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Health Insurance Plans Collecting More Data on Race, Ethnicity, and Language

Surveys of health insurance plans' collection of race, ethnicity, and language data to help address gaps in care

SUMMARY

Between 2003 and 2011, researchers at America's Health Insurance Plans Foundation conducted four surveys of health insurance plans in order to chart the extent to which the plans collected and used data on the race, ethnicity, and language of their enrollees in order to improve quality of care.

Researchers also conducted interviews and held an expert panel meeting with health plan decision-makers and national thought leaders to identify challenges and make recommendations regarding the collection of such data.

America's Health Insurance Plans Foundation, located in Washington, is a nonprofit organization furthering the educational, charitable, and research goals of America's Health Insurance Plans, the trade association representing the insurance industry.

Key Findings

The research team cited these findings in journal articles and reports to the Robert Wood Johnson Foundation (RWJF):

- By 2010, 78.7 percent of health plans were collecting race and ethnicity data of their members, up from 49.6 percent of plans in 2003.
- By 2010, 84.3 percent of health plans were collecting language data of their members, up from 74 percent in 2008 and 57.3 percent in 2003.
- Most plans indicated they were working with external partners—primarily nonprofit community groups—to improve data collection on race, ethnicity, and language and to reduce gaps in care.

Funding

RWJF supported this project through three grants totaling $652,887 to the America's Health Insurance Plans Foundation.

CONTEXT

According to a landmark report issued by the Institute of Medicine in 2003,[1] "Racial and ethnic minorities tend to receive a lower quality of health care than non-minorities, even when access-related factors, such as patients' insurance status and income, are controlled."

The report urged a comprehensive, multilevel approach to address these disparities. Key among its recommendations was that health plans should collect and report data on members' race and ethnicity. The collection of such data is important because, in contrast to health care providers, plans can obtain information about members who do not frequently use the health care system.

RWJF's Interest in This Area

In response to the IOM report, RWJF focused some of its grantmaking efforts on developing an understanding of the many complex factors contributing to disparities and determining which were most amenable to change.

The Foundation's funding in this area was managed initially by its Disparities team, which saw the collection of systematic data on race/ethnicity as a necessary first step toward stimulating interventions to reduce disparities. The project aligned with the Disparities team's strategic objective to reduce racial/ethnic disparities in the care of targeted diseases by 2008.

In the summer of 2007, RWJF combined its efforts to improve inequalities in care with those to improve quality overall, creating the Quality/Equality team. The second two grants were funded under the Quality/Equality team.

THE PROJECT

From 2003 to 2011, researchers conducted surveys of health insurance plans to chart the extent to which the plans collected and used data on the race, ethnicity, and language of their enrollees to improve quality of care. They wrote five journal articles and six reports on their findings. At the time this report was posted, two of the articles had been published; three are available online. (See the Bibliography for details.)

To identify challenges and make recommendations regarding the collection of such data, they also conducted qualitative research consisting of:

- Two sets of interviews with health plan representatives

[1] *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Smedley BD, Stith AY, Nelson AR (eds.). Washington: National Academies Press, 2003. Available online.

- An expert panel meeting with health plan decision-makers and national thought leaders

Surveys

Between 245 and 302 health insurance entities received the surveys—fielded in 2003, 2006, 2008, and 2010. These included commercial, Medicaid, and Medicare issuers of insurance plans. The surveys comprised 42 to 57 questions focusing on:

- Whether plans collected and used data on the race, ethnicity and language of their members. Plans that did not collect ethnicity and race data were asked to explain why in a separate section of the survey.
- Methods used to collect these data—particularly whether the data was collected directly (through self-reporting by the enrollee) or indirectly (e.g., derived through Medicaid or Medicare records, or through geocoding software that attempts to identify race and ethnicity by neighborhood or locality). This question is important because researchers consider direct data collection more reliable than indirect collection.
- Challenges the health plans faced with data collection.

For more details on survey methods, see the Appendix. The research team published an article on the first three surveys in *Health Affairs*[2]. In the *American Journal of Managed Care*,[3] they published a Web exclusive on the 2008 survey's findings related to enrollees' language. A 2011 report[4] by staff summarizes 2008 and 2010 survey finding in the areas of health literacy and clearer communications. For findings, see Survey Findings.

