A review of potential national chronic pain surveillance systems in the United States

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Abstract

Pain has been established as a major public health problem in the United States (U.S.) with 50 million adults experiencing chronic pain and 20 million afflicted with high-impact chronic pain (i.e., chronic pain that interferes with life or work activities). High financial and social costs are associated with chronic pain. Over the past two decades, pain management has been complicated by the marked increase in opioids prescribed to treat chronic non-cancer pain and by the concurrent opioid crisis. Monitoring the prevalence of chronic pain and pain management is especially important because pain management is changing in uncertain ways. We review potential U.S. chronic pain surveillance systems, present potential difficulties of chronic pain surveillance,

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and explore how to address chronic pain surveillance in the current opioid era. We consider case definitions, severity, anatomic site, and varieties of chronic pain management strategies in reviewing and evaluating national surveys for chronic pain surveillance. Based on the criteria evaluated, the National Health Interview Survey offers the best single source for pain surveillance as the pain-related questions administered are brief, valid, and cover a broad scope of pain-related phenomenon.

Perspective: This review article describes data sources that can be leveraged to conduct national chronic pain surveillance in the United States, explores case defining or pain-related questions administered, and evaluates them against eight surveillance attributes.

Keywords

chronic pain; high-impact chronic pain; surveillance; public health

Introduction

Chronic pain (CP) is a common, multifaceted problem that has had a substantial negative impact globally[26,69]; the present paper will focus on the burden of chronic pain in the United States (U.S.). The common occurrence of CP, along with its high costs (direct and indirect costs of $560–635 billion estimated in 2010 dollars), have established pain as a major public health problem [22]. In 2016, the Department of Health and Human Services (HHS), in collaboration with the Interagency Pain Research Coordinating Committee (IPRCC), developed the HHS National Pain Strategy (NPS) [27, 69]. A key issue explored by stakeholders involved in development of the NPS was the need for population-level data on prevalence, progression, and outcomes specific to CP to guide policies aimed at reducing the burden of pain in the U.S. Shortcomings of national surveillance for CP include: methods, definitions, and survey questions on CP are not standardized; data are often specific to only a few conditions (e.g., low back pain); and questions related to pain duration do not differentiate between acute and CP.

Public health surveillance, considered the cornerstone of public health, is the "… systematic, ongoing collection, management, analysis, and interpretation of data followed by the dissemination of these data to public health programs to stimulate public health action" [62]. Efforts to address the public health aspects of CP as a disease are generally lacking. One challenge in conducting national surveillance of pain is the subjective nature of pain, so national surveillance is achieved through self-report surveys by either individuals or their healthcare provider. In addition, CP is often conflated with the acute pain response and viewed as a symptom or result of an injury or underlying disease. In reality, the characteristics and pathophysiology of CP may lend itself to be defined as its own separate chronic disease[64] and might be the most important factor contributing to the disability and costs of said disease. The 2019 National Health Interview Survey findings estimated that 20.4% adults in the U.S. experience CP (pain experienced most or all days in the past three months), and 7.4% of adults have high-impact chronic pain (HICP), i.e., CP that interferes with life or work activities on most or all days in the past three months[73]. These estimates provide a basis for monitoring progress toward achieving the nation's Healthy People 2020 and 2030 pain objectives to reduce the prevalence of adults living with HICP[8, 9]. These

10-year goals for nationwide health promotion and disease prevention focus on the most pressing topics relevant to the health of all Americans. CP research efforts are advancing rapidly in clinical and academic realms, but public health efforts lag behind.

Surveillance of pain management practices is also warranted. Pain management has been complicated over the past two decades by the marked increase in opioids prescribed to treat chronic non-cancer pain [5], by the concomitant opioid crisis[5, 25], opioid-induced hyperalgesia[72], and by the resulting concerns about implementing opioid prescribing guidelines to combat the crisis[18]. Surveillance of the prevalence of pain and changing pain management practices prompted by the opioid crisis is especially important because the treatment of pain[5, 18] is changing in ways that could either help or hurt those with pain. Opioids are becoming less often prescribed for pain management as clinicians actively seek new treatment modalities (both pharmacologic and non-pharmacologic). New avenues of treatment and other drug classes (e.g., cannabinoids) are being more commonly used or encouraged. For now the dual and conflicting public health emergencies of poorly managed CP and the opioid crisis, as CP is often treated with opioids, mean that enhanced surveillance of CP may inform both crises [34]. Further, assessing how effectively adults with pain think they are managing their pain, both pharmacologically and non-pharmacologically, is an important surveillance measure because it addresses what patients care about, as underscored by the Healthy People 2030 developmental objective to increase self-management of HICP[53].

The purpose of this review is to consider 1) possible national surveillance data sources, or combinations of them, that might best capture data needed for CP surveillance, 2) the national surveillance issues related to case definitions of pain and pain-related health conditions, and 3) next steps in national CP surveillance.

METHODS

We reviewed the literature for all potential data sources that had the potential to be leveraged for national CP surveillance. Inclusion criteria for data sources in the review were: 1) national or nationally representative of a defined population in the U.S., 2) collected information on pain-related issues, 3) data available for the last five years (2015–2020), and 4) ongoing data collection. Reviewed literature included all National Center for Health Statistics survey documentation and current literature from PubMed and Embase for potential national data sources collecting information on any pain-related issue. The search strategy used freetext words and MeSH terms including “pain”, “chronic pain”, “pain management”, “pain medication”, and “surveillance”. To expand the scope of search and ensure comprehensive coverage, experts in the field of chronic pain were also consulted to identify additional data sources.

Considering a variety of pain-related phenomena (e.g., pain severity and duration) that are important to public health surveillance, we reviewed existing pain questions available in the eligible national data sources. Case-definition (e.g., whether or not the respondent has pain) and other pain-related questions (e.g., location of pain and severity of pain) were considered if they asked about pain in general or pain-related issues including function limitations and treatments for pain. We evaluated these questions and survey instruments using the Guidelines Working Group standard 2001 guidelines for evaluating public health surveillance systems [23]. One investigator (LMD) evaluated each eligible data source against eight of the ten public health surveillance attributes specified in the guidelines: usefulness, simplicity, flexibility, data quality, acceptability, representativeness, timeliness, and stability; sensitivity and positive predictive value could not be evaluated because no gold standard pain measure exists (Table 1). A second investigator (CGH) independently reviewed and approved the evaluation of the eight attributes. A process for settling disagreements was determined a priori but was not needed. The most promising data sources with pain-related surveillance questions were explored in more detail.

RESULTS

Potential Surveillance Data Sources

National Data Sources.

1. National Health Interview Survey (NHIS): NHIS is a cross-sectional household health interview survey conducted by the National Center for Health Statistics (NCHS). The NHIS uses geographically clustered sampling techniques to select the sample of dwelling units for the survey. The sample is designed to collect data that are representative of the U.S. civilian, non-institutionalized population. Additional details on the NHIS sample design are available online [6].

Because the NHIS is released annually, it is possible to combine data across survey years to increase the statistical power needed to differentiate CP burden within vulnerable populations such as older adults, racial/ethnic minorities, and low socioeconomic status [2, 46]. However, in 2019 the NHIS underwent a questionnaire redesign that may limit comparability of the estimates before and after the redesign period[50]. Information collected in NHIS is relatively timely, as data are publicly available about six to nine months after survey completion. The questionnaire rotates in sponsored sections and adds emerging health topics as needed, increasing flexibility. NHIS survey participants can also be linked to the National Death Index (NDI), the Centers for Medicare & Medicaid Services Medicare enrollment and claims files, the Survivors and Disability Insurance and Supplemental Security Income benefit records collected from the Social Security Administration, and the Medical Expenditure Panel Survey to supplement NHIS data with mortality, healthcare utilization, access and costs, and employment history data. The evaluation of NHIS using the eight surveillance attributes is presented in Table 2 and can be compared to the other potential national surveillance data sources.

