

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

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Data and Discrimination: Improving Data Privacy for Low-Income Older Adults in Managed Care

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INTRODUCTION

Robust collection and sharing of both demographic and health data is essential for coordinating delivery of health care services, for measuring health disparities, and for judging the success of health care models and interventions. The value of accurate data, and effective sharing of information, is especially evident when looking at low-income older adults enrolled in both Medicare and Medicaid. Individuals dually eligible for Medicare and Medicaid disproportionately come from underserved communities, are more likely to have multiple complex conditions and/or need institutional or home care for daily support, and are more likely to have social needs that impact their health and well-being.¹

An increasing number of dually eligible individuals are enrolled in managed care plans for their Medicaid services² or their Medicare services³ or both. When individuals are enrolled in aligned care across programs, the range of providers with potential access to their health and demographic data and the amount of data available both expand. This offers potential to improve care coordination among providers on both the Medicare and Medicaid side: medical providers such as hospitals, physicians, and physical therapists, and Medicaid providers such as long-term care facilities, and providers of home and community-based services, many of whom are not licensed medical professionals. Participation in an aligned system eases communication, for example, between a primary care physician whose services are covered by Medicare and a medical social worker who is working with the same enrollee providing Medicaid-covered services. Coordination between Medicare and Medicaid providers also is critically important when an enrollee transitions from hospital care or post-hospital rehabilitation and needs Medicaid community supports in order to live safely back at home. At the same time, this broader sharing of sensitive health and demographic information increases the importance of privacy policies.

Between information collected by the programs they depend on for their benefits and data collected by their many providers, dually eligible individuals' files are thick with health and non-health information.

Dually eligible individuals, like all of us, care about the privacy of their data. They don't want their data hacked, sold, used to profile them or, manipulated by unknown parties. But frequently their most acute privacy concerns tend to be much closer to the ground. They are less concerned about disclosure of sensitive information to unrelated third parties than about whether a provider or caregiver might deny them service, or discriminate against them, embarrass them, or even abuse them after learning sensitive information about their health history or their personal or demographic traits from their health record.

This paper looks at this very immediate and very personal side to data privacy in health care. It specifically examines tools to address individual privacy concerns in the context of managed care plans that integrate and coordinate the provision of Medicare and Medicaid services with high need dually eligible enrollees. It explores how to address these privacy concerns and the fears that underlie them in ways that do not undermine the potential benefits of demographic analysis and care coordination among providers. The paper focuses on one population and one type of care delivery system, but the privacy issues discussed are not limited to dually eligible individuals or to integrated managed care plans, nor are the opportunities and challenges in addressing them.

The paper considers the potential and the limits of opt-in and opt-out consent procedures for managed care enrollees that the Centers for Medicare and Medicare Services (CMS) has recently proposed. The rule poses significant challenges for data collection and sharing: For instance, navigating consent options is challenging for enrollees; operationalizing data limitations is difficult for plans; and opt-out choices

can significantly impair coordination of care. Alternative approaches might instead focus on the need for strong antidiscrimination policies to complement privacy protections. A combination of measures ranging from cultural competence training to rigorous enforcement of privacy and antidiscrimination protections can create a culture that honors autonomy and empowers enrollees while also facilitating coordination of care through appropriate sharing of health care information.

PRIVACY AT ITS MOST PERSONAL

Older adults, especially those with several chronic conditions, may need assistance with the activities of daily living. They often have a multitude of providers ranging from specialists and primary care physicians to nurses, physical and mental health therapists, and aides who, often on a daily basis, assist them with their most intimate needs—getting out of bed, bathing, toileting, getting dressed, etc. For these individuals the biggest privacy concern may be how they will be treated if the person bathing them knows their personal medical history. For example, will the fact that years ago they fought drug addiction mean that their caregiver won't trust them? Will their criminal record mean that they can't get into a good skilled nursing facility? If they are HIV positive, will the caregiver not want to touch them? And if they move into a congregate living facility, will word get out that they are transgender, and will that affect whether care staff respects them? Will it mean that other residents refuse to sit with them at dinner? What will happen if revelation of a piece of "data" about their sexual orientation causes a rupture in their relationship with their home care aide, who for days at a time may be the only person they see and is their primary source of companionship? These types of incidents not only disrupt care, they also can cause and reinforce trauma.

