**SUPPORTING STATEMENT**

**Part A**

Use of Open-Ended Responses to Explore Disparities in Patient Experience

**Version: September 13, 2023**

Agency of Healthcare Research and Quality (AHRQ)

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# A. Justification

## 1. Circumstances that make the collection of information necessary

The mission of the Agency for Healthcare Research and Quality (AHRQ) set out in its authorizing legislation, The Healthcare Research and Quality Act of 1999 (see http://www.ahrq.gov/hrqa99.pdf), is to enhance the quality, appropriateness, and effectiveness of health services, and access to such services, through the establishment of a broad base of scientific research and through the promotion of improvements in clinical and health systems practices, including the prevention of diseases and other health conditions. AHRQ shall promote health care quality improvement by conducting and supporting:

1. research that develops and presents scientific evidence regarding all aspects of health care; and

2. the synthesis and dissemination of available scientific evidence for use by patients, consumers, practitioners, providers, purchasers, policy makers, and educators; and

3. initiatives to advance private and public efforts to improve health care quality.

Also, AHRQ shall conduct and support research and evaluations, and support demonstration projects, with respect to (A) the delivery of health care in inner-city areas, and in rural areas (including frontier areas); and (B) health care for priority populations, which shall include (1) low-income groups, (2) minority groups, (3) women, (4) children, (5) the elderly, and (6) individuals with special health care needs, including individuals with disabilities and individuals who need chronic care or end-of-life health care.

The Consumer Assessment of Healthcare Providers and Systems (CAHPS®) program, which is sponsored by AHRQ, has the purpose of advancing the scientific understanding of the patient experience of care, including the development and testing of new surveys and/or approaches to data collection to promote or improve the collection of consumer reports and evaluations of their experiences with health care.

Standardized surveys and administration procedures are central components of CAHPS. The CAHPS survey items represent what consumers value and for which they are the best source of information. The CAHPS suite of surveys is extensive and includes items to evaluate ambulatory care (e.g., accountable care organizations--ACOs, health plans, clinicians/groups, patient-centered medical homes), and institutional care (e.g., emergency department, hospital, nursing home). CAHPS survey data are used as a component of provider quality payments programs hosted by CMS, including pay-for-reporting by ACOs under the Medicare Shared Savings Program and Merit-Based Incentive Payment System (MIPS), hospital value-based purchasing payments, and quality bonus payments for Medicare Advantage Plans.

There is growing evidence that consumers are interested in comments posted by patients online regarding their experiences with their doctors; the number and use of websites with such patient comments has increased rapidly in recent years. Comments from patients often cover the same experiential domains as closed-ended items include on CAHPS surveys, but in ways that can be easier to understand, more engaging, and more persuasive to those reading a report than statistically summarized survey scores. This has led AHRQ to develop Narrative Item Sets (NIS), including for the CAHPS Clinician & Group Survey (CG-CAHPS). The CG-CAHPS NIS captures experiences, in patients’ own words, that both align with the scope of CG-CAHPS closed-ended questions and extend beyond them (Grob et al., 2019; Schlesinger et al., 2020).

Important differences have been demonstrated in patient experience by race/ethnicity, gender, and preferred language, as captured in the closed-ended CG-CAHPS survey. For example, studies of people with Medicare have shown that, on average, American Indian and Alaska Native, Asian American/Native Hawaiian/Pacific Islander, Black, and Hispanic people tend to report worse experiences with care than non-Hispanic White people (Elliott et al., 2011; Fongwa et al., 2008; Martino et al., 2016; Martino et al., 2021; Weech-Maldonado et al., 2008). A recent analysis of Medicare’s patient experience data from 2009-2018 showed that although racial/ethnic inequities have lessened over time, sizable inequities remain. Other analyses have shown that preferring a language other than English can compound the problems that racial/ethnic minorities face in getting care that meets their needs (Haskard-Zolnierek et al., 2021; Quigley et al., 2019). In addition, patient experience also differs across genders in nuanced ways. A recent study found that female Medicare Advantage enrollees report worse experiences than male enrollees in getting needed care but better experiences with customer service staff (Burkhart et al., 2020).