2. Medical Expenditure Panel Survey (MEPS): MEPS comprises half of the households sampled in each year's NHIS and is conducted by the Agency for Healthcare Research and Quality. MEPS provides nationally representative data on healthcare use, expenditures, health insurance coverage, and source of payment for medical care for the sample individual and household members. Respondents from individual households self-report demographic information, health status, access to care, prescribed medications, employment status, and satisfaction with healthcare. For some respondents, these data are supplemented by their medical providers (including doctors, hospitals, and pharmacies). There is an additional survey for employers of a subset of respondents that provides information on the number and types of employer-based health insurance plans offered, including benefits, premiums, and contributions made by employers and employees. Sampling of households is based on a complex survey design and analytic weights are applied to generate nationally representative estimates; supplemental surveys (e.g., medical providers, employers) seek information on specific groups of MEPS respondents and are not generalizable to the entire US population. Additional details on the MEPS survey administration and design are available online [1].

MEPS is designed as a panel survey with five rounds of interviews spanning two years, occurring about every six months. Therefore, while MEPS data are not as timely as NHIS for public health surveillance purposes, they have the benefit of being longitudinal within this two-year time span; each two-year wave arises from separate cross-sectional samples. Also, some of the questions specific to CP have remained stable since its start in 1996. The ability to link MEPS to NHIS enhances the usefulness attribute of the survey while simultaneously reducing simplicity (Table 2).

3. National Health and Nutrition Examination Survey (NHANES): Similar to the abovementioned national surveys, the NHANES is a stratified multistage probability sample of the civilian non-institutionalized population in the United States. The NHANES is a series of cross-sectional surveys that uniquely combines household interviews with physical examinations, consisting of medical, dental, nutrition, serology testing, and physiological measurements collected in mobile examination centers. The survey is conducted over two-year cycles, with data collection and release on a nationally representative sample for each 2-year cycle. Although a plethora of pain-related questions have been inconsistently implemented since the 1999–2000 cycle (i.e. location of pain and related visit to clinician [2017–2018], arthritis/musculoskeletal conditions and related treatment [2009–2010], muscle pain/soreness [2011–2014], eye [2009–2010], sinus [2013–2014], mouth [2003–2020 except 2009–2010], foot [2009–2010], diabetes [2003–2004], abdominal [2017–2020], and hand pain [2011–2014], pain while walking [1999–2000], and miscellaneous pain and related treatment [2003–2004]), generic pain-related questions have not been administered in the NHANES since the 2011–2012 survey. In pervious cycles (2007–2012) the question “During the past 30 days, for about how many days did pain make it hard for you to do your usual activities such as self-care, work, or recreation?” (Table 2) was included. Additional survey details, including sampling design, survey questions, and data are available online [12].

4. National Ambulatory Medical Care Survey (NAMCS): The NAMCS includes data on health care visits to non-federal office-based physicians; the patient’s office visit is the basic sampling unit. The survey is completed by sampled physicians and uses a multistage probability design to make data nationally representative of visits to physician offices in the U.S. Each physician is randomly assigned to a one-week reporting period during which a random sample of visits are recorded by U.S. Census interviewers. More information about the survey methodology can be found online [10]. The NAMCS is conducted annually, and data are released a few years after the period of collection.

Patients experiencing pain who visit physician offices can be identified as having pain using NAMCS data in one of three ways: 1) patients' self-reported reason for the visit; 2) International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) (and ICD-10-CM starting with 2016) diagnosis code for either assessment of persistent nonmalignant pain or specific painful chronic conditions coded by the physician; or 3) prescription of pain management medication during the visit. The NAMCS could be a suitable data source for national surveillance of pain issues for those using the healthcare system, such as pain management, but the survey data are nationally representative of visits to physicians, not the U.S. population overall (Table 2).

5. National Electronic Health Records Survey (NEHRS): Beginning in 2008, NEHRS was added as a mail supplement to the NAMCS. This survey collects information on physicians' adoption and use of electronic health records (EHRs), the health information exchange, and controlled substances prescribing practices both overall and in response to state prescription drug monitoring programs. The NEHRS is a nationally representative survey of physicians, administered annually since 2012 by postal mail, telephone, and online by the NCHS. Additional information on survey administration, questions, and design are available online [11].

Pain management prescribing practices are assessed in the NEHRS. Additional questions on how often the physician or designated staff member checks the state's prescription drug monitoring program prior to prescribing a controlled substance to a patient for the first time, as well as behavior changes resulting from the prescription drug monitoring program, are also collected. Because the NEHRS collects information about physicians and not patients, pain-related questions are not reported on the individual patient-level. The NEHRS alone is not adequate for national CP surveillance, though it meets the useful surveillance system attribute for assessing pain management and prescribing trends among physicians (Table 2).

6. National Hospital Care Survey (NHCS): The NCHS' National Hospital Care Survey (NHCS) obtains patient care data in hospital settings to assess healthcare utilization patterns (it succeeds the National Hospital Discharge Survey, which ended in 2010). The survey is administered to a sample of hospitals which, in turn, submit data on all inpatient and emergency department visits from the hospital's EHR or Uniform Billing (UB)-04 administrative claims. Details on the survey methodology are available online [13]. Pain can be identified among inpatient visits using NHCS with pain-related ICD-9/ICD-10 diagnosis and procedure codes submitted by the hospital. Additionally, patients identified in the NHCS can be linked to external databases, such as the NDI and the Drug-Involved Mortality database to expand upon the healthcare utilization data.

NHCS is intended to be national in scope; however, because of the low response rate, it is not currently able to produce reliable estimates representative of the U.S. population. Survey data are available starting in 2013. Since then, the diagnostic codes used to identify pain transitioned from ICD-9-CM to ICD-10-CM. NHCS meets the useful surveillance system attribute in its ability to assess opioid- and pain-related hospital visits, including monitoring the transition from acute pain to CP among individual patients and temporal differences in pain management practices, but does not fulfill all surveillance criteria

(Table 2). For the 2016 NHCS data, an enhanced opioid-identification algorithm was developed utilizing natural language processing and machine learning techniques to analyze all available structured and unstructured data items collected in the EHR and Uniform Bill (UB)-04 administrative claims data to improve the identification of opioid-involved hospital encounters[48].

7. Electronic Health Record (EHR)/Medical Claims: Increasing availability of EHR and medical claims data could enhance national public health surveillance of pain. The Health Information Technology for Economic and Clinical Health Act (HITECH) was established in 2009 to incentivize sharing of EHRs by healthcare systems and physicians with public health entities for the purpose of public health surveillance [33]. However, data quality issues complicating national pain surveillance exist. Inaccuracies and missingness in demographic information, underlying painful conditions, and pain duration; the lack of standardized variable definitions across EHRs; and selection bias create nontrivial problems [14, 67]. For example, EHR data are limited to individuals receiving health care and these individuals may differ from the general population with respect to factors likely influencing CP (e.g., socioeconomic status). Although EHR and medical claims data are timely and data standards exist to increase the interoperability across systems, barriers to implementation of the standards nationally and the data quality issues described above prevent current use of these data streams for national pain surveillance (Table 2).

As large, standardized EHR-based databases are more widely available across the U.S., there is growing potential to leverage these sources for national pain surveillance. One large administrative claims database, Clinformatics Commercial™ from Optum Clinformatics™ Data Mart Database [54], contains health information (i.e., medical claims, diagnostic codes, demographic data, insurance plan membership information, and prescription medications) on 73 million privately-insured enrollees across the U.S. Similarly, the Health Care Systems Research Network, a public virtual data warehouse combining and standardizing EHR data from 19 healthcare systems across the U.S., offers interoperable healthcare data which may soon overcome some of the current challenges outlined above [30].

