It's probably got a lot to do with both of us taking pain medicine." Even though he had no relationship difficulties with people other than his son, he decided to answer 'yes.'

OPIOID PILE SORT STUDY

Pile sorting, which is sometimes known as a card sorting in usability research, is a method with roots in cognitive anthropology (Weller and Romney, 1988; Bernard, 2011, Gravlee et al 2017). It is designed to uncover the connections between items within a cultural domain—that is, similar and related concepts that tend to be grouped by people within a culture. For instance, pile sorting has been used to explore how people link and divide personality traits (Rosenberg and Vivekanathan, 1968), understand how American Indian communities think about barriers to cancer screening (Trotter and Potter, 2008), and how Navajo teenagers conceptualize drug and AIDS risks (Yeh et al., 2014). The method allows researchers to develop a *folk taxonomy,* or underlying taxonomic structure of a set of items (in this case, pain relievers). In short, participants are given a set of cards, with each either naming or depicting an individual item within a domain (in this case, each card had the picture and name of a pain reliever). They are then asked to group the cards they believe are similar—either in a set number of piles (known as a "directed pile sort") or in any number of piles they want (an "open pile sort"). Interviewers then typically ask the participants to name and describe the piles and use the piles as a basis for further discussion. The piles and this resulting textual data are analyzed qualitatively, graphically (via hierarchical clustering and multidimensional scaling, or MDS), and quantitatively (via matrix-based distance analysis).

As part of the larger cognitive interviewing study presented earlier in this report, we used pile sorting to better understand how respondents classify and group individual opioid medication and pain relievers in relation to one another. Understanding the taxonomic structure associated with opioids may uncover potential sources of survey response error.

Methodology

In this particular use of pile sorting, respondents were given a set of 46 cards, with the name of a pain reliever printed on one side, and the name and a picture printed on the opposite side. The cards included all the opioid pain relievers asked about on the NSDUH, as well as nine OTC pain relievers. The pile sorting activity was conducted at the end of the cognitive interview. Respondents were asked to group drugs that they thought were similar and separate drugs they thought were different. They were then asked to name each group and explain why they piled items together in the way they did.

In total 152 pile sorts were completed (this activity was not conducted in 28 interviews given time constraints). In general, the anthropological methods literature suggests that a minimum of 10-15 individual pile sorts are necessary for graphical and quantitative analysis for any group or sub-group. Data were compiled in comma-separated value (csv) format, and analysis was conducted using R (R Core Team, 2020). While R functions and packages exist for conducting cluster analysis, MDS, and the quadratic assignment procedure (QAP, the most common form of matrix-based subgroup analysis), no pile sorting-specific packages exist. Additionally, recent methodological work has suggested that the commonly-used version of QAP is inadequate for subgroup analysis of pile sorts, as the method includes comparisons against empirically-improbable card combinations (Borgatti, 2002). As such, a series of R programs specifically designed to analyze pile sorting data using the most up-to-date analytic procedures was written for this project; this code is available from NCHS upon request.

Findings

There are three broad areas of findings from the analysis of the opioid pile sorts: the overall folk taxonomy of pain relievers; the analysis of unknown opioid pain relievers; subgroup differences in both taxonomies and unknown drugs.

Overall taxonomy

Qualitatively, respondents used similar terms to label and explain the reasoning behind their piles, suggesting that a common folk taxonomy exists. For instance, nearly all respondents created a pile of "unknown" drugs—things that they had never heard of or were not sure about. On the other hand, most respondents also created a pile that included common over-the-counter pain killers such as acetaminophen and ibuprofen. Many respondents also created piles corresponding to the (perceived) strength of the drug—typically coming up with both "everyday" pain killer and a "strong" pain killer piles that they thought would only be provided in a hospital or supervised setting. These qualitative findings provide context to the quantitative and graphical analysis of the piles using hierarchical clustering and non-metric multi-dimensional scaling (or MDS) .

Hierarchical clustering and MDS are analytic techniques that rely on distance (or, from the opposite perspective, similarity) measures. In this case, the distance or similarity between two cards is based on the number of times respondents placed them in the same pile. So, for instance, if two cards were placed in the same pile by all respondents, they would be very similar; if instead the two cards were never placed in the same pile they would be very distant. Both hierarchical clustering and MDS rely on these underlying distance metrics to produce visualizations. Figures 1 and 2 below show the results of these analyses, respectively.