These fears are not unfounded, and often draw from repeated trauma in dealing with the health

care system. In *Stories from the Field*, Justice in Aging reported numerous cases where LGBTQI+ older adults experienced discrimination in long-term care facilities ranging from verbal and physical harassment, to visiting restrictions and isolation, to being denied basic care such as a shower, or being discharged or refused admission.⁴ Care refusals and disrespectful treatment by medical professionals, also grounded in discrimination, happen in every health care setting, even with providers in emergency rooms.⁵

These fears can be deep but they coexist with the competing desires of older adults—and indeed all of us—to tell their stories and be able to live as their whole selves in their community. Indeed, there is a growing body of research on the therapeutic value of personal storytelling on the physical and mental health of older adults, including those living with dementia.⁶ One set of studies, for example, found that storytelling decreased depression in dementia patients while also assisting staff with providing person-centered care.⁷

Older adults want to be seen and want to be heard, but they want control of their own narrative. They want to control when and with whom they share the details of their life, particularly when those details involve sensitive matters. Those with serious health needs often have lost almost all physical privacy, with aides necessarily involved in the most intimate and personal activities of their daily life and an endless parade of doctors, nurses, and other providers examining them inside and out. They have little control over those aspects of their life but keeping control over their personal information, the data that defines who they are and what they have been through in their life, allows them a measure of dignity and personal autonomy.

DATA AND MANAGED CARE FOR DUALY ELIGIBLE INDIVIDUALS: WHO CONTROLS THE INFORMATION?

An increasing number of individuals who are dually eligible for Medicare and Medicaid health coverage are enrolled in managed care plans that, at least to some extent, coordinate their health care services across both programs. In some models, a managed care health plan sponsor provides all or most of Medicare and Medicaid covered services through either a single entity, such as a Fully Integrated Dual-Eligible Special Needs Plan (FIDE-SNP) or a Medicare-Medicaid plan (MMP), or a Program of All Inclusive Care for the Elderly (PACE) program.⁸

In other models, Medicare and Medicaid plans operate separately but coordinate services. A plan sponsor offers all Medicare covered services through a Medicare Advantage (MA) plan and some or all the members of that plan also are enrolled in a Medicaid managed care plan (MCO) operated by the same sponsor.⁹ A key element in all these models is coordination of care among all providers across both programs, with a care manager assigned to the enrollee. A goal for these models is person-centered planning and empowerment of the individual to take an active role in managing their care.

These integrated plans hold a wide range of data about their enrollees. They have basic demographic data (age, sex, race, marital status, employment status, disability status) collected by the Social Security Administration for Medicare enrollment. Much of this information is already known by SSA from Social Security enrollment records but it is confirmed during the Medicare application process, which is often conducted over the phone. Plans also have demographic data collected by state Medicaid agencies. The level of demographic detail in Medicaid applications can vary. For example, the Alabama Medicaid application for Aged &

Disabled Medicaid lists six “Race” categories.¹⁰ The California application lists fifteen.¹¹

Plans have additional information that they collect when individuals enroll in their Medicare and Medicaid managed care plans, and they have access to the records of both their Medicare and Medicaid network providers. With the enrollee’s permission, they also have access to a wide range of prior health information including prior employer plans, Marketplace plans, correctional health care systems plans, safety net providers, and others.

Health Risk Assessments (HRAs) conducted by the plans can also contain a significant amount of non-health data. For example, all Special Needs Plans (SNPs) are required by regulation to include questions addressing food security, housing stability, and transportation access in their HRAs.¹² Other information gleaned by care managers in their interaction with enrollees add to the wealth of data that the plan can hold. Provider records, besides containing information on health and steps taken by providers, may also contain personal information that the provider deems relevant.

By regulation, all MA plans are required to have procedures that specify the purposes for which health and enrollment information of enrollees will be used within the organization and to whom and for what purposes it will disclose the information outside the organization.¹³ They also are required to abide by all applicable state and federal privacy laws.¹⁴ Within those parameters, plans have broad authority to set limits and conditions for data sharing with network providers and with the plan’s own employees. Plans could, for example, decide what enrollee data they would share with their non-emergency transportation contractor or what level of information access they would allow for home health aides. Plans could also require that provider groups in their network block access of their front office staff to certain categories of sensitive enrollee data.