Special National Populations and Sub-National Data Sources.—Given the high prevalence of CP, national surveillance could be done for special groups, such as veterans or older adults, or for geographic areas or sub-national sampling units, such as states, counties, or healthcare systems. The data sources described in this section do not meet the criteria for national surveillance of all U.S. adults as they are only nationally representative of defined sub-populations of the U.S. Sub-national data sources (e.g., state or county-level sources) may be used to support local surveillance and are therefore also included in this section even though they are similarly not nationally representative of all U.S adults.

1. Veterans.: In the U.S., many veterans are treated in the Department of Veterans Affairs system where all associated healthcare data are maintained electronically. The Veterans Affairs healthcare system is the largest integrated healthcare system in the United States. Using the Veterans' Health Administration EHR, it is possible to conduct CP surveillance among the veteran population who use it. The Department of Veterans Affairs and Department of Defense are on the forefront of pain management and self-assessment measures. Recently, the Department of Veterans Affairs and Department of Defense pain rating scale was released which improves upon the older pain assessment technique by not only measuring the severity of pain but also incorporating the impact of pain on daily function[43]. Unfortunately, access to the EHR is typically limited to Department of Veterans Affairs researchers. Alternatively, the NHIS collects national information on veteran status that can be used to assess differences in CP and HICP prevalence between veterans compared with nonveterans [47, 57]. Military health insurance can be used to determine veteran status.

2. Healthcare systems.: Similarly, healthcare system data may be utilized to conduct surveillance of CP [63]. For example, Kaiser Permanente has a virtual data warehouse containing longitudinal EHR and medical claims data among all enrollees in one of Kaiser's health insurance plans that can be leveraged to conduct population-level CP surveillance among their enrollees. Similar to the Veterans Affairs, access is usually limited to Kaiser Permanente researchers.

3. Age cohorts.: Among the population aged 65 years and older, the Centers for Medicare & Medicaid Services (CMS) collect medical claims data that might be used to assess national trends in CP prevalence among individuals covered by Medicare. Specific plan types (e.g., HMO, PPO) or capitated (i.e., set fee per patient) Medicare (e.g., Advantage), which provides Medicare benefits in combination with the state and a private health insurer, can be identified using CMS administrative files. Medicare beneficiaries with CP, or a chronic painful condition, can be assessed using Medicare enrollment files and inpatient, outpatient, and carrier claims. Additionally, the Medicare Current Beneficiary Survey administers specific pain questions in a random sample of Medicare recipients. Pain questions administered in the 2019 survey match those in the 2019 NHIS survey. To better understand the chronic pain burden among the subpopulation of older adults (aged 65 years and older), NHIS data for a single year, or pooled across multiple years, can be used to supplement the CMS data.

The National Health and Aging study collect pain-related information on a representative sample of Medicare beneficiaries aged 65 years and older using the following questions in 2019 "In the last month, have you been bothered by pain?", "In the last month, has pain ever limited your activities?", and "In the last month, how often did you take medication for pain: every day, most days, some days, rarely, or never?". Detailed inquiries are included on the anatomic site of pain: back, hip, knee, foot, hand, wrist, shoulder, head, neck, arm, leg, stomach, and other locations.

The Health and Retirement Survey, a longstanding longitudinal panel study that is representative of adults aged 51–61 years at baseline also administers pain-related questions. The Health and Retirement Survey has included questions about pain for many years. In 2020, respondents were asked, "Are you often troubled with pain?", "How bad is the pain most of the time: mild, moderate, or severe?", and "Does the pain make it difficult for you to do your usual activities such as household chores or work?". Also in 2020, the following pain management questions were included: "In the past three months have you taken any over-the-counter pain medications for the treatment of pain?" and "In the past three months, have you taken any opioid pain medications?”. There are separate questions in the Health and Retirement Survey inquiring about back pain and headaches individually.

On the other end of the age spectrum, the National Longitudinal Study of Adolescent Health will begin data collection as early as Spring 2021 for wave six. In this phase of the study, pain in adolescents will be assessed with the question, “How often have you had aches, pains, or soreness in your muscles or joints?”

4. States.: At the state level, the Behavioral Risk Factor Surveillance System (BRFSS) could be used for CP surveillance. The BRFSS is designed as an annual, cross-sectional, state-based telephone survey, comprising core questions that each state is required to implement, optional modules for special topics of interest, and stateadded questions, conducted by state health departments with technical and methodological assistance from the Centers for Disease Control and Prevention. The BRFSS contains state and territorial level data on chronic conditions, healthcare access, and preventive care behaviors ascertained from all 50 states, the District of Columbia, Puerto Rico, and Guam, and every four or five years in the U.S. Virgin Islands. BRFSS participants are selected from households with landlines or cellular telephones based on a disproportionate stratified sample design used for landline telephone numbers and random sampling of 1,000 number-blocks for cellular telephone numbers. Additional details on the design of the BRFSS are available online [7].

The BRFSS meets the useful surveillance system attribute for conducting CP surveillance at the state-level. Data collection is conducted separately by each state, which increases flexibility of questions administered since states can chose to add any, all, or none of the optional modules, as well as choosing to add their own state-specific modules. The BRFSS is administered annually and data are available within eight–nine months of survey completion. The BRFSS is specifically designed to generate state-specific estimates and not national estimates. Currently no CP-specific questions are asked in BRFSS except for joint pain in odd-numbered years.

Some individual states similarly have their own health surveys capturing pain data. For example, the California Health Interview Survey adult questionnaire included the following question in 2018, “In the past 12 months, did you use any prescription pain killer in a way that did not follow your doctor’s directions?” and has a separate question itemizing CP, “What condition or conditions are you taking the medicine for?” with response options of “dental work/dental pain”, “surgery, no accident”, “recent injury”, “chronic pain, regardless of the cause” and “other” [66]. Other states may collect additional pain-related information generalizable to the state-level.

Potential Surveillance Case Definitions

Possible case definitions of pain and pain-related issues.—National pain surveillance issues considered in this review include pain persistence (duration), interference, and bothersomeness (severity), as well as body region experiencing pain, and pain management (e.g., treatments for pain, incorporating costs and effectiveness). No gold standard measure for pain exists, therefore in each survey we assessed potential case defining questions based on the presence or absence of these above-mentioned measures. None of the pain-related questions, or corresponding data sources, were considered the gold standard. Pain question descriptions administered in NHIS from 2015–2020 are provided in Table 3. In addition to pain-related questions, national pain surveillance may be conducted using predetermined painful conditions identified in data sources using ICD-based definitions [36].

1. Pain Persistence (duration): The NHIS administers a pain persistence (or pain duration) question aimed at defining CP: "In the past three months, how often did you have pain? Would you say never, some days, most days, or every day?" and respondents have to answer, "most or every day" to be defined as having CP (Table 3). NHIS is the only survey capturing pain persistence. The CP question has been administered in NHIS from 2010–2020; from 2010–2015 and 2018–2020 a three-month time horizon was used with a change to a six-month horizon in 2016 and 2017. From 2011–2015 the pain duration question appears in the section titled Adult Functioning and Disability at the end of the sample adult survey for a random quarter or random half of the sample adults, depending on the year. In 2016 and 2017, the six-month time horizon was included in the main sample adult survey, the survey administered to all sample adults, while the three-month pain duration question remained in the Adult Functioning and Disability section. As such, an individual's answer to the sample adult interview (six-month horizon) dictated whether or not they would later be asked about pain using the three-month time horizon (i.e., if the sample adult reported that they experienced no pain over the past six months, they were not later asked in the Adult Functioning and Disability section about pain experienced in the last three months). In 2018, the three-month pain duration question became part of the full NHIS adult sample questionnaire and all sample adults were asked this question. From 2019 onward, the year NHIS was redesigned, the three-month time horizon was maintained and will continue to be maintained as part of the rotating biennial Chronic Pain supplement; the question may appear in off years if supplemental funding is provided (e.g., 2020). As a result, the 2016 and 2017 pain duration questions cannot be compared to the 2010–2015 or 2018–2020 data, which are all derived from a random sample of adults or administered to the entire adult sample.