Interviews

The research team conducted interviews with key health plan representatives in 2004 and 2009 to explore:

- Why health plans collect or forgo collecting data on race, ethnicity, and language
- The challenges encountered with collecting and using such data for quality improvement

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[2] Escarce JJ, Carreon R, Veselovskiy G and Lawson EH. "Collection Of Race And Ethnicity Data By Health Plans Has Grown Substantially, But Opportunities Remain To Expand EffortsCollection and Use of Race and Ethnicity Data by Health Plans in the United States." *Health Affairs*, 30(10): 1984–1991, 2011. Abstract available online.

[3] Lawson, EH, Carreon R, Veselovskiy G and Escarce JJ. "Collection of Language Data and Services Provided by Health Plans." *American Journal of Managed Care* (Web exclusive), 17(12): e479–e487, 2011. Available online.

[4] *Health Literacy and America's Health Insurance Plans: Laying the Foundation and Beyond*. Washington: America's Health Insurance Plans, October 2011. Available online.

(See Findings from Interviews.)

Expert Panel Meeting

The research team held an expert panel meeting in 2004 to discuss survey data collection and its use. Sixteen people—including health plan decision-makers and national thought leaders from the academic field, the hospital community, and the federal government—participated in the meeting.

The panel recommended a two-pronged strategy to focus future activities:

- Continue to foster relationship building between health plans and other health care organizations to encourage knowledge sharing and identify best practices for data collection.
- Increase awareness about the importance of data collection among health plan audiences, particularly health plan enrollees.

FINDINGS

Survey Findings

The research team cited these findings in *Health Affairs*, the *American Journal of Managed Care*, the report *Health Literacy and America's Health Insurance Plans: Laying the Foundation and Beyond*, unpublished reports, including reports the grantee filed with RWJF to meet the requirements of grants ID#s 49540 (2005) and 62295 (2011).[5]

Plans' Collection of Race and Ethnicity Data

- **The proportion of health plans of all type collecting race and ethnicity data on their members rose from 49.6 percent of plans in 2003 to 74.8 percent in 2008 to 78.7 percent in 2010.** (*Major Findings for 2010 RWJF-AHIPF Survey on Race, Ethnicity, and Language Data Collection by Health Plans*)
- **Commercial plans lagged Medicaid and Medicare plans in these years in collecting race and ethnicity data on their members.** Medicaid and Medicare plans often receive these data from the Centers for Medicare & Medicaid Services or state agencies, whereas commercial plans need to rely on multiple methods for collecting these data. The percentage collecting such data, by type of plan, were:
  - Commercial plans: 31 percent in 2003, rising to 66.1 percent in 2010

[5] In order to include the most recent survey data (2010), this Findings section relies principally on a report submitted to RWJF in fulfillment of grant requirements for ID# 62295, and two unpublished reports listed in the Bibliography. Used sparingly are findings drawn from published materials that use less recent data.

— Medicaid: 69.6 percent in 2003, rising to 92.2 percent in 2010

— Medicare: 54.5 percent in 2003, rising to 82.4 percent in 2010

(*Major Findings for 2010 RWJF-AHIPF Survey…)*

- **Health plans continued to increase the *proportion* of their total enrollees for which they had data on race and ethnicity.** In 2010, the collecting plans had data on 62.0 percent of their enrollees compared to 32.6 percent in 2006 and 45.7 percent in 2008. The increase was especially noted for commercial plans—from 23.9 percent of enrollees in 2006 to 57.4 percent in 2010. (*Major Findings for 2010 RWJF-AHIPF Survey…*)

- **Regulatory environments played a role in plans' collection of race and ethnicity data.** In 2008, one-third of commercial plans, one-half of Medicaid plans, and one-third of Medicare plans reported that there was a current or pending regulatory requirement in their markets regarding the collection of data on health plan members' race and ethnicity. ("Collection and Use of Race and Ethnicity Data by Health Plans in the United States," *Health Affairs*, 2011)

- **Among health plans that reported *not* collecting race and ethnicity data in 2010, few (7.4%) reported any plans for initiating data collection within the next year.** (*Major Findings for 2010 RWJF-AHIPF Survey…*)

- **The use of *indirect* methods by all types of plans to collect race and ethnicity data on their members continued to decline (from 39.4% in 2006 to 32.0% in 2010).** While a mix of both direct and indirect data collection continued for most commercial and Medicaid plans, Medicare plans increasingly relied only on direct data collection (from 15.4% in 2006 to 42.9% in 2010). (*Major Findings for 2010 RWJF-AHIPF Survey…*)