Because integrated plans contract with a wide range of providers, however, there are practical limits on the extent to which plans could actually enforce controls on how contracted providers handle data once the provider is given access. Though a plan might want, as noted in the above example, to require that all medical providers set specific limits on categories of data shared with non-medical staff, it would be difficult to operationalize such a requirement with a large medical group unless the group set up systems to limit access to that data for all its patients, not just enrollees in that plan. Enforcing such a requirement might be equally challenging in the office of a sole practitioner where staff perform multiple functions and data segregation would be difficult.

CURRENT EFFORTS TO MANAGE PRIVACY CHOICES

Disclosures and consent forms offer a starting point for data protection. In an important and extensive recent Notice of Proposed Rulemaking (NPRM), CMS proposed both technical and procedural requirements for the handling of data by managed health care plans, including requirements around consent by enrollees for data sharing.¹⁵ If adopted, the rules proposed in the NPRM would enhance plans' ability to share data with providers, with other plans, and with their enrollees. To address individual privacy concerns, the NPRM utilizes written electronic notices of both opt-in and opt-out mechanisms to offer enrollees the opportunity to refuse data-sharing.

The proposals offer privacy protections beyond those of the Health Insurance Portability and Accountability Act (HIPAA), which generally gives covered entities the option to deny an individual's request to withhold health data from providers.¹⁶ They also go beyond current Medicare Advantage confidentiality requirements, which require compliance with federal and state law and require procedures that specify the purposes for which information will be used within the

organization and to whom and for what purposes the information will be disclosed outside the organization.¹⁷ The detailed opt-in and opt-out provisions also are new.

The NPRM proposes an opt-out mechanism for individuals who do not want to permit plans to share their health information with providers. Under the proposal, plans would be required to provide written notice, both upon enrollment and annually thereafter, of the opportunity to opt out of data sharing with plan providers. Permission to share health and demographic information would be assumed unless the individual specifically chooses to deny permission for such sharing.¹⁸

In contrast, for data sharing between managed care plans, affirmative consent through an opt-in process would be required. Sharing between plans might occur when an individual changes plan enrollment or, in the case of those who are dually eligible for Medicare and Medicaid, when individuals are concurrently enrolled in more than one plan. As with the opt-out provision, written notice would be required annually and an individual could change preferences at any time.

As currently drafted, both proposed rules would only require that a plan offer all or nothing consent options. Thus, if an enrollee opted out of data sharing with providers, that choice would mean that the plan would be prohibited from sharing any health files and could only share the bare minimum of demographic data needed in connection with submission of payment requests. Similarly, a choice by an individual not to opt in to data sharing between plans would mean that no health files from a prior health plan could be shared. When an individual has concurrent coverage, such as both Medicare and Medicaid coverage, a choice not to opt into sharing of health information would mean that only information related to eligibility and information needed to coordinate payment between payers would be shared.

In both cases, if an individual denies consent, the decision would impose very significant barriers to care coordination. If, for example, an individual refused to allow a plan to share records with any plan provider, that would mean that each provider would be starting from scratch and would be forced to rely exclusively on the enrollee to develop a medical history and identify other providers working with the enrollee. This would be especially challenging with dually eligible older adults with more complex medical histories, especially those with low health literacy who may have a hard time providing medical history with any specificity or accuracy. It would also mean that, unless an enrollee shared information about a disability in their record, the provider would not know to be prepared to meet accessibility needs. Similarly, an enrollee's refusal to allow data sharing between Medicare and Medicaid programs would exacerbate the gaps in care that occur when Medicaid providers of home and community-based services are not made aware of the specific transition needs of their enrollees leaving hospitals or other acute care settings or may not even be made aware at all that the individual was hospitalized.

CMS did, however, encourage plans to give enrollees more control of choices by offering the opportunity to opt out of data exchange with specific providers or categories of providers.¹⁹ The agency also asked for comment on whether it should require giving enrollees power to control which data they permit the plan to share, such as setting limiting timeframes for data that can be shared.²⁰ Under this option, an individual might, for example, not allow sharing of records that are more than ten years old.

If the more granular options were adopted, either voluntarily by plans or by regulation, they would be helpful in giving enrollees agency to protect the demographic or health information that they consider most sensitive. The ability to exclude particular providers from access to one's records or to ensure the privacy of data from particular

times in one's life could go a long way to empower enrollees to control information that they believe would interfere with their relationship with needed providers. Knowing that they could carve out information or providers from data sharing also would give enrollees more confidence in allowing other data sharing needed for effective teamwork with and among their providers.