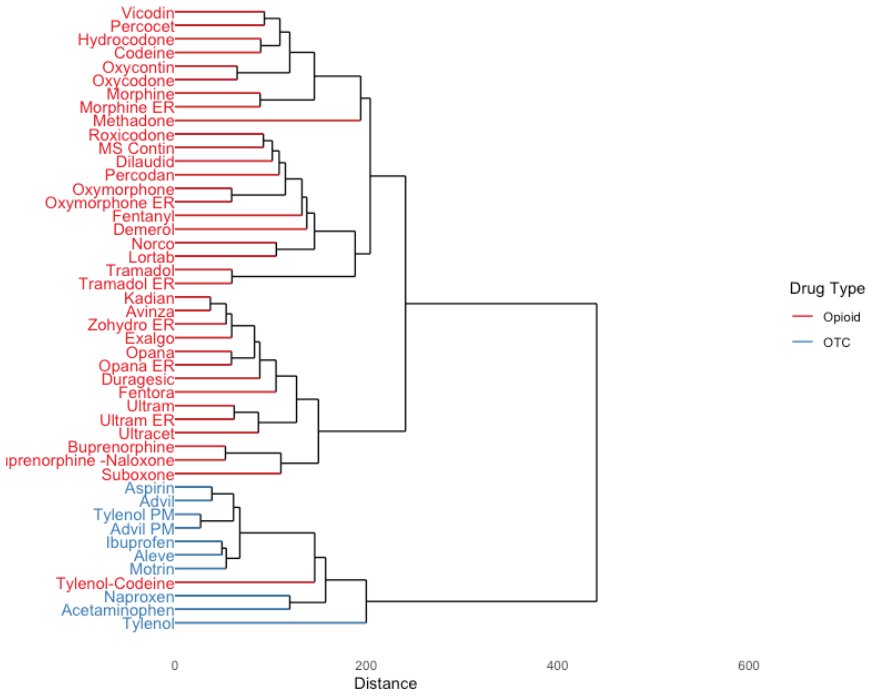


Figure 1: Dendrogram of the Pain Reliever Taxonomy Based on All Pile Sorts (n=152)

The visualization of the hierarchical cluster analysis in Figure 1, typically referred to as a dendrogram, provides information about how similar or distant pairs or groups of drugs are to one another. The height of the connection (represented by the x-axis in this figure) between drugs or groups (shown along the y-axis) indicates how similar they are: lower (shorter) connection points indicate more similarity whereas higher (longer) connections indicate more distance. For instance, the most similar pair of drugs in this sample were Tylenol PM and Advil PM; whereas the greatest difference was found between the group that included OTC drugs (the bottom 11 items on the chart) and the group that included the other 35 drugs. Additionally, this cluster analysis reveals that respondents commonly grouped Tylenol-Codeine (also sometimes called "Tylenol-3") with the over-the-counter painkillers, and not with the other opioid pain killers.

The MDS visualization, found in Figure 2, attempts to group all the interconnected distances between the 46 separate drugs into two dimensions representing latent classes. MDS is used as an exploratory technique to easily see how individual items cluster with one another. In Figure 2, two major clusters are visible (largely corresponding to OTC pain relievers on the left and opioid pain relievers on the right). (Please note that due to the scaling of the image, not all 46 drugs are visible in Figure 2 as their locations on the plot overlap.)