Cognitive testing by the Washington Group on Disability Statistics assessed the underlying construct captured by this question, finding that respondents interpreted the reference to pain in the question as a physical sensation (not mental pain) and did not refer to the six-month time frame when answering but instead focused on the current physical sensation of pain [20, 35]. When respondents were probed about stability of pain over time, a majority reported that their pain has remained stable over the previous six-month period [35]. These findings demonstrate that the CP question administered in NHIS adequately captures the pain persistence construct. Finally, the pain persistence question is a key health indicator in the NHIS Early Release Program and can be assessed by subgroups using the NCHS NHIS interactive data query tool[44, 45].

2. Pain Interference: Pain inference, or pain that substantially restricts life or work activities, in combination with CP, defines HICP. Pain interference among those with CP is assessed in the NHIS using the question, "Over the past three months, how often did your pain limit your life or work activities? Would you say never, some days, most days, or every day?" The pain interference question was included in the 2016, 2017, and 2019 surveys, and the timeframe changed from six (2016, 2017) to three months in 2019 (Table 3). The Washington Group on Disability Statistics performed cognitive testing on the pain interference question and found a majority of respondents reported limitations in general activities of everyday life, often mentioning their pain affected all aspects of their life rather than one particular life or work activity. Other individuals commented on work, hobbies, or exercises they are no longer able to perform. Administering a global pain interference question, without the use of specific examples of life or work activities, proved to be the most effective method of asking about limitations due to pain [35].

MEPS does not have a case defining question for CP prevalence overall; however, pain interference can be assessed with the question "During the past four weeks, has pain interfered with normal work outside the home and housework? Not at all, a little bit, moderately, quite a bit, or extremely", included in the Adult Self-Administered Questionnaire in survey years 2015–2019. While the impact of pain is assessed in this question, the four-week timeframe by itself fails to distinguish chronic from acute pain. Since MEPS is longitudinal, combined responses to two annual MEPS pain interference questions has been used as a proxy for CP [61]. MEPS is an ideal data source for estimating healthcare expenditure measures related to high-impact pain. Prior studies have used the MEPS pain interference question to examine its association with long-term trends in healthcare utilization and annual healthcare expenditures, both overall and for outpatient, inpatient, emergency department visits, and prescription medication, and also in association with opioid use and daily function among adults with arthritis and osteoarthritis [38, 42, 60, 61]. Because MEPS is conducted in half of households participating in the previous year's NHIS, it is possible to analyze antecedent NHIS data for MEPS-focused analyses, including costs attributable to CP, and to supplement NHIS-focused analyses with subsequent MEPS estimates.

Generic pain-related questions have not been administered in the NHANES since the 2011–2012 survey, when the question "During the past 30 days, for about how many days did pain make it hard for you to do usual activities such as self-care, work, or recreation?" was asked in the health status section.

BRFSS does not administer a question specific to overall CP but does collect information on pain interference at the state-level using the question, "During the past 30 days, for about how many days did pain make it hard for you to do your usual activities, such as self-care, work, or recreation? Report number of days" in survey years 2015–2017 as part of the health-related quality of life measures. The 30-day timeframe likewise does not allow for the determination of chronic versus acute pain.

3. **High-Impact Chronic Pain (HICP):** Although others have studied the combination of pain and interference, the NPS proposed HICP as a pain surveillance standard [69]. HICP incorporates both pain duration (pain persistence) and level of life interference attributed to pain to identify those more severely impacted by CP (see sections on pain persistence and

interference above) [55, 69]. As part of the NHIS, pain interference among those with CP was used to define HICP using the question, “Over the past three months, how often did your pain limit your life or work activities? Would you say never, some days, most days, or every day?” and respondents have to answer, “most or every day”.

A recent study based on a random sample of the adult populations served by Kaiser Permanente Washington and Kaiser Permanente Northwest demonstrates concurrent validity of HICP in its ability to differentiate HICP from mild and bothersome CP based on activity limitations [68]. The questions defining HICP and severe CP in NHIS are responsive to changes in health status, predict long-term outcomes specific to pain, and are well accepted; the question refusal rate for the CP and the impact of CP questions are low (ranging from 0.01% to 0.05% from 2015–2017) [6, 39–41, 65, 69].

4. Pain bothersomeness (severity): The concept of pain bothersomeness is well established in the pain community[19, 39]. Pain bothersomeness, or the severity of pain experienced, in combination with pain duration has been proposed as an alternative coding system to create categories of increasing pain severity for use in national surveys [37]. Pain bothersomeness can be assessed with the NHIS question, “Thinking about the last time you had pain, how much pain did you have? Would you say a little, a lot, or between a little and a lot?”. A matrix of possible responses for the pain duration and bothersomeness questions was developed, and those reporting CP “most or every day” in the prior three-month period in combination with pain that bothers them “a lot” were classified as having severe CP [37]. NHIS administered the pain bothersomeness question needed to define severe CP in 2010–2020 (Table 3). Varying levels of disability, health status, and number of healthcare visits have been described between four CP severity groups (i.e., a little pain on some days, somewhere between a little and a lot of pain on most days or every day, a lot of pain on some days, and a lot of pain on most days or every day), highlighting the ability of these CP severity groups to discriminate effectively [39, 40].

5. Anatomy of pain (body regions): Pain questions specific to location (e.g., low back) may provide additional national surveillance measures of body region-specific CP. NHIS collects data on back pain, low back and corresponding pain spread to either leg below the knee, orofacial pain, neck pain, and severe headache or migraine occurring over the past three months from 2015–2018 (Table 3); in 2019 sponsored content allowed for pain reported in the upper extremities, lower extremities, pelvis or groin, and toothache or jaw pain to be added. Body region-specific prevalence estimates for back pain, orofacial pain, and migraine or headache have been reported previously using NHIS data [16, 29, 56, 71].A better understanding of CP occurring from one or more specific conditions, depicted by variations in body regions experiencing pain, may yield insight into underlying disease etiology as an extension to the broad CP case-defining question. A back pain questionnaire was administered during the 2009–2010 NHANES cycle to establish the prevalence of inflammatory back pain in the U.S. Since 2009–2010, questions on chest pain and oral pain have been administered every NHANES cycle through 2019–2020. Muscle pain or soreness in the last three days was measured in 2011–2012 and 2013–2014, location of pain and pain related visit to clinician in 2017–2018, arthritis/musculoskeletal conditions and related treatment in 2009–2010, pain in the eye in 2009–2010, sinus in 2013–2014, mouth in 2003–2020 (except the 2009–2010 cycle), foot in 2009–2010, hand in 2011–2014 cycles, pain while walking in 1999–2000, miscellaneous pain and related treatment in 2003–2004, and presence of abdominal pain in the 2017–2018 and 2019–2020 cycles.

Neither MEPS nor BRFSS collect information on body region experiencing pain, pain duration greater than one month, or degree of pain bothersomeness. The NAMCS and NHCS do not include specific case-defining questions; but, instead, individuals can be identified as having pain or a painful condition using ICD-9/ICD-10 diagnosis or procedure codes. The National Pain Strategy diagnostic codes for identifying CP conditions have been refined and extended to cover ICD-10 [36]. Further chronic primary pain (CPP), or pain that has persisted for more than 3 months and is associated with significant emotional distress and/or functional disability where the pain is not better accounted for by another condition, has been defined as a disease and is included as a diagnosis in ICD-11[52].