These more nuanced options, however, would be difficult to operationalize effectively and challenging to communicate to dually eligible enrollees with low health and computer literacy and limited internet access.²¹ Many enrollees with high needs have a large and ever evolving cast of health providers in many fields, and likely could not even name them all. Moreover, their concern about sensitive information often is about protecting that information when they are seeking or working with new providers with whom they have not established a relationship of trust. Further, though the NPRM proposes rules that would facilitate review of their own health information by enrollees, the practicalities of sorting through files, identifying data an individual considers sensitive, and designating specific limits would be beyond the technical capabilities of many dually eligible older adults.

Given the operational limits to even a carefully designed notice of privacy choice option, what other measures could be more effective in ensuring enrollee privacy and less problematic for care coordination?

UNDERSTANDING WHAT MATTERS TO THE INDIVIDUAL—THE ROLE OF CARE COORDINATORS IN PROTECTING PRIVACY

One of the advantages of enrollment in a managed care plan, particularly a plan that coordinates both Medicare and Medicaid services, is that an enrollee should have a care manager, i.e., one point

of contact who can help the enrollee navigate care and troubleshoot relationships with and between providers. An explanation of a plan's privacy policies and enrollee rights by the care manager, rather than simply providing the limited written notice proposed in the NPRM, can provide an excellent springboard for identifying specific privacy concerns that an enrollee might have and honing in on how to address them. If, for example, an enrollee is fearful of sharing HIV status because of a negative experience with a provider in the past, the care coordinator could respond with an explanation of the plan's policy with respect to which providers would have access to that kind of data and why. Another enrollee may be returning to the community after incarceration and have worries about which providers will see that information. In both cases, the coordinator and enrollee together might strategize about ways for the enrollee to discuss the information and whether a conversation first between the coordinator and the provider to lay the groundwork would be helpful.

The care coordinator could also emphasize the legal protections available if the enrollee, in fact, encounters problems and the plan's commitment to respond. Particularly for an enrollee who is considering opting out of data sharing, this information and assistance can provide more context for a reasoned decision. Moreover, for all enrollees, engaging the enrollee from the start in this kind of collaborative decision-making could be a particularly good vehicle for establishing trust between the enrollee and the care coordinator.

PRIVACY AND DISCRIMINATION: TWO SIDES OF THE SAME COIN

Addressing enrollee privacy concerns necessarily includes working to ensure that plan providers do not engage in discriminatory conduct against enrollees. For a health plan, particularly one sharing an enrollee's data over a very wide range of Medicare and Medicaid providers, establishing

a culture across its network that does not tolerate discrimination and treats all enrollees with respect is an essential element in its privacy commitment to its enrollees.

Training: Training, with respect to both privacy and discrimination, is particularly important in plans primarily serving dually eligible enrollees. Both dually eligible enrollees and the workforce serving them are highly diverse. Only half of people with Medicaid and Medicare identify as "white/non-Hispanic," compared to eighty-two percent of Medicare-only enrollees.²² Diversity characterizes the direct care workforce as well. In 2019, for example, thirty-seven percent of home health care workers were immigrants.²³ Attitudes on everything from sexual orientation to religion to age itself may diverge widely among health plan providers and between providers and enrollees.

Plans have a duty to give their employees and providers the tools they need to understand the people they are serving. The HHS Office for Civil Rights (OCR) underscored that duty in recently proposed rules implementing Section 1557 of the Patient Protection and Affordable Care Act (ACA), the primary statute prohibiting discrimination in health care.²⁴ In that rulemaking, OCR proposed a regulation that would require plans and other covered entities to train relevant employees on Section 1557 policies and procedures.²⁵ The rules have not yet been finalized but the need is clear. Without training, there are far too many opportunities for discriminatory or disrespectful treatment, often entirely unwitting but extremely harmful. Once the rules are finalized, CMS can play an important role by providing additional guidance to plans, developing best practices for required Section 1557 training, and monitoring plan compliance with employee training requirements.

