

Risks and Rewards of Demographic Data Collection: How Effective Data Privacy Can Promote Health Equity

This four-part report series is a joint project of the National Health Law Program, DREDF, Justice in Aging, Movement Advancement Project, and Race Forward



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Administrative Data: Providing Information to Advance Autonomy and Drive Equality

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INTRODUCTION

While the term “administrative data” may sound wonky and complicated, the truth is that these types of data are everywhere. Administrative data are generated in individuals’ interactions with system, and are collected and stored in the day-to-day running of a program, such as an insurance program. Individuals’ administrative data can be linked to other pieces of information to identify them or be de-identified depending on the context or usage. For example, health care administrative data includes data from government programs like Medicaid, Medicare, and Supplemental Security Income, vital records, child welfare records, and data from social service providers who receive federal funding.

In health care, administrative data and electronic health records (EHR) are both places where lots of information is collected and kept.¹ For example, the Centers for Medicare and Medicaid Services (CMS) have vast administrative data including program application and eligibility information, enrollment information, and claims data. Health providers or health systems also collect and maintain health care data, often in EHRs. Thus, when you fill out a medical intake form at a new clinic, when test results come back from a procedure or a prescription is filled, when your health care provider submits a billing code to your health insurance provider for reimbursement, these are all data points that are generated. Some of these pieces of information are stored in your electronic medical record, while they may also be submitted for a particular purpose to a specific program, which generates administrative data.

Administrative data are different from, and provide a different picture than, other types of data such as data collected by surveys. Together, for example, administrative data—including electronic medical records—tell a story, often over multiple points of time, that is quite different from survey data, which is often one point in time and is reliant entirely on self-reporting.² Because these data are generated and collected as part of regular processes, they generally have much lower costs than survey data and do not require a new survey or effort to collect. Administrative data also include participants across a program, so they have the potential for more representativeness than a survey and larger samples that allow for deeper and richer analyses. There are also ways to link separate administrative data sets to see how people move through systems and follow their experiences over their lives. For example, a program at Chapin Hall pairs data about birth weights from birth records paired with Internal Revenue Service data, Census data, and other administrative data records to examine the relationship between health at birth and later life outcomes, including the impact of early health interventions.³

This brief highlights some of the important opportunities for administrative data in the health care context for individuals, for health care systems, and for broader society, while also demonstrating that it is critical that administrative data collection systems are examined to ensure they are as inclusive as possible. Specifically, this means developing measures of vital demographic characteristics, many of which are directly related to health care, including sexual orientation and gender identity, disability, and race and ethnicity. Some of this data is perceived as private, particularly in the health care context. However, research finds that a) individuals understand the importance of this data to their own care and b) such data can be used to shape system-level care as well as to inform the development of better policies. Ideally, when the “why” of collecting this information is shared—along with the presence of robust privacy safeguards—individuals can express the autonomy and agency in making decisions about whether to disclose this information.

WHY IS IT IMPORTANT FOR ADMINISTRATIVE DATA TO HAVE INCLUSIVE DEMOGRAPHIC FIELDS?

Existing research has clearly established existing health care disparities for various communities and for people who are members of many communities. These include people of color, people with disabilities, gender and sexual minorities, and low-income people. Importantly, people do not live singular lives, and many people live at the intersections of marginalized identities. For example, a Deaf Black lesbian will experience unique experiences of discrimination and resiliency along the various dimensions of her identity.

Administrative data sets provide richer data, collected over time with relative consistency. When they have inclusive demographic fields, allowing people to report their race and ethnicity, their sexual orientation and gender identity, and their disability status, these data can have multiple benefits, as shown in Figure 1. This is why many organizations, including the National Academy of Medicine, the Joint Commission, the Institute of Medicine, the American Medical Association, the National Medical Association, the American Nurses Association, and the American Pharmacists Association have called for improved demographic data inclusion.⁴ Yet, currently it is still rare for the vehicles by which administrative data is collected, such as intake forms, electronic health records, eligibility applications, and other places, to include explicit and complete measures of these important demographic characteristics.^{5,6}

Figure 1



(an icon of a single person)

Ensuring compassionate, clinically and culturally appropriate individual care



(an icon of a school building)

Shaping institutional programs and services



(an icon of a group of people)

Improving understanding of, and policies to address, disparities



Ensuring Compassionate, Appropriate Individual Care. Inclusive demographic fields in administrative data have several key benefits for individual patients, including:

- Improving trust and communication between individuals and providers⁷
- Enhancing shared decision making between individuals and providers⁸

- Helping providers identify appropriate procedures or identifying particular risk factors
- Allow individuals to identify health care providers that are welcoming and exclude those who have been found to discriminate or violate civil rights