6. Pain management

Non-pharmacologic treatment: Non-pharmacologic treatment modalities are increasingly important for pain relief and are often preferred over pharmacological treatments by adults with pain [31]. To quantify the number of individuals with CP using non-pharmacologic therapy, the 2019 NHIS asked the following nine questions (response options for each: yes or no): “Over the past three months, did you use any of the following to manage your pain: physical therapy, rehabilitative therapy, occupational therapy; chiropractic care, spinal manipulation or other forms of chiropractic care; talk therapies such as cognitive-behavioral therapy; CP self-management program or workshop; CP peer support group; yoga or tai chi; massage; meditation, guided imagery or other relaxation technique; or any other approaches?” (Table 4). The very detailed non-pharmacologic treatment data in NHIS allow for the quantification of heterogeneity and overlap among specific non-pharmacological treatment modalities and are among the first survey data that can be used to describe a national picture of nonpharmacologic therapy for CP. In the 2020 NHIS, the response option of “other forms of exercise, such as walking, swimming, bike riding, stretching, or strength training” was added and “a CP self-management program or workshop” and “CP peer support group” were removed. Qi Gong was also added as an option to the “yoga or Tai Chi” response. These non-pharmacologic treatment measures in NHIS are sponsored content and therefore may not be routinely collected. Previous iterations of the NHIS (2002, 2007, and 2012) included the assessment of a variety of nonpharmacologic treatment modalities and natural products, with the language inclusive of overall use or for the treatment of specific conditions, and researchers have examined the use of these approaches in relation to the presence of pain conditions [4, 15, 17, 70, 74].

In the MEPS, each office visit includes information on the type of treatments received (e.g., physical therapy, occupational therapy, psychotherapy, etc.) that can be used to assess use of non-pharmacological therapy among individuals with CP. Also, the NAMCS collects information on non-pharmacologic approaches both with a checklist of the most common approaches, such as physical therapy and counseling, as well as through Current Procedural Terminology (CPT) codes [21].

Pharmacologic treatment: Pharmacologic treatment for individuals with CP varies widely, often a result of differences in underlying disease etiology or disease history or regional practices [24, 58, 59]. The use of non-steroidal anti-inflammatory drugs (NSAIDs), anti-depressants such as serotonin-norepinephrine reuptake inhibitors (SNRIs) or selective serotonin reuptake inhibitors (SSRIs), acetaminophen, anticonvulsants, muscle relaxants, and opioids are often prescribed as pharmacologic treatments for CP [32]. The prevalence of prescription opioid use among individuals with CP can be assessed in the 2019 and 2020 NHIS using the question, "During the past three months, did you take a prescription opioid to treat long-term or chronic pain, such as low back pain or neck pain, frequent headaches or migraines, or joint pain or arthritis?" In the 2020 NHIS, another question was added "Over the past three months, did you use any of the following to manage your pain?" and the response options were "over-the-counter medications such as aspirin, Tylenol, Advil, or Aleve?" and "a pain reliever opioid prescribed by a doctor, dentist, or other health professional?" (Table 4).

Detailed prescription data are available in MEPS because all respondents are asked to list their prescription medications, and, for around half of the prescriptions, each respective pharmacy provides information on the type of medication, dosage, and payment for each dispensed prescription [1]. Those data can then be used to identify dispensed outpatient prescription medications used to treat CP, or those purchased through a retail, mail-order, or HMO/clinic/hospital pharmacy. For example, if prescribed opioids among adults with CP are of interest, generic and brand drug names for narcotic analgesics and combinations of narcotic analgesics, National Drug Codes, and Cerner Multum therapeutic subclasses can be used to identify opioids prescribed among individuals with at least one outpatient prescription dispensed during the survey year [38]. Unfortunately, MEPS does not collect prescription medication data per healthcare encounter but instead the data can be linked to specific health conditions. To overcome this challenge a prior study used the MEPS data to examine opioid use prevalence among individuals with selected medical conditions known to be associated with CP [3]. Prescription of pain management medication during a healthcare visit is collected in the NAMCS, NHCS (not currently made available in the public use data files), and NHANES (using the prescription medications questionnaire)[49]. The NAMCS and the NHANES additionally collects information on natural product use (i.e., dietary supplements), and the NHCS employs the use of SNOMED-CT coding, which contains information on analgesic pharmacologic treatment as well as some natural products.

In other surveys, questions about pain management are limited and vary. BRFSS has only one question, administered in an optional module in 2015 and 2017, for obtaining information on pharmacologic treatment for pain, "Do you take aspirin to relieve pain?" Pain management can be assessed generally in the NEHRS using the question "How frequently do you prescribe controlled substances? Would you say often, sometimes, rarely, never, or not applicable?" Due to increased attention on the use of cannabis to treat CP, the BRFSS administers two questions in an optional module on cannabis use: "During the past 30 days, on how many days did you use marijuana or hashish?" and "During the past 30 days, how did you use marijuana?" Similarly, the NHANES administers questions on cannabis use as part of the Drug Use questionnaire including ever having used cannabis, age of first use, age when started to use cannabis regularly, amount used, frequency of use, and time since last use. Some of the questions administered include, but are not limited to, “Have you ever smoked marijuana or hashish at least once a month for more than one year?”, “During the time that you smoked marijuana or hashish, how often would you usually use it?”, and “During the past 30 days, on how many days did you use marijuana or hashish?”.

Self-efficacy: Patient satisfaction is often used to assess effectiveness of standard of care. To assess pain management effectiveness, in 2019 the NHIS administered the question, “Over the past three months, how effective do you think you were in managing your pain? Would you say very effective, somewhat effective, only a little effective, or not at all effective?” (Table 4).

DISCUSSION

A national pain surveillance system is urgently needed to monitor generic pain-related issues in the U.S. adult population, especially as the opioid crisis provokes changes in pain management and specifically as opioid prescribing guidelines for the treatment of chronic non-cancer pain continue to change. Findings from this review demonstrate a variety of pain-related questions that might be used for different aspects of national pain surveillance. Based on existing surveillance criteria, the NHIS offers the best single source for pain surveillance because questions administered are brief, have been cognitively tested, and cover a broad range of pain-related phenomenon important to public health addressing both CP and HICP. Available questions have broad scope, assessing CP and HICP overall, by body region experiencing pain, or pharmacologic vs. non-pharmacological treatments for pain. Sponsored questions can be added to elaborate or provide more detail on pain-related issues. NHIS is subject to recall bias and may underrepresent nonnative English speakers or the older population as individuals in institutional care facilities are excluded. Though, the rich variety of additional NHIS survey questions creates numerous analytic opportunities to quantify disparities in the burden of CP and HICP across different subgroups of the population in isolation or complemented with other data sources (e.g., MEPS), such as by age, sex, race/ethnicity, psychological factors, other chronic conditions (e.g., arthritis), and geographic location, which has already begun for CP alone [45]. Understanding these differences in pain outcomes across populations can inform the Healthy People 2030 objective to reduce the prevalence of adults experiencing HICP [9]. NHIS was designed to lead the way in generating nationally representative public health data for people living in the U.S., serving as a potential launching point for national CP surveillance.

The remaining potential data sources examined in this review have various strengths and weaknesses. While MEPS alone is not able to differentiate CP from acute pain in each panel, CP can be ascertained by examining pain longitudinally across at least two survey rounds or by linking to NHIS. The ability to link NHIS with MEPS, and therefore attach diseases to reported pain factors, may prove valuable to the public health surveillance mission of “interpretation of data followed by the dissemination of these data to public health programs to stimulate public health practice.” MEPS additionally offers healthcare expenditure data related to pain and can identify painful conditions through the use of diagnosis codes. The NHANES has not administered a generic pain-related question since the 2011–2012 survey.