Providers and all staff interacting with enrollees need training on their legal obligations not to engage in discriminatory treatment but, to be effective, that training should be paired with cultural competency training on sexual

orientation and gender identity (SOGI), sex, race, ethnicity, language access, disability, and age. Care coordinators need even more intensive training on privacy and discrimination protections so that they are able to explain plan policies clearly and accurately, in a culturally and linguistically appropriate manner, to enrollees in a way that is easy to understand and accessible, when necessary.

Providers also need to understand the privacy rights of plan members and receive clear guidance on what their responsibilities are to protect private information. Home health aides in particular often face privacy challenges. They may see an individual more frequently than anyone else on the care team. Their ability to monitor and report changes in health status, cognitive capacity, self-care, mental health and other matters can be critical to a plan's efforts to maintain the health and well-being of a plan enrollee. They also frequently develop friendships with the enrollees they care for and may be treated as a confidant. They need practical guidance about what information becomes new "data" for an enrollee's file and what is private, and should not be left to fend for themselves on delicate privacy issues.

Beyond staff—other residents: Many dually eligible enrollees spend some or all of their time in congregate facilities that are part of a plan's network. In these places, such as nursing facilities, assisted living facilities and day health centers, enrollees gather, form community, and exchange news. Plans and their providers, through staff training and resident programming, and by modeling behavior, can play an important role in setting a tone of inclusion and respect among residents and participants. Though plans may not be responsible for the actions of their enrollees or of other individuals, their providers and staff do have tools to create an atmosphere that strongly discourages acts that isolate or discriminate against other residents or participants.

STRONG REMEDIES WHEN PRIVACY IS VIOLATED

Although much of the discussion in this paper is about "soft" solutions by managed care plans to address data privacy concerns, enrollees also need access to and notice of strong enforcement mechanisms for both privacy violations and discriminatory actions. Enrollees need additional, understandable, accessible, and culturally competent explanations of their rights.

Internal grievances: Plans must be responsive to grievances about privacy and confidentiality as well as discrimination and ensure that provider violations are promptly and thoroughly addressed.²⁶ This necessarily includes decisive action with respect to identified provider or employee misconduct. CMS and states both have oversight of plan responses to grievances, and can provide technical assistance with remedies.

Privacy enforcement: Because HIPAA applies primarily to improper sharing of information outside of a provider system, it may not be relevant to many of the internal privacy issues with a plan's data policy discussed in this paper.²⁷ Plans, however, are required to have policies with regard to internal handling of health and enrollment information.²⁸ They can implement those policies by including data sharing limitations in their contracts with network providers and can invoke those contractual requirements if network providers do not comply with their provisions.

Discrimination enforcement: Section 1557 provides broad protection against discrimination in health care on the basis of race, color, national origin, sex, including sexual orientation and gender identity, age, or disability. Individuals can file complaints with the HHS Office for Civil Rights.²⁹ As mentioned, OCR has proposed regulations that would strengthen both applicability and enforcement of Section 1557 and the final rule is still pending. In addition

to Section 1557, individuals have protections under other civil rights statutes including Title VI of the Civil Rights Act of 1964,³⁰ the Age Discrimination Act of 1975,³¹ Section 504 of the Rehabilitation Act of 1973³², and the Americans with Disabilities Act.³³ In addition to rigorous enforcement of Section 1557 protections, both CMS and plans can work to educate individuals about the scope of Section 1557 civil rights protections. The proposed Section 1557 regulations would require providing a notice of nondiscrimination, which is a good starting point but notices are rarely read and, even more rarely, absorbed. Additional culturally and linguistically competent consumer education at a low literacy level would help enrollees understand their protections, giving them more confidence about allowing information to be shared and empowering them to raise their voice if violations occur.

Monitoring: Reliance only on grievances filed with a plan or complaints filed with OCR may not be adequate to surface all significant problems with discrimination and privacy, particularly because older adults may be fearful or reluctant to cause trouble. At the plan level, a care coordinator could periodically, for example, during an annual care plan review, check in with an enrollee about their interaction with network providers. Consumer Advisory Councils, which are mandated for D-SNPs, could also discuss privacy and antidiscrimination protections at their meetings. Besides monitoring plan grievances related to discrimination or privacy, CMS could consider other more proactive approaches, such as inclusion of privacy and discrimination concerns in member surveys or focus group discussions, with required compilation of results and reporting to CMS.