  Considering only *numbers of enrollees*, not plans, in 2010 the percentage of Medicaid enrollees in surveyed plans showed a significant increase in direct collection of their race and ethnicity data—from 8.7 percent in 2008 to 22.1 percent in 2010. (*Major Findings for 2010 RWJF-AHIPF Survey…*)

- **Since 2006, less than half of all plans have collected race and ethnicity data on physicians/clinicians (45.4 percent in 2006; 39.3 percent in 2008; 45.2 percent in 2010).** (*Major Findings for 2010 RWJF-AHIPF Survey…*)

- **The proportion of plans of all types that collect data about primary or preferred language of their members rose from 57.3 percent in 2003 to 84.3 percent in 2010.** Each category of plan—commercial, Medicaid, and Medicare—showed increases in this type data collection throughout the study period. ("Collection of Language Data and Services Provided by Health Plans," *American Journal of Managed Care*, and *Major Findings for 2010 RWJF-AHIPF Survey…*)

Plans' Use of Data They Collected

- **All health plans reported in 2008 that they collected data on race and ethnicity to monitor and improve the care provided to diverse member populations.** For commercial plans, the most frequently reported *specific* reasons were:
  - Implementing or strengthening quality improvement efforts (71.1 %)
  - Identifying disparities in care (65.8 %)
  - Supporting culturally and linguistically appropriate communications to members (63.2 %)

  These were also among the most frequently reported reasons for Medicaid and Medicare plans, although these plans often used the data to assess variation in quality measures across racial and ethnic groups as well. (*Health Affairs* article)

- **The proportion of plans that identified racial and ethnic disparities among their enrollees rose from 44.9 percent in 2006 to 57.6 percent in 2008 to 58.6 percent in 2010.** In 2010, the three most common areas in which health plans identified disparities were:
  - Uptake of preventive health services
  - Prevalence of one or more chronic conditions
  - Treatment of one or more chronic conditions

  (*Major Findings for 2010 RWJF-AHIPF Survey…*)

- **For the first time in the series of surveys (reaching back to 2003), all health plans in 2010 reported providing language access services to their enrollees.** Examples of access services are telephonic or face-to-face interpreters and the provision of multilingual nurse lines. ("Collection of Language Data and Services Provided by Health Plans" and report to RWJF to meet the requirements of grant ID# 62295)

- **Over the 2003–2010 period, health plans of all types showed significant progress in the use of data on enrollees' race, ethnicity, and language to:**
  - Identify gaps in care and develop or strengthen quality-of-care improvement efforts in these areas
  - Implement staff and provider training in areas such as cultural competency training and health literacy efforts
  - Improve health plan communication materials and health literacy initiatives for members

  (*American Journal of Managed Care* article and Report to RWJF to meet the requirements of grant ID# 62295)

- **The proportion of plans of all types that addressed the health literacy of its enrollees in some fashion rose from 69 percent of plans in 2008 to 83 percent in 2010.** This increase in addressing health literacy was seen particularly among Medicaid and commercial plans. By 2010, also, most health plans were:

  — Adopting a targeted reading level for written consumer communications (90%) and standardizing member communications in clear, plain language (81%)

  — Emphasizing principles of clear communication with plan members through improved awareness and training for staff who interact directly with members or have written communication with them (increasing from 58.4% of staff trained in 2008 to 70.6% in 2010)

  (*Health Literacy and America's Health Insurance Plans: Laying the Foundation and Beyond)*

Findings from Interviews

The research team reported the following findings in an unpublished article[6] and in a 2005 report to RWJF:

- **Most plans indicated they were working with external partners to improve data collection on race, ethnicity, and language and to reduce gaps in care.** Health plans collaborated primarily with nonprofit community groups serving uninsured or minority populations, such as federally qualified community health centers and faith-based organizations, in addition to universities and professional associations.

  Some interviewees also stressed the importance of sharing best practices and lessons learned from program interventions with key stakeholders, such as provider organizations and government agencies. (Gazmararian unpublished article)

- **Barriers to efforts to collect data on race, ethnicity, and language include:**

  — Concerns about potential enrollee reactions to collecting personal information. Plans with these concerns, however, generally found ways to address disparities besides data collection, through partnerships with external organizations, such as foundations, government agencies, and universities.

  — The costs associated with adapting information technology systems to accommodate new functions, such as new data fields, appropriate software, and analytical tools

  — The lack of standard codes for race and ethnicity

  (Report to RWJF to meet the requirements of grant ID# 49540 (2005) and unpublished Gazmararian article)

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[6] Gazmararian J, Carreon R, Olson N and Lardy B. "Exploring Health Plan Perspectives in Collecting and Using Race, Ethnicity, and Language Data." Unpublished.