These benefits come despite the frequent incorrect assumption that some demographic questions are “overly sensitive.” For example, that is frequently a response to requests to include measures of sexual orientation or gender identity. In a 2017 study of both patients and providers, 88% of providers felt that collecting sexual orientation data would offend patients. Yet only 11% of LGBT patients said they would be offended.⁹

Research finds that when patients know there are privacy considerations in place (see more below) and that the information is being utilized to advance care, LGBTQ+ people want to share relevant information. For example, in a survey of patients at health centers across the United States, most respondents, regardless of whether they were LGBT or not, answered sexual orientation and gender identity questions—and they indicated they would answer such questions into the future.¹⁰ In an oncology and urology clinical setting, over 79% of urology and 73% of oncology patients said they would respond to a sexual orientation question within an electronic medical record completed online prior to their appointment, with no differences for sexual minority versus heterosexual respondents.¹¹ When patients do disclose demographic information, research finds they are then more likely to feel comfortable discussing health and risk behaviors, all of which can drive better health care.¹²



Shaping Institutional Programs and Services. When institutions have inclusive data fields in their administrative data, they can utilize such data to identify population differences.¹³ These could include:

- Differences in safety, quality measures, and outcomes within a particular hospital or health care system
- Identifying variations in satisfaction by demographic characteristics with clinicians, clinics, or services
- Comparing health outcomes for patients with a particular demographic characteristic to national samples
- To establish system-level best practices for prevention, screening, and early detection of conditions
- Monitoring compliance with civil rights laws

For example, if transgender patients are less likely to return for a second annual exam, an institution may want to explore whether transgender patients overall are having a negative experience with a particular clinician or facility. Researchers have utilized data from the Department of Veterans Affairs (VA) to identify people who had diagnoses that are related to gender identity.¹⁴ Such data make possible the examination of quality of care, disparities in care, and outcomes for a subset of transgender people in the VA system. While transgender people were identified using diagnoses and treatment codes, not all transgender people who use the VA system may be identified in this

way. For example, some transgender people may not have sought transition-related care and are not identifiable in this data set. Asking people for their gender identity is an easier, more straightforward, and accurate way to identify transgender people who use VA services and to examine their experiences with care and health care outcomes.



Improving Understanding of Disparities at a State or National Level and Establish and Evaluate Policy. Administrative data can be utilized for an entire program across institutions for multiple functions, all of which can help drive evidence-based improvements.

For example, administrative data can be aggregated across geographies and systems to understand population-level experiences. These can include:

- Identifying gaps in treatments for diagnoses by demographic characteristics
- Measuring disparities and identifying potential interventions
- Examining relationships between diagnosis, treatments, and outcomes with demographic characteristics
- Understanding access to programs based on demographic characteristics, including who applies but does not enroll, who enrolls but does not utilize services, and who enrolls but loses access at a redetermination period due to churn
- Identifying the impact of innovative programs

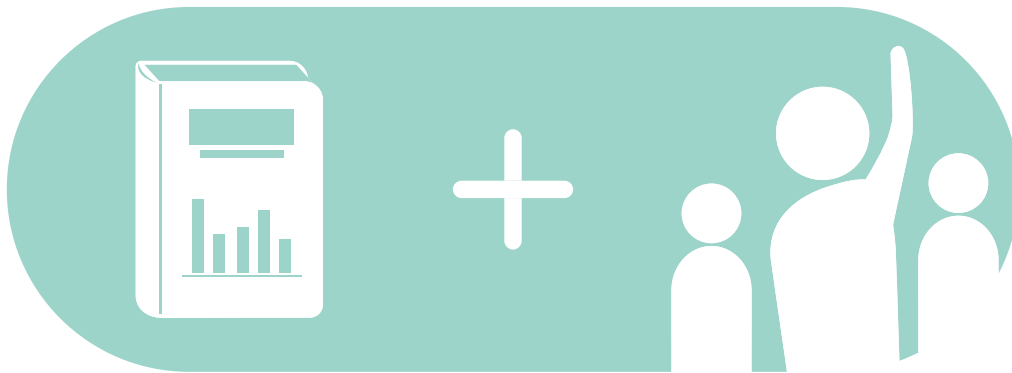
For example, in St. Louis during the COVID-19 pandemic, a regional data-sharing collaboration allowed researchers to bring together electronic health records and analyze it to help government leaders and health officials have a better sense of what was happening in the region with COVID-19 cases.¹⁵ Because the data had measures of race and ethnicity, researchers quickly identified that 60% of the region's COVID-19 cases were among African Americans despite comprising 20% of the area's population.