CONCLUSION

The most pressing privacy and data concerns among many older adults are wrapped up with fears of embarrassment or discriminatory treatment by the very health care providers who serve them. Addressing these concerns through selective withholding of data from providers creates serious operational challenges, and broader denial of data access impedes the important goal of care coordination. This is at best an imperfect partial solution.

Managed care plans serving people dually eligible for Medicare and Medicaid hold and have the capacity to share significant amounts of personal data. They also have the opportunity to address the very personal concerns of older adults about the privacy of sensitive data with a multi-faceted and more nuanced response that empowers individuals to control the telling of their story and, through training and consistent enforcement of anti-discrimination mandates among plan components, create a culture that reduces discriminatory misuse of sensitive data.

ENDNOTES

- 1 For demographic and health status data on the dually eligible population, see MEDICARE PAYMENT ADVISORY COMM'N (MEDPAC) & MEDICAID AND CHIP PAYMENT AND ACCESS COMM'N (MACPAC), DATA BOOK: BENEFICIARIES DUALY ELIGIBLE FOR MEDICARE AND MEDICAID 35-37 (FEB. 2023) [HEREINAFTER *2023 DATA BOOK*], https://www.macpac.gov/wp-content/uploads/2023/02/Feb23_MedPAC_MACPAC_DualsDataBook-WEB-508.pdf.
- 2 Three-quarters of dually eligible individuals with full Medicaid benefits receive some or all of their Medicaid services through managed care plans. See MACPAC, DELIVERY SYSTEM: DUALY ELIGIBLE BENEFICIARIES, <https://www.macpac.gov/subtopic/dually-eligible-beneficiaries-delivery-system/> (last visited Mar. 20, 2023).
- 3 About 42 percent of full benefit dually eligible individuals receive Medicare benefits through managed care. See *2023 Data Book*, *supra* note 1, at 43.
- 4 JUSTICE IN AGING ET AL., LGBT OLDER ADULTS IN LONG-TERM CARE FACILITIES: STORIES FROM THE FIELD (updated June 2015), https://www.justiceinaging.org/wp-content/uploads/2011/04/RE_LGBT-Stories-from-the-Field.pdf. See also Nat'l Ctr. Elder Abuse, Mistreatment of Lesbian, Gay, Bisexual, and Transgender (LGBT) Elders (2020), https://ncea.acl.gov/getmedia/ed85bf0d-b7a8-4467-80d3-3a5d78898c29/NCEA_RB_LGBT2021.aspx.
- 5 NAT'L WOMEN'S LAW CTR., HEALTH CARE REFUSALS HARM PATIENTS: THE THREAT TO LGBT PEOPLE AND INDIVIDUALS LIVING WITH HIV/AIDS (May 2014), https://nwl.org/wp-content/uploads/2015/08/lgbt_refusals_factsheet_05-09-14.pdf.
- 6 See, e.g., Julie Hayes, *4 Ways that Storytelling Benefits Older People and Their Caregivers*, GUIDEPOSTS, <https://guideposts.org/positive-living/health-and-wellness/caregiving/family-caregiving/aging-parents/4-ways-that-storytelling-benefits-older-people-and-their-caregivers/> (last visited Mar. 29, 2023); Susan B. Garland, *Telling Their Life Stories, Older Adults Find Peace in Looking Back*, N.Y. TIMES (Dec. 9, 2016), <https://www.nytimes.com/2016/12/09/your-money/telling-their-life-stories-older-adults-find-peace-in-looking-back.html>.
- 7 LIFE BIO, RESEARCH AND HEALTH CARE TRANSFORMATION, <https://www.lifebio.org/research-and-healthcare-transformation/> (last visited Apr. 4, 2023).
- 8 Medicare-Medicaid Managed Care Plans are part of a demonstration program that will end December 31, 2025. For a fuller description of the types of integrated Medicare managed care plans, see MACPAC, INTEGRATED CARE FOR DUALY ELIGIBLE BENEFICIARIES, <https://www.macpac.gov/subtopic/integrated-care-for-dually-eligible-beneficiaries/> (last visited Mar. 21, 2023) (citing further articles); ALEXANDRA KRUSE & MICHELLE HERMAN SOPER, CTR. FOR HEALTH CARE STRATEGIES, STATE EFFORTS TO INTEGRATE CARE FOR DUALY ELIGIBLE BENEFICIARIES: 2020 UPDATE (Feb. 2020), https://www.chcs.org/media/State-Efforts-to-Integrate-Care-for-Dually-Eligible-Beneficiaries_022720.pdf.
- 9 The most integrated of these separate models are Highly Integrated Dual Eligible Special Needs Plans (HIDE-SNPs). See ERIN WEIR LAKHMANI, INTEGRATED CARE RES. CTR., DEFINITIONS OF DIFFERENT MEDICARE ADVANTAGE DUAL ELIGIBLE SPECIAL NEEDS PLAN (D-SNP) TYPES IN 2023 AND 2025 (Dec. 2022), https://www.integratedcareresourcecenter.com/sites/default/files/ICRC_DSNPDefinitions_2023-2025_0.pdf; MACPAC, MEDICARE ADVANTAGE DUAL ELIGIBLE SPECIAL NEEDS PLANS, <https://www.macpac.gov/subtopic/medicare-advantage-dual-eligible-special-needs-plans-aligned-with-medicaid-managed-long-term-services-and-supports/> (last visited Mar. 29, 2023).
- 10 They are “White, Black, American Indian, Hispanic, Asian, and Other.” Alabama Medicaid Agency, Application/Redetermination for Elderly and Disabled Programs, [9.4.1 Form 204-205 EnD App 1-14-21.pdf \(alabama.gov\)](https://www.alabamagov.com/Portals/0/Forms/9.4.1_Form_204-205_EnD_App_1-14-21.pdf), (last visited April 12, 2023).
- 11 They are White, Black or African American, American Indian or Alaska Native, Asian Indian, Cambodian, Chinese, Filipino, Hmong, Japanese, Korean, Laotian, Vietnamese, Native Hawaiian, Guamanian or Chamorro, Samoan and Other. A separate question asks whether the applicant is Hispanic, Latino or Spanish origin and, if so, whether, Mexican/Mexican American/ Chicano, Salvadoran, Cuban, Guatemalan, Puerto Rican, or Other Hispanic, Latino, or Spanish origin, with an opportunity to specify further. Covered California, Application for Health Insurance, [ENG-CASingleStreamApp.pdf](https://www.coveredca.com/Portals/0/Forms/ENG-CASingleStreamApp.pdf) (last visited April 12, 2023).
- 12 42 C.F.R. § 422.101(f)(1)(i)(2023).
- 13 42 C.F.R. § 422.118(a)(2023).
- 14 *Id.*
- 15 Medicare and Medicaid Programs; Patient Protection and Affordable Care Act; Advancing Interoperability and Improving Prior Authorization Processes for Medicare Advantage Organizations, Medicaid Managed Care Plans, State Medicaid