Unlike responses to closed-ended survey questions, organizations fielding surveys often review and analyze patients’ open-ended responses (narratives) by hand, which requires time, resources, and human coders with specialized training. As health systems and hospitals have moved toward collecting narratives in greater quantities and at greater frequency, the need for automated analysis of narratives is growing. Health systems and hospitals need assistance in categorizing and sorting comments into groups to assist with processing voluminous narrative data into meaningful and usable content. More and more, health systems are turning to automated analysis of patent narratives using “off-the-shelf” Natural Language Processing (NLP) software, but these programs may not be well-aligned with the specific language and terminology used to describe healthcare experiences. Furthermore, a growing concern surrounding the actual deployment of these methods in real-world decision-making is the risk of “algorithmic bias.” In general, algorithmic bias refers to circumstances where predictive machine learning algorithms unintentionally reinforce or even exacerbate biases because of differential algorithmic performance across a sensitive attribute, such as race/ethnicity (Vyas et al., 2020), a problem that persists even when such sensitive attributes are not algorithmic inputs (Cabreros et al., in press; Pedreshi et al., 2008). That said, potential algorithmic adjustments include the input for these programs (i.e., the human-coded data on which algorithms are trained) or the outputs (i.e., the prevalence estimates used to characterize the experiences of different patient groups).

This research has the following goals:

1) Use open-ended (narrative) responses to provide context, detail, and understanding regarding observed differences in patient experience based on race, ethnicity, gender, disability status, and preferred language.

2) Use CG-CAHPS NIS-generated narrative data to examine potential algorithmic bias in NLP programs that could potentially be used to code large quantities of narrative data.

3) Where algorithmic bias is uncovered, use this analysis to identify adjustments that can be applied to both the input for these programs or the outputs.

To achieve the goals of this project the following data collections will be implemented:

Online survey: Data will be collected from a sample of 4,998 survey respondents drawn from the Ipsos KnowledgePanel, a large nationwide online panel of American adults (over 50,000 panelists) with demographic characteristics consistent with the adult U.S. population. Equal-sized subsamples will be drawn for each of the following groups: non-Hispanic Asian American, Native Hawaiian, or Other Pacific Islander; non-Hispanic Black; Spanish-speaking Hispanic; English-speaking Hispanic; non-Hispanic Multiracial; and non-Hispanic White. Within these six subsamples, we will strive to recruit a roughly equal split of men and women. The survey will be fielded in English and Spanish based on respondent-preferred language.

This study is being conducted by AHRQ through its contractor, the RAND Corporation, pursuant to AHRQ’s statutory authority to conduct and support research on healthcare and on systems for the delivery of such care, including activities with respect to the quality, effectiveness, efficiency, appropriateness and value of healthcare services and with respect to quality measurement and improvement. 42 U.S.C. 299a(a)(1) and (2).

Attachment A presents the study invitation that will be used for recruitment. Attachment B presents the CG-CAHPS 3.1 survey; the NIS for CG-CAHPS; and a closed-ended item, recently developed by CMS for inclusion on the Medicare CAHPS survey[[1]](#footnote-2), to assess perceived unfair or insensitive healthcare treatment because of a range of individual characteristics, as well as a follow-up open-ended question asking them to explain their closed-ended responses. The closed-ended item was modified slightly to fit the current clinician and group context. Attachment C presents the informed consent language all respondents will receive. Attachment D presents the Ipsos Confidentiality Agreement with their survey panelists.

## 2. Purpose and Use of Information

This new data collection effort is a one-time effort to be completed in 2023-2024. Respondents will be asked to complete the Online Survey, which includes the CG-CAHPS closed-ended survey instrument, followed by the CG-CAHPS NIS. Responses to the open-ended items that compose the NIS will be hand coded and NLP coded, including codes for perceived unfair or insensitive treatment based on race/ethnicity, gender, disability status, or language preference. Because the NIS was not designed to specifically elicit perceptions of bias, unfair or insensitive treatment, an additional closed-ended question on perceived unfair or insensitive treatment, and an open-ended follow-up question will be used to establish the NIS’s ability to detect these experiences and to obtain further descriptive detail.

Analyses of these data will inform AHRQ guidance on addressing equity in healthcare experience, as well as use of general NLP products for coding of NIS data.

## 3. Use of Improved Information Technology

Participants will complete the experiment through a secure online connection from their homes. Online Survey data are collected by a web-based survey system (internally referred to as “Dimensions”). This application runs on top of a secured Windows environment that has been hardened through various network and host-based security techniques. Participants take online surveys by using a web-browser to access a unique, secured web URL that is both emailed to them and made available through a secured web-portal. The URL provides access to click through to a highly-available load-balanced farm of web servers that hosts the Online Survey. This survey URL can be exposed via either standard http or over SSL and TLS encrypted https, depending on the client requirements. Throughout the interview process, questionnaire data are copied to a secured, centralized database for data processing.