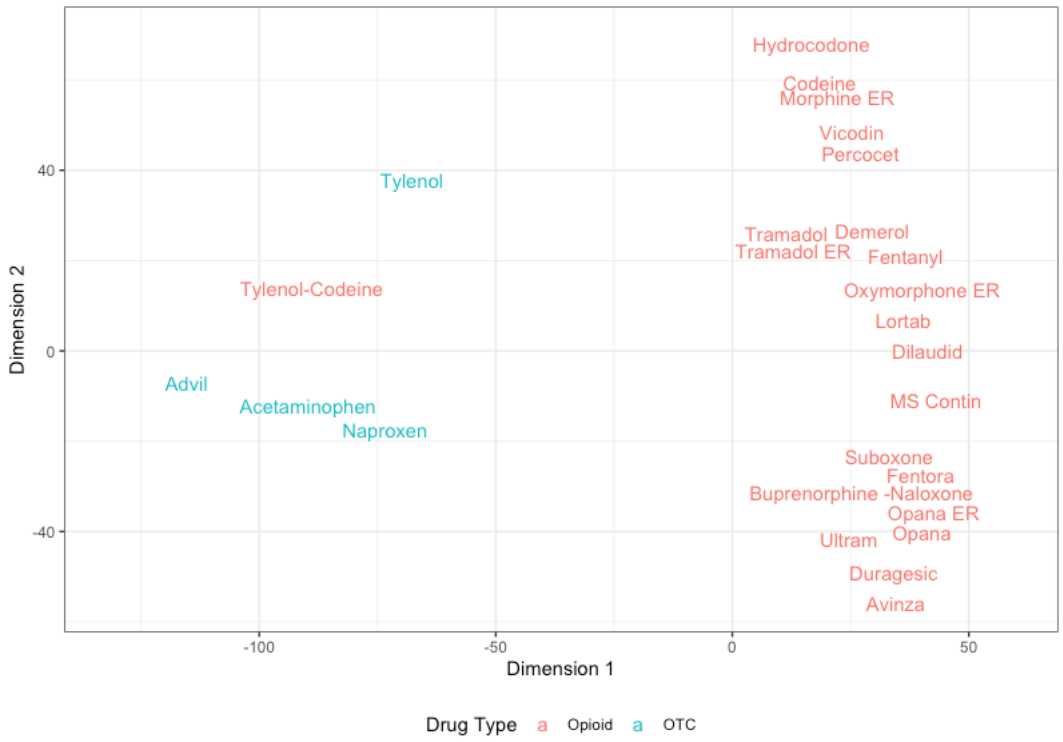


Figure 2: Multidimensional Scaling (MDS) Plot of Pain Relievers Based on All Pile Sorts (n=152, Kruskal Stress = 5.03%)

By analyzing the patterns visible across both of these figures, the latent classes represented by the two dimensions in Figure 2 can be better understood. First, just as seen in both figures, respondents largely differentiated between OTC and opioid pain relievers. The exception to this was again Tylenol with codeine. While this drug is not available over the counter, respondents tended to group it with the OTC pills, and this represents a potential source of response error, which was also identified in the cognitive interviewing study. Second, by examining the taxonomic hierarchy in Figure 1 and the groupings in

Figure 2, some within-opioid divisions are noticeable. Three distinct clusters of opioid pain killers are visible on the right-hand side of Figure 2:

1) Several opioids that nearly all respondents indicated they did not know cluster at the top right of the plot
2) Just below that are opioids that respondents tended to label as a strong or dangerous group (i.e., Dilaudid, oxymorphone, and fentanyl)
3) Those perceived as weaker or "everyday" opioids (including Tramadol, Percocet, and Oxycodone) are clustered at the bottom left of Figure 3 (corresponding to the bottom right of Figure 2).

Based on both the qualitative findings and the graphical analysis of the dendrogram and MDS, it appears as though the two major continuums that respondents used to differentiate pain relievers were knowledge or familiarity with a drug and drug efficacy or potency.

Unknown Opioid Pain Relievers

The pile sorting exercise used in this project relied on what is known as an "unconstrained" sort, meaning that the researchers did not tell the respondents to create a certain number or types of piles. However, all but four of the 152 respondents who participated in the activity created some sort of "Don't know" or unknown pile. In most cases, respondents explicitly labeled one of their piles "Unknown."

When analyzing these unknown piles there was a large amount of agreement across the respondents in terms of knowledge of pain relievers. It is clear that some pain relievers were known by almost none of the respondents—Exalgo, Kadian, Zohydro ER, and Avinza were all placed in more than 80% of the respondents' "Unknown" piles; a full half of the pain relievers (23 out of 46) were placed in more than 50% of the respondents' "Unknown" piles.