The NAMCS offers an option for surveillance of pain issues or pain management based on visits to the healthcare system. The survey does note whether the primary reason for the visit is chronic or new and lends itself to identifying CP at the healthcare encounter-level [21] but those with HICP could not be identified. In this survey, pain is identified by the primary reason for the visit, diagnosis codes received, or prescription of pain medications. The NAMCS is not representative of the U.S. population, but does present a national picture of healthcare visits. Similarly, the NEHRS is a survey of physicians so is not representative of the U.S. population. This data source can be used to assess prescribing practices by physicians. The NHCS is a source for surveillance of opioid- and pain-related hospital encounters using diagnostic and procedure codes to identify pain, but no case-defining questions are administered. In addition, the survey is not currently representative of the U.S. adult population due to low survey response rates. Across self-report surveys, questions on medication use don’t always capture information on other commonly used medications such as antimigraine drugs, or disease-modifying antirheumatic drugs, or muscle relaxants, nor do they differentiate use of cannabidiol (CBD) from marijuana use. EHRs are not yet feasible on a national scale but have the potential to be used as a national surveillance source if the ease at which EHRs can be combined across different healthcare systems is increased and data standards (i.e., pain ontologies) for pain surveillance are developed.

Surveillance of CP on a sub-national level or among special populations is becoming increasingly useful as interventions and targeted approaches to improve CP may have geographic variation. BRFSS, a state-level data source, is as timely as NHIS. BRFSS is currently flexible, as the system permits states to add questions of their own design to the survey but is uniform enough to allow state-to-state comparisons for certain questions. These state-specific questions can address emergent and locally important health concerns. BRFSS currently does not offer a question to distinguish acute pain from CP. Next, the utilization of healthcare records to assess CP burden among enrollees is possible among the Department of Veterans Affairs system, Centers for Medicare & Medicaid Services medical claims data, and among other specific healthcare systems or health insurers. These above mention data sources can be used to obtain a national picture of CP among defined populations.

Next steps in moving forward on national CP surveillance.

This paper represents a first step to review or implement what the Population Research Working Group (formed by the Interagency Pain Research Coordinating Committee (IPRCC)/Implementation Group in 2016 to implement NPS strategies) recommended, which is to address the lack of pain surveillance data. The Working Group identified three objectives to address the lack of these data; the objectives and proposed next steps in pain surveillance are described in Supplemental Table 1. One next step identified by the Working Group is the need to convene a group of stakeholders to refine CP self-assessment questions and management strategies, such as examining whether response shift or adaption to pain influences past responses to pain questions as people adapt to their current state of pain and also determining which pain-related survey questions can be combined into the single most relevant measure of pain impact. The diverse landscape, or breadth of pain-related questions covered in this review, carry the danger of producing data that are unactionable with limited capacity to inform direct patient care. HICP alternatively offers a single measure with the ability to intervene medically, underscoring the value in monitoring the burden of HICP nationally. Concomitantly, validation efforts aimed at non-pharmacologic treatment measures for pain relief may begin to determine the potential effectiveness of these different treatment modalities. HICP is well-suited to measure such effectiveness because a cultural change in pain relief is a transition from the outdated concept of “eliminating pain completely” to reducing pain to a manageable level [27]. Communicating chronic pain does not need medical treatment is a way of empowering people to manage their own pain.

Another necessary step is a stakeholder gathering to convene representatives from the Health Care Systems Research Network to continue standardizing EHR data to a common data model for pain surveillance, perhaps in conjunction with others who have been working in the space of standardization for exchanging healthcare information electronically (i.e., Fast Healthcare Interoperability Resources[28]). Specifically, if such a group were formed they could provide insight on the use of diagnostic clusters and treatment indicators to improve the understanding of treatment patterns and eventually study risk factors for the transition from acute to CP, or from CP to HICP, as well as maintenance of either CP and/or HICP, or recovery from HICP. These risk factors need to be determined both overall and for specific painful conditions and for various population groups. This information is needed to understand the burden of these disease states (acute pain, CP, and HICP) and ultimately to guide action, including efforts to reduce the impact of CP using primary prevention (e.g., workspace ergonomics), secondary prevention (e.g., early intervention to prevent the transition from acute to CP), and tertiary prevention (e.g., to limit the development of complications and other disabilities after CP onset).

Another potential step is to validate all pain questions administered against a gold standard. The National Institutes of Health (NIH) Helping to End Addiction Long-Term (HEAL) initiative seeks to develop an objective pain measure. HEAL, aimed at advancing research into the opioid crisis, was launched in April 2018 with half of the $945 million award allocated to address pain issues, including the development of objective pain biomarkers and validated clinical endpoints [51]. Using objective measures of CP, approaches can be developed to evaluate the impact of CP in longitudinal studies of pain perception, activity limitations, pain treatments and their usage, healthcare utilization, and long-term outcomes.

Conclusion

While some types of CP surveillance are already underway, including existing pain objectives in the Healthy People 2020 and 2030, other national CP surveillance can start now with the existing CP questions used in the NHIS. This can be supplemented with healthcare expenditure data using MEPS, either linked to NHIS or MEPS alone. Leveraging these data sources allow for better recognition of the underlying healthcare burden of CP in the U.S. overall and among defined subpopulations and present an opportunity to inform policy makers and public health professionals about better ways to recognize the chronic pain public health problems and the resources needed to implement population-based interventions which can address those problems.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Highlights

- Reviewed data sources to conduct national chronic pain surveillance in the US
- Questions cover pain duration, severity, body region with pain, and pain management
- The National Health Interview Survey offers the best source for pain surveillance

Table 1:

Ten attributes used to evaluate a surveillance system.

Attribute	Definition	Method to assess attribute in a surveillance system
Usefulness	A public health surveillance system is useful if it contributes to the prevention and control of adverse health-related events, including an improved understanding of the public health implications of such events. A public health surveillance system can also be useful if it helps to determine that an adverse health-related event previously thought to be unimportant is actually important.	Review the objectives of the surveillance system and consider the system's effect on policy decisions and disease-control programs.
Simplicity	Simplicity of a public health surveillance system refers to both its structure and ease of operation.	A chart describing the flow of data and the lines of response in a surveillance system can help assess the simplicity or complexity of a surveillance system.
Flexibility	A flexible public health surveillance system can adapt to changing information needs or operating conditions with little additional time, personnel, or allocated funds. Flexible systems can accommodate, for example, new health-related events, changes in case definitions or technology, and variations in funding or reporting sources.	Flexibility is best evaluated retrospectively by observing how a system has responded to a new demand.
Data quality	Data quality reflects the completeness and validity of the data recorded in the public health surveillance system.	Examining the percentage of "unknown" or "blank" responses to items on surveillance forms is a straightforward and easy measure of data quality. Data of high quality will have low percentages of such responses. However, a full analytic assessment of the completeness and validity of the system's data (sensitivity, positive predictive value, etc.) is often required.
Acceptability	Acceptability reflects the willingness of persons and organizations to participate in the surveillance system.	To assess acceptability, quantitative measures include subject or agency participation rate or interview completion rates and question refusal rates.
Sensitivity *	The sensitivity of a surveillance system can be considered on two levels. First, at the level of case reporting, sensitivity refers to the proportion of cases of a disease (or other health-related event) detected by the surveillance system. Second, sensitivity can refer to the ability to detect outbreaks, including the ability to monitor changes in the number of cases over time.	Sensitivity can be calculated as the number of true positives divided by the sum of the number of true positives plus false negatives.
Positive predictive value *	Positive predictive value is the proportion of reported cases that actually have the health-related event under surveillance.	Positive predictive value is calculated as the number of true positives divided by the sum of the number of true positives plus false positives.
Representativeness	A public health surveillance system that is representative accurately describes the occurrence of a health-related event over time and its distribution in the population by place and person.	Representativeness is assessed by comparing the characteristics of reported events to all such actual events. Although the latter information is generally not known, some judgment of the representativeness of surveillance data is possible.
Timeliness	Timeliness reflects the speed between steps in a public health surveillance system.	Timeliness can be assessed as the time taken to conduct each step in the surveillance system or the time required for identification of trends, outbreaks, or other effect of control and prevention measures.
Stability	Stability refers to the reliability (i.e., the ability to collect, manage, and provide data properly without failure) and availability (the ability to be operational when it is needed) of the public health surveillance system.	Measures of the system's stability can include the desired and actual amount of time required for the system to manage the data (including transfer, entry, editing, storage, and back-up) or the amount of time required for the system to collect or retrieve data.