## 4. Efforts to Identify Duplication

AHRQ is aware of no other investigations conducted that would have produced data comparable to the one described here, and NIS-elicited narrative data systematically sampled across demographic groups is currently unavailable. Hence, the proposed information collection does not duplicate any other effort and the information cannot be obtained from any other source.

## 5. Involvement of Small Entities

Online Survey respondents are consumers of health care services, and the test will employ a standard internet survey protocol, which is designed to minimize burden on survey respondents. Small businesses or other small entities will be not significantly impacted by the field test.

## 6. Consequences if Information Collected Less Frequently

This is a one-time data collection.

## 7. Special Circumstances

This request is consistent with the general information collection guidelines of 5 CFR 1320.5(d)(2). No special circumstances apply.

## 8. Federal Register Notice and Outside Consultations

***8.a.*** ***Federal Register Notice***

As required by 5 CFR 1320.8(d), notice was published in the Federal Register on June 27, 2023, page 41619 for 60 days (see Attachment E). No comments were received.

## 8.b. Outside Consultations

Given the nature of the data collection effort, which targets as-yet unanswered research questions involving one-time survey respondents, outside consultations were not necessary for this effort.

## 9. Payments/Gifts to Respondents

Remuneration will be provided by Ipsos to participants, according to their usual business practices. Ipsos incentivizes panelists primarily through the use of a point system, to encourage participation and create member loyalty. Members can redeem their points—for cash, merchandise, gift cards, or game entries—whenever they want. Point values depend to some extent on the type of reward panelists select when redeeming their points, but each 1,000 points is roughly the cash-equivalent of $1 (and most panelists choose to redeem their points for cash). Panelists would earn 1,000 points for completing this survey, plus earn an entry into a sweepstakes.

A past study with patients about their experiences with healthcare showed a greater response rate (57% vs. 50%) for those respondents offered incentives versus those who were not offered incentives, and similar but higher completion rates among those responding (99% vs. 97%; Brown et al., 2016). A second study showed increases in survey response rates (54% vs. 45%; Beebe et al., 2005). The proposed incentive amounts will offset potential increased recruitment costs to the project, thereby limiting the probability of survey non-response.

## 10. Assurance of Confidentiality

Individuals and organizations will be assured of the confidentiality of their replies under Section 944(c) of the Public Health Service Act.  42 U.S.C. 299c-3(c).  That law requires that information collected for research conducted or supported by AHRQ that identifies individuals or establishments be used only for the purpose for which it was supplied.

Information that can directly identify the respondent, such as name and/or social security number will not be collected.

## 11. Questions of a Sensitive Nature

The Online Survey includes questions regarding healthcare experiences and experiences with unfair or insensitive healthcare treatment. These questions are necessary to adequately address the proposed research goals. Responses will be used to illuminate important documented racial/ethnic, sex, and language-based differences in closed-ended CAHPS survey responses, as well as understand potential algorithmic bias in automated coding of narrative data. The nature of these questions, as well as the research team’s inability to link these responses to personally identifying information, will be described to respondents in an informed consent procedure implemented prior to participation.

AHRQ will explicitly collect informed consent from all respondents, as detailed in Attachment C. These materials include the following statement: “The confidentiality of your responses are protected by Sections 944(c) and 308(d) of the Public Health Service Act [42 U.S.C. 299c-3(c) and 42 U.S.C. 242m(d)]. Information that could identify you will not be disclosed unless you have consented to that disclosure.” Attachment D provides the Confidentiality Agreement with their panelists.

Whereas no direct identifiers will be included in the data, it is possible that respondents will provide identifying information, or information that could allow identification by inference, in their narrative responses. Initial data files will be encrypted and transmitted via secure file transfer. All data will be kept on password-protected computers. Initial data will first be screened and any potentially identifying information redacted within analytic datasets.

## 12. Estimates of Annualized Burden Hours and Costs

Exhibit 1 shows the estimated annualized burden hours for survey respondents' time to participate in this data collection. All participants will complete the Online Survey, which is estimated to take 17 minutes per response. The total annual burden hours are estimated to be 1,416 hours.

Exhibit 2 shows the estimated annualized cost burden associated with the respondents' time to participate in this data collection. The cost burden is estimated to be $39,662.