A trend also emerges when comparing the percent of instances a drug was grouped as unknown with its membership in the clusters that emerged out of the taxonomic analysis. As shown below in Table 1, while the OTC pain relievers were only placed in an unknown pile 9.63% of the time, the drugs that clustered in the "Don't know" grouping were listed as unknown 75.92% of the time.

Table 1: *Percent of Instances Pain Relievers were Classified as "Unknown" in the Pile Sort Activity, by Pain Reliever Cluster*

Pain Reliever Cluster		Percent of Component Drugs that were Placed in "Unknown" Piles
Over the Counter		9.63
Opioids (Overall)		56.79
	Weak/Everyday Opioids	31.63
	Strong Opioids	55.63
	Unknown Opioids	75.92

Overall, the analysis of both the unknowns and the taxonomy indicates that the individual drugs that comprise "opioid pain relievers" are not universally known, and that respondents appear to differentiate between them based on personal knowledge and perceived efficacy and strength.

Subgroup Analysis

Two types of analysis were used to explore the similarities and differences between subgroups' pile sorting data. First, the average number of cards that individuals in each subgroup (e.g., for Gender, men versus women) put in the "Unknown" pile were compared using a permutation-based general test of independence using an approximated distribution of the test statistic via Monte Carlo resampling (with 10,000 replicates), implemented via the Coin package in R (Hothorn et al., 2006). Second, a variant of the quadratic assignment procedure (QAP) was used to compare the differences between subgroups' taxonomies (for example, comparing the differences in the aggregate distance matrices for men and women that produce visualizations such as the dendrogram shown in Figure 1). QAP is a simulation-based approach that uses resampling of pairs of randomly-produced similarity matrices in order to produce a probability distribution, which is then compared to the observed correlation between subgroups' aggregate similarity matrices in order to produce a p-value (Hubert and Schultz, 1976). Borgatti (2002) argues that for the analysis of pile sorting data, the randomly-produced pairs of matrices should be empirically based (instead of produced via random permutations of the matrices' rows or columns); the analysis here follows this advice and the probability distribution is based on randomly-selected pairs of the 152 pile sorts. Table 2 summarizes these findings.

Table 2: Unknown and Taxonomic Subgroup Analysis Based on All Pile Sorts

Sub-Group [a]		Difference in Assignment to Unknown Pile			Taxonomic Subgroup Analysis	
		z score	p-value	Cohen's d	Dissimilarity [i]	p-value [j]
Gender [b]		1.249	0.212	0.205	0.050	0.476
Race/Ethnicity [c]						
	NH Black	1.370	0.176	0.330	0.104	0.162
	Hispanic	2.887	0.003**	0.502	0.075	0.263
	NH White	2.069	0.038*	0.266	0.059	0.374
	NH Other	0.307	0.772	0.131	0.133	0.122
Education [d]						
	Less than High School	1.342	0.179	0.295	0.070	0.287
	H.S. Diploma /GED	0.677	0.503	0.033	0.035	0.858
	Some College	0.509	0.611	0.091	0.039	0.735
	Bachelors	2.021	0.041*	0.349	0.070	0.292
	Postgraduate	1.085	0.279	0.258	0.133	0.012*
Language [e]		1.559	0.118	0.222	0.103	0.167
Location [f]						
	Alabama	2.227	0.027*	0.581	0.141	0.110
	DC	1.976	0.049*	0.211	0.209	0.045*
	Kansas	0.109	0.926	0.725	0.103	0.170
	Kentucky	1.007	0.319	0.026	0.124	0.129
	Illinois	0.674	0.507	0.274	0.116	0.144
	Massachusetts	1.153	0.261	0.283	0.110	0.152
	Texas	2.042	0.042*	0.372	0.063	0.332

	Washington		2.319	0.021*	0.577	0.095	0.187
Opioid Use [g]			2.356	0.018*	0.694	0.154	0.107
	Extent of Use [h]						
		Briefly	0.295	0.774	0.049	0.049	0.484
		Previous	1.873	0.060	0.413	0.092	0.194
		Current	3.143	0.002**	0.552	0.058	0.385