* Unable to assess due to the lack of a gold standard.

Ref: German RR, Lee LM, Horan JM, et al. Updated guidelines for evaluating public health surveillance systems: recommendations from the Guidelines Working Group. *MMWR Recommendations and reports : Morbidity and mortality weekly report Recommendations and reports* 2001;50(Rr-13):1-35; quiz CE1-7

Table 2:

Surveillance system attributes evaluated across the potential national surveillance data sources

Attribute	NHIS	MEPS	NHANES	NAMCS	NEHRS	NHCS	EHRs
Usefulness	Has already provided prevalence estimates and baseline data for surveillance and HP2030.	MEPS is the US standard for estimating nationally representative healthcare expenditure and therefore ideal data source for estimating costs of high-impact pain. Difficult to assess chronic pain without linking to NHIS.	Generic pain questions have not been administered since the 2011–2012 survey. Unable to assess chronic pain or high-impact chronic pain.	Useful for surveillance of pain issues, such as pain management, for those using the healthcare system.	This is a physician survey, so pain questions are not reported at the individual-level. The survey is useful for assessing pain management and prescribing trends in the health care setting.	Useful to assess opioid- and pain-related hospital visits, potentially as a result of differences in pain management practices.	The nonexistence of data standards for electronic health record or medical claims data make it difficult to perform national chronic pain surveillance at this time.
Simplicity	Uses existing data collection infrastructure and standardized survey methodology. Data can be easily obtained from survey website and interactive data tool[46].	Uses existing data collection infrastructure and standardized survey methodology, but its complexity, especially when linking to NHIS, is substantial.	Uses existing data collection infrastructure and standardized survey methodology. Data can be easily obtained from survey website.	Uses existing data collection infrastructure and standardized survey methodology. Data can be easily obtained from survey website.	Uses existing data collection infrastructure and standardized survey methodology. Data can be easily obtained from survey website.	Uses existing data collection infrastructure and standardized survey methodology. Data can be obtained from NCHS Research Data Center.	The fragmented nature of the US healthcare system makes the use of EHRs for national surveillance complex.
Flexibility	Moderately flexible. With some lead time the ability exists to add sponsored emerging health topics as needed; many additional pain questions were added for 2019 and later surveys.	Unknown.	Moderately flexible. With lead time the ability exists to add sponsored emerging health topics as needed.	Administers standard questions, survey has not been redesigned recently. Limited ability to add emerging health topics.	Moderately flexible. With lead time the ability exists to add sponsored emerging health topics as needed.	Moderately flexible. Since survey includes a short questionnaire and submission of all diagnosis codes, NHCS can quickly adapt to changing information needs.	Difficult to add questions in EHRs nationally, differences in EHR vendors complicate the process.
Data quality	Chronic pain and highimpact chronic pain questions were developed and cognitively tested prior to being added to the survey. Potential for recall bias.	Pain interference question has been shown to discriminate across different levels of health status and health care utilization. Potential for recall bias.	Prescription medication data obtained by NHANES is high quality based on collection procedures.	Validation of diagnosis codes for assessment of persistent, nonmalignant pain has not been performed.	The frequency with which physicians prescribe controlled substances in this questionnaire has not be validated.	Validation of diagnosis codes for assessment of persistent, nonmalignant pain has not been performed.	Poor data quality, issues with inaccuracies, missingness and no data standardization specific to chronic pain surveillance.
Acceptability	Question refusal rate for CP and HICP are low, only 0.05% and 0.01% respectively, in 2016. Total	Survey response rate for the public use MEPS files was 46.0% in 2016.	Acceptability is declining, in the 2015–2016 survey 61.3% of persons asked to do the interview	Participation rates for eligible physicians who completed at	The overall unweighted response rate of the 2015 survey was 51.9%.	~20% of the 581 hospitals sampled during the 2013–2016	Acceptability of EHRs in health care setting across the U.S. is growing.

Attribute	NHIS	MEPS	NHANES	NAMCS	NEHRS	NHCS	EHRs
	household response rate was 67.9% in 2016.		completed the survey.	least one patient record form was 39.3% in 2016.		survey years participated.	
Representativeness	National; representative of the U.S. civilian, noninstitutionalized population. Does not include individuals in institutional care facilities, therefore may underrepresent older population.	Derives from prior year's NHIS; National; representative of the U.S. civilian, noninstitutionalized population. Does not include individuals in institutional care facilities, therefore may underrepresent older population.	National; representative of the U.S. civilian noninstitutionalized population. Does not include individuals in institutional care facilities, therefore may underrepresent older population.	National; representative of physician visits in the U.S.	Survey data are nationally representative of physicians practicing in U.S. health care settings.	Response rates are not high enough to produce nationally representative data.	Representative of individuals who seek health care within specific EHR catchment areas; not nationally representative.
Timeliness	Survey conducted annually; survey data are made available ~nine months after survey completion.	Survey conducted annually and begins one year after NHIS completion. Survey data are made available ~nine months after survey completion.	Survey data are released biennially; no generic pain questions administered since the 2011–2012 survey.	Survey conducted annually; survey data are not available for use in a timely manner	Survey conducted annually; survey data are made available ~12–18 months after survey completion.	Survey conducted annually; survey data are made available ~two years after survey completion.	Rapid, EHR data is available in near real-time.
Stability	Established in 1957 and repeated annually since. Well-accepted standard approaches to the survey and data preparation exist.	Established in 1997 and has been repeated annually since. Survey data are highly consistent over time, however there are redesigns that may affect comparability of data.	Established in 1999 and has been repeated biennially since. Pain questions are intermittently administered.	Established in 1973. Survey is now annual and has remained stable since 2006 when a subset of community health centers was added. There was a transition from ICD-9 to ICD-10 codes in 2016.	Established in 2008. Became an independent survey in 2012 and has been administered annually since.	Established in 2013. Survey continues to be administered regularly. There was a transition from ICD-9 to ICD-10 codes around 2015.	EHRs are continually evolving and there is now widespread adoption. There was a transition from ICD-9 to ICD-10 codes around 2015.

[*] Positive predictive value and sensitivity were unable to be assessed due to the non-existence of a gold standard for pain measurement. HP2030 = Healthy People 2030; NHIS = National Health Interview Survey; MEPS = Medical Expenditure Panel Survey; NHANES = National Health and Nutrition Examination Survey; NAMCS = National Ambulatory Medical Care Survey; NCHS = National Center for Health Statistics; NEHRS = National Electronic Health Records Survey; NHCS = National Hospital Care Survey; EHRs = electronic health records.