**Exhibit 1.  Estimated annualized burden hours**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Form Name | Number of respondents | Number of responses per respondent | Hours per response | Total burden hours |
| Online Survey | 4,998 | 1 | 17/60 | 1,416 |
| **Total** | 4,998 | na | na | 1,416 |

**Exhibit 2. Estimated annualized cost burden**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Form Name | Number of respondents | Total burden hours | Average hourly wage rate\* | Total cost burden |
| Online Survey | 4,998 | 1,416 | $28.01a | $39,662 |
| **Total** | 4,998 | 1,416 | na | $39,662 |

\* The May 2017 National Employment and Wage Estimates reported by the Bureau of Labor statistics indicate an average hourly wage of $28.01 across the 50 U.S. states and the District of Columbia. The national average has been used to estimate the wages of survey respondents. The Knowledge Panel consists of a broad cross-section of the U.S. adult population, and thus a national average should be a reasonable estimate of the wages of survey respondents. National Compensation Survey: Occupational wages in the United States May 2021, “U.S. Department of Labor, Bureau of Labor Statistics.”

aBased on the mean wages for all occupations, code 00-0000

## 13. Estimates of Annualized Respondent Capital and Maintenance Costs

Capital and maintenance costs include the purchase of equipment, computers or computer software or services, or storage facilities for records, as a result of complying with this data collection.There are no direct costs to respondents other than their time to participate in the study.

## 14. Estimates of Total and Annualized Cost to the Government

**Exhibit 3a.  Estimated Total and Annualized Cost**

|  |  |  |
| --- | --- | --- |
| **Cost Component**  | **Total Cost** | **Annualized Cost** |
| Project Development | $58,550 | $29,225 |
| Data Collection Activities | $120,280 | $60,140 |
| Data Processing and Analysis | $101,010 | $50,505 |
| Publication of Results | $56,650 | $28,325 |
| Project Management | $15,000 | $7,500 |
| **Total** | $351,490 | $175,745 |

**Exhibit 3b. Federal Government Personnel Cost**

|  |  |  |
| --- | --- | --- |
| **Federal Personnel** | **%Time** | **Cost** |
| GS 14.5 | 3% | $4,500 |
|  |  |  |

<http://www.opm.gov/policy-data-oversight/pay-leave/salaries-wages/salary-tables/pdf/2023/DCB.pdf>

## 15. Changes in Hour Burden

This is a new collection of information.

## 16. Time Schedule, Publication and Analysis Plans

AHRQ will not generate or publish population estimates from this field test. AHRQ, through its contractor RAND, will publish methodological findings to further the purpose of CAHPS to advance the scientific understanding of the patient experience. The methodological findings will be generated from the analysis of the data collected using the NIS in comparison to the CG-CAHPS survey, and from the analysis of NIS data comparing human-coded to machine-coded (i.e., NLP) data. AHRQ will test for differences across subsamples corresponding to race/ethnicity, gender, disability status, and language preference, as well as the prevalence and distribution of valence (positive versus negative comments) and themes contained in the narratives, identified through qualitative coding techniques, compared to those identified through NLP coding techniques. AHRQ will test the significance of differences in valence and themes by group or coding technique using between and within group t-tests and chi-square tests, as appropriate.

For planning purposes, AHRQ anticipates data collection will begin as early as October 2023 and no later than December 2023. The table below provides an approximate timeline for survey tasks including tabulation of data following review and approval of this survey.

|  |  |
| --- | --- |
| **Activity**  | **Proposed Timing of Activity**  |
| Code and test Online Survey instrument | Month 1 |
| Field Online Survey (4,999 participants) | Month 2 to 5 |
| Update coding scheme and hand-code data | Months 6 to 12 |
| Use NLP to machine-code data | Months 9 to 12 |
| Data analysis | Months 12 to 18 |

## 17. Exemption for Display of Expiration Date

AHRQ does not seek this exemption.

**List of Attachments:**

Attachment A -- CG-CAHPS NEP Invitation.docx

Attachment B -- Survey Instrument.docx

Attachment C -- Informed consent.docx

Attachment D -- Ipsos Confidentiality Agreement.docx

Attachment E -- 60 Day Federal Register Notice

1. 1 This item is currently undergoing field testing under a contract between RAND and CMS: National Implementation of Medicare Advantage and Prescription Drug Plan CAHPS Surveys. Centers for Medicare & Medicaid Services contract with the RAND Corporation (GS-10F-0275P/75FCMC20F0101). Elliott MN (Project Director). [↑](#footnote-ref-2)