NOTES: p-value: * <0.05, **<0.01, ***<0.001 a) All subgroup analyses compare individuals from a specified subgroup category (e.g., NH black) to all other respondents. b) n=68 males and n=83 females. One respondent who refused to answer the gender question was excluded from analysis. c) Race/ethnicity analysis show individual races versus all other respondents, n=20 NH Black, n=54 Hispanic, n=67 NH White, n=11 NH Other (NH American Indian or Alaska Native, NH Asian, and self-identified "NH Other"). d) n=25 Less than High School, n=46 H.S. Diploma/GED, n=44 Some College, n=25 Bachelors, n=12 Postgraduate. e) n=39 Spanish and n=113 English speakers. f) n=17 AL, n=11 IL, n=8 DC, n=20 KS, n=15 KY, n=19 MA, n=43 TX, n=19 WA. g) n=139 Used Ever, n=13 Never Used. h) n=61 Brief Use in Past, n=25 Previous Extensive Use, n=53 Current Extensive Use. i) 1 minus the correlation of the subgroups' aggregate similarity matrices. j) The proportion of the correlations of pairs of randomly-generated similarity matrices that were lower than the direct correlation of the subgroups' similarity matrices. Based on 2,000 randomly-generated pairs for each analysis.

Overall, respondents of different genders, and languages did not appear to have significantly different understandings or perceptions of pain relievers. However, it does appear that race and ethnicity, educational attainment, location and opioid use do lead to some difference in how pain relievers are understood and perceived. For instance, Table 2 shows that respondents in Alabama, Washington DC, Texas, and Washington State assigned a significantly different number of drugs to the "unknown" piles than average for the national sample; furthermore, the overall folk taxonomy of pain killers for respondents in Washington DC differed significantly from the rest of the sample. These findings reinforce those from the cognitive interviewing study, and indicate that not only an individual's personal history with pain relievers and opioids, but also their local media and healthcare environment (which would include health communications from state and local health departments) affects how they conceptualize questions about this domain. (Given the distribution of race and ethnicity across the sample for this project, with non-Hispanic black respondents, for instance, concentrated in the Washington DC and Alabama samples, race and ethnicity and geography cannot be disentangled.) Therefore, these characteristics should be considered when developing and analyzing survey questions about opioid pain relievers.

Conclusion

In this project, CCQDER added a pile sorting component to not only explore the way respondents, and sub-groups of respondents, comprehend opioids and other pain relievers as a whole, but also to provide data for triangulation with the cognitive interviewing findings.

When considering the ways that respondents understand and structure the cultural domain of "pain relievers," three major findings emerged. First, (with the notable exception of Tylenol-3, or Tylenol with Codeine, which is discussed below) respondents largely differentiated between OTC and opioid pain relievers. Furthermore, within the opioid pain relievers respondents tended to group the drugs based on their perceived strength, drug efficacy, and the related potential for addiction (see Figure 3).

Second, in addition to the strength-based taxonomy, there are a number of drugs that most respondents simply did not know or had not heard about. Without being instructed to do so, 97.4% of the respondents in the sample created an "unknown" or "don't know" pile of pain relievers, and there was

consistency across the drugs that respondents included in these groups. For instance, Exalgo, Kadian, Zohydro ER, and Avinza were included in over 80% of the "unknown" piles.

Third, when exploring subgroups, a few groups appeared to significantly understand the folk taxonomy of pain relievers in different ways than the rest of the sample. In particular, both location and previous opioid use appeared to influence how respondents understood and grouped pain relievers.

These findings largely coincide with the findings from the cognitive interviewing study. For instance, across the cognitive interviews, Tylenol-3 emerged as a potential source of error in the version of the opioid use question that asks about individual drugs. Furthermore, across the cognitive interviewing study, both respondents who had and did not have experience with opioids thought about the drug efficacy, strength and relatedly, the potential for addiction when discussing use and misuse of pain relievers. Lastly, as suggested here in the subgroup analysis, both location and opioid use emerged as salient factors in the question response process The fact that the findings from this pile sort activity overlap with those from the cognitive interviews provide additional confidence in the overall findings from this project.