Table 3:

Description of the pain-related questions administered in the National Health Interview Survey by year, 2015–2020

	National Health Interview Survey
2015	[*]**Pain Persistence** •In the past three months, how often did you have pain? Never, some days, most days, every day, refused, don’t know; **Pain Bothersomeness** •Thinking about the last time you had pain, how much pain did you have? A little, a lot, somewhere between a little and a lot, refused, don’t know; **Anatomy of Pain** •During the past three months, did you have low back pain? Yes, no, refused, don’t know; ○ Among those with low back pain, did this pain spread down either leg to areas below the knees? Yes, no, refused, don’t know; •During the past three months, how often did you have low back pain? Some days, most days, every day, refused, don’t know; •During the past three months, did you have facial ache or pain in the jaw muscles or the joint in front of the ear? Yes, no, refused, don’t know; •During the past three months, did you have neck pain? Yes, no, refused, don’t know; During the past three months, did you have severe headache or migraine? Yes, no, refused, don’t know
2016	**Pain Persistence** •In the past six months, how often did you have pain? Never, some days, most days, every day, refused, don’t know; **Pain Interference** •Over the past six months, how often did pain limit your life or work activities? Never, some days, most days, every day, refused, don’t know; **Anatomy of Pain** •During the past three months, did you have neck pain? Yes, no, refused, don’t know; •During the past three months, did you have low back pain? Yes, no, refused, don’t know; •○Among those with low back pain, did this pain spread down either leg to areas below the knees? Yes, no, refused, don’t know; •During the past three months, did you have facial ache or pain in the jaw muscles or the joint in front of the ear? Yes, no, refused, don’t know; •During the past three months, did you have severe headache or migraine? Yes, no, refused, don’t know; [*]**Pain Persistence** •In the past three months, how often did you have pain? Never, some days, most days, every day, refused, don’t know; [*]**Pain Bothersomeness** •Thinking about the last time you had pain, how much pain did you have? A little, a lot, somewhere between a little and a lot, refused, don’t know
2017	**Pain Persistence** •In the past six months, how often did you have pain? Never, some days, most days, every day, refused, don’t know; **Pain Interference** •Over the past six months, how often did pain limit your life or work activities? Never, some days, most days, every day, refused, don’t know; **Anatomy of Pain** •During the past three months, did you have neck pain? Yes, no, refused, don’t know; •During the past three months, did you have low back pain? Yes, no, refused, don’t know; •Among those with low back pain, did this pain spread down either leg to areas below the knees? Yes, no, refused, don’t know; •During the past three months, did you have facial ache or pain in the jaw muscles or the joint in front of the ear? Yes, no, refused, don’t know; •During the past three months, did you have severe headache or migraine? Yes, no, refused, don’t know; [*]**Pain Persistence** •In the past three months, how often did you have pain? Never, some days, most days, every day, refused, don’t know; [*]**Pain Bothersomeness** •Thinking about the last time you had pain, how much pain did you have? A little, a lot, somewhere between a little and a lot, refused, don’t know
2018	**Pain Persistence** •In the past three months, how often did you have pain? Never, some days, most days, every day, refused, don’t know; **Pain Bothersomeness** •Thinking about the last time you had pain, how much pain did you have? A little, a lot, somewhere between a little and a lot, refused, don’t know; **Anatomy of Pain** •During the past three months, did you have neck pain? Yes, no, refused, don’t know; •During the past three months, did you have low back pain? Yes, no, refused, don’t know;

	National Health Interview Survey
	○Among those with low back pain, did this pain spread down either leg to areas below the knees? Yes, no, refused, don't know; •During the past three months, did you have facial ache or pain in the jaw muscles or the joint in front of the ear? Yes, no, refused, don't know; •During the past three months, did you have severe headache or migraine? Yes, no, refused, don't know
2019[**]	**Pain Persistence** •In the past three months, how often did you have pain? Never, some days, most days, every day, refused, don't know; **Pain Interference** •Over the past three months, how often did pain limit your life or work activities? Never, some days, most days, every day, refused, don't know; **Pain Bothersomeness** •Thinking about the last time you had pain, how much pain did you have? A little, a lot, somewhere between a little and a lot, refused, don't know; **Anatomy of Pain** •Over the past three months, how much have you been bothered by ○back pain, ○pain in your hands, arms, or shoulders, ○pain in your hips, knees, or feet, ○headache or migraine, ○abdominal, pelvic, or genital pain, ○toothache or jaw pain? ■Not at all, a little, a lot, somewhere in between a little and a lot, refused, don't know; **Additional Question** •Over the past three months, how often did your pain affect your family and significant others? Never, some days, most days, every day, refused, don't know
2020	**Pain Persistence** •In the past three months, how often did you have pain? Never, some days, most days, every day, refused, don't know; **Pain Bothersomeness** •Thinking about the last time you had pain, how much pain did you have? A little, a lot, somewhere in between a little and a lot, refused, don't know

[*] Administered in the Adult Functioning and Disability section;

[**] Survey redesign and start of the biennial rotating Chronic Pain supplement

Table 4:

Description of the pain management questions administered in the National Health Interview Survey by year, 2015–2020

	National Health Interview Survey
2015–2018	None
2019	**Pharmacologic** •During the past 12 months, have you taken any opioid pain relievers prescribed by a doctor, dentist, or other health professional? Yes, no, refused, don't know; •During the past 3 months, have you taken any opioid pain relievers prescribed by a doctor, dentist, or other health professional? Yes, no, refused, don't know; •During the past 3 months, did you take a prescription opioid to treat short-term or acute pain, such as pain due to a broken bone or muscle sprain, pain from dental work, or pain following surgery? Yes, no, refused, don't know; •During the past 3 months, did you take a prescription opioid to treat long-term or chronic pain, such as low back pain or neck pain, frequent headaches or migraines, or joint pain or arthritis? Yes, no, refused, don't know; •During the past 3 months, how often did you take a prescription opioid? Some days, most days, every day, refused, don't know; **Non-pharmacologic** •Over the past three months, did you use any of the following to manage your pain ○physical therapy, rehabilitative therapy, or occupational therapy, ○spinal manipulation or other forms of chiropractic care, ○talk therapies such as cognitive-behavioral therapy, ○a chronic pain self-management program or workshop, ○chronic pain peer support group, ○yoga or Tai Chi, ○massage, ○meditation, guided imagery, or other relaxation technique? ■Yes, no, refused, don't know; •Over the past three months, did you use any other approaches to manage your pain? Yes, no, refused, don't know; **Additional Question** •Over the past three months, how effective do you think you were in managing your pain? Very effective, somewhat effective, only a little effective, not at all effective, refused, don't know
2020	**Pharmacologic** •During the past 12 months, have you taken any opioid pain relievers prescribed by a doctor, dentist, or other health professional? Yes, no, refused, don't know; •During the past 3 months, have you taken any opioid pain relievers prescribed by a doctor, dentist, or other health professional? Yes, no, refused, don't know; •During the past 3 months, did you take a prescription opioid to treat short-term or acute pain, such as pain due to a broken bone or muscle sprain, pain from dental work, or pain following surgery? Yes, no, refused, don't know; •During the past 3 months, did you take a prescription opioid to treat long-term or chronic pain, such as low back pain or neck pain, frequent headaches or migraines, or joint pain or arthritis? Yes, no, refused, don't know; •During the past 3 months, how often did you take a prescription opioid? Some days, most days, every day, refused, don't know; •Over the past three months, did you use any of the following to manage your pain? ○over-the-counter medications such as aspirin, Tylenol, Advil, or Aleve? ○a pain reliever ^ opioid prescribed by a doctor, dentist, or other health professional? ■Yes, no, refused, don't know; **Non-pharmacologic** •Over the past three months, did you use any of the following to manage your pain? ○physical therapy, rehabilitative therapy, or occupational therapy, ○spinal manipulation or other forms of chiropractic care, ○talk therapies such as cognitive-behavioral therapy, ○yoga, Tai Chi, or Qi Gong,

	National Health Interview Survey
	○ massage, ○ other forms of exercise, such as walking, swimming, bike riding, stretching, or strength training, ○ meditation, guided imagery, or other relaxation technique? ■ Yes, no, refused, don't know; • Over the past three months, did you use any other approaches to manage your pain? Yes, no, refused, don't know

^ Note that there is a fill that says other than a prescription opioid if that was reported earlier.