Medicare claim records have been utilized to identify beneficiaries who may be transgender by utilizing billing codes, prescriptions, procedures, and diagnoses.¹⁶ Studies have examined various health-related outcomes and utilization of care, providing a previously inaccessible level of detail about this population.¹⁷ That said, without explicit questions about gender identity, researchers both within health systems and examining population-level dynamics are left to put together a puzzle of billing codes, prescriptions, and diagnoses. Rather, when questions about gender identity are asked, in the waiting room on an intake form, in the exam through with a health care provider, or both, it facilitates both better care and allows for better analyses about quality of care, access to care, barriers, and opportunities for innovation.

BALANCING RISK & BENEFIT: AGENCY FOR INDIVIDUALS PAIRED WITH INFORMATION

There are clear benefits to individual patients, health care institutions and programs, and nationally for policy to having inclusive and robust demographic data inclusion in administrative data. But how should it be done? And how can individuals who are already often marginalized in health care settings and in government programs be respected in the process? This is where knowledge and information sharing paired with voluntary participation give individuals agency about whether and how to provide this information.

Figure 2: Pairing Knowledge with Voluntary Participation Results in Agency for Individuals to Disclose and Share Information About Themselves



(an icon of a book mathematically being added to a group of people, one of whom has a raised hand)

Importance of Knowledge Sharing

Program staff, quality control departments, and researchers understand the value of robust demographic data and all that it can do in terms of improving individual care, improving systems, and driving evidence-based policy. But rarely do individual patients or program participants have insight into those benefits. Rather, they are more frequently confronted with questions on an intake form or during a clinical visit without the important context. Thus, it is critical that information be shared with individuals about a) why they are being asked a particular demographic question and its connection to their care; b) how the information will be used or stored; c) the privacy protections that exist for individuals within a particular facility or system where they are.¹⁸ In all these communications, care should be taken to ensure that communication is done in plain language, accessible for different populations including in various languages, for those with visual disabilities, and varying cognitive abilities.

Why collecting demographic information impacts patient care. People should not be asked questions that are entirely irrelevant to their care. Rather, they should know that the questions being asked have a purpose—for example, a purpose that is directly related to their care or for identifying broader system—improvements, or both. Take the example of questions about sex assigned at birth alongside a question

about current gender. On the one hand, this information, together, allows for identification of transgender patients and could be useful for population health purposes like demographic analyses. It could also help identify trends in patient satisfaction for transgender patients compared to their cisgender peers. At the same time, asking patients questions that allow for transgender patients to identify themselves are useful for individual patient screenings and clinical purposes, such as determining whether a patient may qualify for a diagnostic test for individuals with a cervix.¹⁹ When patients understand the need for these questions, patients see such questions as acceptable and respond at high rates.

How information will be used or stored. There must be protections in place to restrict the use of the data to those goals and individuals should have those protections clearly explained.²⁰ This may require having different privacy policies and rubrics for data usage and sharing in clinical contexts and for broader quality control or research purposes. For example, it may not make sense for every person who engages with a patient individually, such as front office staff or a pharmacy technician, to know a patient's sex assigned at birth. For them, merely having information about the correct pronouns could be appropriate. That said, a quality control analyst may want to assess how a practice is doing in terms of patient satisfaction for transgender patients, so utilizing this data could be warranted.

What protections exist for individuals. It is also vital that individuals know about their own rights and protections related to their health care data, including answers to demographic questions. This includes clear and accessible communication about federal, state, and program protection against unauthorized disclosure and discrimination.²¹

Health care data are explicitly protected from unauthorized disclosure by covered entities in the Health Insurance Portability and Accountability Act (HIPAA) and the Affordable Care Act (ACA), as well as state laws, where they exist. Under HIPAA, "protected health information" or PHI are articulated types of health information that may have specific protections about disclosure and use. HIPAA seeks to protect individual's information while still allowing for information sharing that can support individual health care and advance broader public health goals. It outlines a definition of protected health information, which includes:

- Past, present, or future physical or mental health or condition;
- The provision of health care to the individual;
- The past, present, or future payment for the provision of health care to the individual; and
- Information that can—or could reasonably be thought to—be used to identify an individual such as name, address, birth date, Social Security number.

Thus, demographic information such as gender identity or disability status could be considered protected health information and must be treated with the same protections as other PHI under HIPAA. These protections against use and disclosure without an individual's permission can help individuals feel certain that their information is safe.