Appendix 1: 2018-19 Cognitive Interview Study Interviewer Guide

General Health

1. Would you say your health in general is excellent, very good, good, fair or poor?
   - ☐ Excellent
   - ☐ Very good
   - ☐ Good
   - ☐ Fair
   - ☐ Poor

2. Have you ever been told by a doctor or other health professional that you had…
   - ☐ Hypertension, also called high blood pressure
   - ☐ High cholesterol?
   - ☐ Chronic Obstructive Pulmonary Disease or COPD, emphysema, or chronic bronchitis
   - ☐ Asthma
   - ☐ Diabetes, prediabetes or borderline diabetes
   - ☐ Some form of arthritis, rheumatoid arthritis, gout, lupus, or fibromyalgia
   - ☐ Dementia, including Alzheimer's disease
   - ☐ Any type of anxiety disorder
   - ☐ Any type of depression
   - ☐ Cancer or a malignancy of any kind

3. In the past three months, how often did you have pain?
   - ☐ Never
   - ☐ Some days
   - ☐ Most days
   - ☐ Every day

4. Over the past three months, how often did pain limit your life or work activities?
   - ☐ Never
   - ☐ Some days
   - ☐ Most days
   - ☐ Every day

5. Thinking about the last time you had pain, how much pain did you have?
   - ☐ A little
   - ☐ A lot
   - ☐ Somewhere in between

Access to Health Care

6. The next few questions are about health insurance, including health insurance obtained through employment or purchased directly, as well as government programs like Medicare and Medicaid that provide medical care or help pay medical bills. Are you covered by any kind of health insurance or some other kind of health care plan?
   - ☐ Yes
   - ☐ No

7. Do you have any of the following kinds of health insurance or health care coverage? Include those plans that pay for only one type of service, such as nursing home care, accidents, or dental care. Exclude private plans that only provide extra cash while hospitalized. *(Select all that apply)*
   - ☐ Private Health Insurance
   - ☐ Medicare
   - ☐ Medi-Gap
   - ☐ Medicaid
   - ☐ SCHIP (CHIP/Children's Health Insurance Program)
   - ☐ Military health care (TRICARE/VA/CHAMP-VA)
   - ☐ Indian Health Service

- ☐ State-sponsored health plan
- ☐ Other government program
- ☐ Single service plan (e.g., dental, vision, prescriptions)

8. Is there a place that you USUALLY go to if you are sick?
   - ☐ Yes
   - ☐ There is no place
   - ☐ There is more than one place

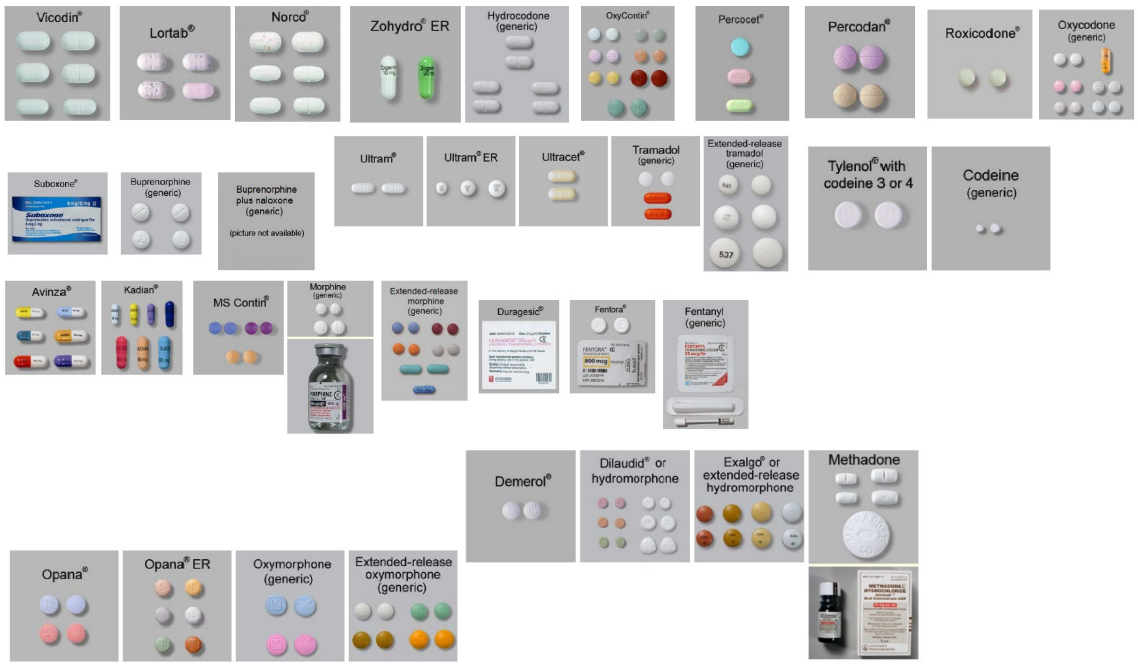
9. What kind of place is it?
   - ☐ A doctor's office or health center
   - ☐ A walk-in clinic, urgent care center, or retail clinic in a pharmacy or grocery store
   - ☐ An emergency room
   - ☐ A VA Medical Center or VA outpatient clinic
   - ☐ Some other place