The project director included the following observations from the interviews in a report to RWJF:

- Executive and senior leadership is critical for initiating, maintaining, and sustaining race, ethnicity, and language data collection activities.
- Uniform race, ethnicity, and primary language data categories are needed that are comparable, meaningful, and actionable.
- Obtaining sufficient and accurate race, ethnicity, and language data takes multiple data collection approaches, significant resource allocation, and a long-term commitment.
- Health plans that currently do not collect race and ethnicity data are taking initial steps to assess their organization's infrastructure and policies to best address new markets and changing demographics of communities served.
- Health plans realize that more needs to be done to make progress in improving health care equity and that successful outcomes can only be achieved with the support, buy-in, and participation from key stakeholder groups such as hospitals, physicians, and employer plan sponsors, among others.

(Report to RWJF to meet the requirements of grant ID# 62295)

SIGNIFICANCE OF THE PROJECT

This project's surveys presented the first comprehensive and nationwide picture of health plans' activities and experiences collecting enrollees' race, ethnicity and language to date. According to Principal Investigator Barbara D. Lardy, MPH, this project's survey findings also provided considerable guidance to the work of the Institute of Medicine's 2009 subcommittee on data standardization and the 2010 Health Literacy Roundtable meeting on state health exchanges and health literacy practices.

LESSONS LEARNED

1. **Follow up surveys (which tend to focus on the immediate past) with other research tools that allow respondents to take a future perspective.** According to Principal Investigator Lardy, following surveys with interviews and an expert panel was "an excellent method for capturing the different views of health plans and consumers about how to address disparities in care and identify actions for moving forward."

2. **A pilot study can help researchers catch design errors before they force difficult choices midstream, or worse, significantly affect data analysis.** To keep an important trend analysis "alive" over successive surveys, project researchers had no choice but to retain a 2003 definition—governing "direct" and "indirect" methods

plans used to collect enrollee data—that was at odds with the definition used by most of the field. (By 2011, separate guidelines for "direct" and "indirect" had been issued by the Office of Management and Budget, the Institute of Medicine, and various states. Most recently, the U.S. Department of Health and Human Services proposed new standards under the Affordable Care Act. (Principal Investigator/Lardy)

AFTERWARD

According to Lardy, the research team is pursuing publication of three additional manuscripts on the surveys. She also notes that the team will likely field a fifth survey before 2014, although as of November 2011, there are no immediate plans.

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APPENDIX

Survey Methodologies

2003 Survey

- Sample size: 302 health insurance plans
- Number of respondents: 137, or 45.3 percent (58 commercial plans, 46 Medicaid plans, 33 Medicare plans). The plans represented a total of 88.1 million covered lives.
- Number of questions: 57
- Plans were asked to respond for only one of their products.
- Survey was conducted by sending an email invitation to plans with a link to a Web-based questionnaire.

2006 Survey

- Sample size: 260 health insurance plans
- Number of respondents: 156, or 60 percent (89 commercial plans, 50 Medicaid plans, 17 Medicare plans). The plans represented a total of 87.1 million covered lives.
- Number of questions: 42
- Plans were asked to respond for only one of their products.
- Survey was conducted by sending an email invitation to plans with a link to a Web-based questionnaire.

2008 Survey

- Sample size: 245 health insurance plans
- Number of respondents: 123, or 50.2 percent (65 commercial plans, 46 Medicaid plans, 12 Medicare plans). The plans represented a total of 133.9 million covered lives.
- Number of questions: 50
- Plans were asked to respond for the product with the highest enrollment. However, because most health plans have the highest enrollment in their commercial products, some multiproduct plans were also asked to respond for one additional Medicare or Medicaid product, so that the distribution of product-specific enrollment in the sample reflected the composition of the industry.
- Survey was fielded by distributing an Excel spreadsheet via email.

2010 Survey

- Sample size: 250 health insurance plans
- Number of respondents: 127, or 50.8 percent (59 commercial plans, 51 Medicaid plans, 17 Medicare plans). The plans represented a total of 170 million covered lives.
- Number of questions: 51
- Plans were asked to respond for the product with the highest enrollment. However, because most health plans have the highest enrollment in their commercial products, some multiproduct plans were also asked to respond for one additional Medicare or Medicaid product, so that the distribution of product-specific enrollment in the sample reflected the composition of the industry.
- Survey was fielded by distributing an Excel spreadsheet via email.

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