The ACA also includes robust nondiscrimination provisions for health care, as do many state laws. In the ACA, Section 1557 prohibits discrimination based on race, color, national origin, sex, age, or disability in certain health programs and activities. Protections against sex discrimination have been interpreted

to be inclusive of sexual orientation and gender identity by the U.S. Department of Health and Human Services²² and subsequently by the U.S. Supreme Court in its 2020 ruling in *Bostock v. Clayton County*.²³ It is critical that patients are informed of these protections frequently throughout their health care experiences, but especially when being asked to provide demographic information. Patients should know that—regardless of whether they provide this information, but especially if they disclose—any discrimination they experience based on these characteristics is illegal and they have recourse.

It is necessary that facilities back up their commitments to HIPAA information protection requirements and nondiscrimination requirements with comprehensive internal processes and trainings. This includes frequent and comprehensive staff training specifically about bias, discrimination, and legal requirements related to serving diverse communities. Trainings must be required for all staff, including health care providers, intake staff, staff who will be analyzing the data, and others.²⁴ This will help ensure that there are clear protocols for demographic information, how it is accessed and by whom and for what purpose. Frequent and comprehensive training can minimize the risk that any individual who provides such data is treated adversely, and that the data is not disclosed when it should not be.

Importance of Voluntary Participation

Particularly when it comes to questions about sexual orientation and gender identity, race and ethnicity, disability status, and a few other dimensions of identity, it is critical to acknowledge that real and present fears of discrimination, harassment, and even violence that some have experienced related to these parts of themselves. As such, it is vital that responses to demographic questions be voluntary.²⁵ Research shows that it is possible to ease concerns and increase voluntary reporting by implementing recommended practices.²⁶

Notably, when information is not provided, this leaves gaps in the data which make both institution or system and broader public health investigations more challenging. In these instances, researchers may “impute” or make estimates about the missing fields based on other information available.²⁷ For example, in an examination of insurance data from health plans offered through federal marketplaces and state-based exchanges called the Multidimensional Insurance Data Analytic System (MIDAS), a 2022 report by RAND found that voluntary self-reported race and ethnicity questions were not completed by approximately 33% of enrollees.²⁸ They used previous year’s records to reduce the missing data, but then attempted to impute race and ethnicity based on other pieces of information such as surnames, first names, and residential addresses for the remaining missing fields. They determined this worked very well for some racial and ethnic groups, but not for others. This did not work well for American Indian/Alaskan Native or multiracial enrollees. Notably, there is far less research showing how imputation for missing data works for demographic characteristics such as sexual orientation, gender identity (specifically transgender identity), or disability.

Agency is Critical for Frequently Marginalized Communities

When individuals are given information about why they are being asked to provide demographic information, they can ascertain that the information is appropriately used and contributes to broader goals around equity. When they understand how the information will be collected, stored, and accessed

and what rights and protections are in place for their data, they can make an educated and empowered decision about disclosure. Research confirms that when individuals receive explanatory background about demographic data collection and privacy protections, they are willing to provide demographic information.²⁹ For example, in a survey of transgender patients, having information shared with them about the medical relevance of the information they were being asked to share, along the patients feeling that the provider or health center was LGBT-friendly, boosted willingness to disclose.³⁰

Agency given to the individual is critical not only for the collection of such data but also for building trust and creating a respectful relationship.

SPOTLIGHT: City and County of San Francisco’s Demographic Data Policies

Beginning in 2017, the City and County of San Francisco required that when demographic data about an individual’s gender, race, or ethnicity is asked, questions about sexual orientation and gender identity must also be included.³¹ This applies to many public departments that offer vital services, including the Department of Public Health, the Department of Human Services, the Department of Aging and Adult Services, the Department of Children, Youth, and Families, the Department of Homelessness and Supportive Housing, and the Mayor’s Office of Housing and Community Development. This requirement also applies to contractors or grantees of these departments.

In the collection of this information, the city outlined key requirements including:

- That clients are told that the sexual orientation and gender identity information is voluntary
- That clients are told no services will be denied if they decline to provide such information
- Clients be advised that the entity collecting the information will protect it from unauthorized disclosure to the extent permitted by law
- Each department will develop robust systems for data collection, coding, and reporting the information.

CONCLUSION

Administrative data that is inclusive of key demographic characteristics have incredible promise. Paired with electronic medical records, when patients voluntarily provide data about their race and ethnicity, sexual orientation, gender identity, preferred written and spoken language, and disability status, there is opportunity not only for improved individual patient experience, but for improvements in health care delivery at a system level and policy-level change. Yet, far too often, these questions are not included. This stems from concerns about patient privacy and reluctance. However, as shown in this brief, when patients are given information about why they are being asked these questions, how the information will be used, and what protections they and their data have, patients want to answer these questions and will do so.

ENDNOTES

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