Opioid Use

10. These next questions are about the use of prescription pain relievers called opioids. When answering these questions, please do not include over-the-counter pain relievers such as aspirin, Tylenol, Advil or Aleve.

    During the past 12 months, have you taken any opioid pain relievers prescribed by a doctor or dentist? Examples include hydrocodone, Vicodin, Norco, Lortab, oxycodone, OxyContin, Percocet and Percodan.
    - ☐ Yes
    - ☐ No

11. Please look at the names and pictures of the pain relievers shown below. In the past 12 months, which, if any, of these pain relievers have you used? _____



12. Have you ever, even once, used any prescription pain reliever? Remember, do not report your use of "over-the-counter" pain relievers such as aspirin, Tylenol, Advil, or Aleve.
    - ☐ Yes
    - ☐ No

13. What were the reasons you used [Fill drug name] the last time?

- ☐ To relieve physical pain
- ☐ To relax or relieve tension
- ☐ To increase or decrease the effect(s) of some other drug
- ☐ To experiment or to see what it's/they're like
- ☐ To feel good or get high
- ☐ To help with my sleep
- ☐ To help me with my feelings or emotions
- ☐ Because I am "hooked" or I have to have it/them
- ☐ I used it/them for some other reason
- ☐ Suicide attempt/suicidal thoughts
- ☐ Peer pressure/friends/feel cool
- ☐ To increase my energy level
- ☐ To replace another/other drug(s) I am addicted to

Impairment

14. When taking opioids, do you feel any of the following side effects?
    - ☐ Drowsiness
    - ☐ Dizziness
    - ☐ Confusion
    - ☐ Calm
    - ☐ Carefree
    - ☐ Lack of concentration
    - ☐ Blurred vision
    - ☐ Off balance
    - ☐ Irrational
    - ☐ Paranoid

15. During the past 30 days, have you gone to work at a paid job while experiencing those side effects?
    - ☐ Yes
    - ☐ No

    15a. [If yes] How many times in the past 30 days, would you say this happened?
    _____ times

16. During the past 30 days, have you driven a car while experiencing those side effects?
    - ☐ Yes
    - ☐ No

    16a. [If yes] How many times in the past 30 days, would you say this happened?
    _____times

17. During the past 30 days, have you had an injury or hurt yourself because of the opioids or the side effects?
    - ☐ Yes
    - ☐ No

Opioid Misuse

18. The next question asks about using prescription pain relievers in any way a doctor did not direct you to use them. When you answer these questions, please think only about your use of the drug in any way a doctor did not direct you to use it, including:

    • Using it without a prescription of your own
    • Using it in greater amounts, more often, or longer than you were told to take it
    • Using it in any other way a doctor did not direct you to use it

    Have you ever, even once, used any prescription pain reliever in any way a doctor did not direct you to use it?

    - ☐ Yes
    - ☐ No

19. In the past 30 days, that is, from [Fill date] up to and including today, did you use [Fill drug name] in any way a doctor did not direct you to use [Fill drug name]?
    - ☐ Yes
    - ☐ No

20. During the past 30 days, on how many days did you use [Fill drug name] in any way a doctor did not direct you to use [Fill drug name]? _____

21. What is your best estimate of the number of days you used [Fill drug name] in any way a doctor did not direct you to use [Fill drug name] during the past 30 days? _____

Opioid Use Disorder

22. During the past 12 months, was there a month or more when you spent a lot of your time getting or using prescription pain relievers?
    - ☐ Yes
    - ☐ No

23. During the past 12 months, was there a month or more when you spent a lot of your time getting over the effects of the prescription pain relievers you used?
    - ☐ Yes
    - ☐ No

24. During the past 12 months, did you try to set limits on how often or how much prescription pain relievers you would use?
    - ☐ Yes
    - ☐ No

    24a. [If yes] Were you able to keep to the limits you set, or did you often use prescription pain relievers more than you intended to?

    - ☐ Usually kept to the limits set
    - ☐ Often used more than intended

25. During the past 12 months, did you need to use more prescription pain relievers than you used to in order to get the effect you wanted?
    - ☐ Yes
    - ☐ No

26. During the past 12 months, did you notice that using the same amount of prescription pain relievers had less effect on you than it used to?
    - ☐ Yes
    - ☐ No

27. During the past 12 months, did you want to or try to cut down or stop using prescription pain relievers?
    - ☐ Yes
    - ☐ No

28. During the past 12 months, were you able to cut down or stop using prescription pain relievers every time you wanted to or tried to?
    - ☐ Yes
    - ☐ No

29. During the past 12 months, did you cut down or stop using prescription pain relievers at least one time?
    - ☐ Yes
    - ☐ No

30. Please look at the symptoms listed below:
    • Feeling kind of blue or down • Vomiting or feeling nauseous • Having cramps or muscle aches • Having teary eyes or a runny nose • Feeling sweaty, having enlarged eye pupils, or having body hair standing up on your skin • Having diarrhea • Yawning • Having a fever • Having trouble sleeping

During the past 12 months, did you have 3 or more of these symptoms after you cut back or stopped using prescription pain relievers?

☐ Yes
☐ No

31. Please look at the symptoms listed below:
• Feeling kind of blue or down • Vomiting or feeling nauseous • Having cramps or muscle aches • Having teary eyes or a runny nose • Feeling sweaty, having enlarged eye pupils, or having body hair standing up on your skin • Having diarrhea • Yawning • Having a fever • Having trouble sleeping
During the past 12 months, did you have 3 or more of these symptoms at the same time that lasted for longer than a day after you cut back or stopped using prescription pain relievers?

☐ Yes
☐ No

32. During the past 12 months, did you have any problems with your emotions, nerves, or mental health that were probably caused or made worse by your use of prescription pain relievers?

☐ Yes
☐ No

32a. [If yes] Did you continue to use prescription pain relievers even though you thought this was causing you to have problems with your emotions, nerves, or mental health?

☐ Yes
☐ No

33. During the past 12 months, did you have any physical health problems that were probably caused or made worse by your use of prescription pain relievers?

☐ Yes
☐ No

33a. [If yes] Did you continue to use prescription pain relievers even though you thought this was causing you to have physical problems?

☐ Yes
☐ No

34. This question is about important activities such as working, going to school, taking care of children, doing fun things such as hobbies and sports, and spending time with friends and family. During the past 12 months, did using prescription pain relievers cause you to give up or spend less time doing these types of important activities?

☐ Yes
☐ No

35. Sometimes people who use prescription pain relievers have serious problems at home, work or school — such as: • neglecting their children • missing work or school • doing a poor job at work or school • losing a job or dropping out of school. During the past 12 months, did using prescription pain relievers cause you to have serious problems like this either at home, work, or school?

☐ Yes
☐ No

36. During the past 12 months, did you regularly use prescription pain relievers and then do something where using prescription pain relievers might have put you in physical danger?

☐ Yes
☐ No

37. During the past 12 months, did using prescription pain relievers cause you to do things that repeatedly got you in trouble with the law?

☐ Yes
☐ No

38. During the past 12 months, did you have any problems with family or friends that were probably caused by your use of prescription pain relievers?

- ☐ Yes
- ☐ No

    38a. [If yes] Did you continue to use prescription pain relievers even though you thought this caused problems with family or friends?

    - ☐ Yes
    - ☐ No

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