Agencies, Children’s Health Insurance Program (CHIP) Agencies and CHIP Managed Care Entities, Issuers of Qualified Health Plans on the Federally-Facilitated Exchanges, Merit-Based Incentive Payment System (MIPS) Eligible Clinicians, and Eligible Hospitals and Critical Access Hospitals in the Medicare Promoting Interoperability Program, 87 Fed. Reg. 76238 (Dec. 13, 2022) [hereinafter *NPRM*]. Note that the *NPRM*, which addresses more than Medicare and Medicaid managed care plans, uses the term “payer” rather than “plan” throughout.

- 16 See 45 C.F.R. § 164.522 (2023). See also, e.g., U.S. DEP’T OF HEALTH & HUM. SERVS., UNDER HIPAA, MAY AN INDIVIDUAL REQUEST THAT A COVERED ENTITY RESTRICT HOW IT USES OR DISCLOSES THAT INDIVIDUAL’S PROTECTED HEALTH INFORMATION (PHE)? <https://www.hhs.gov/hipaa/for-professionals/faq/3026/under-hipaa-may-an-individual-request-that-a-covered-entity-restrict-how-it-uses-or-discloses-that-individuals-protect-health-information/index.html> (last visited Apr. 4, 2023).
- 17 [42 C.F.R. § 422.118](#)
- 18 *Id.* at 76259.
- 19 *Id.* at 76259.
- 20 *Id.* at 76261.
- 21 CMS has acknowledged that lack of computer literacy and access to the internet create barriers and, in the *NPRM*, noted that mail, fax or telephonic methods may be necessary alternatives for enrollees. See *id.* at 76259. For these alternate channels, however, though they may work well enough for a simple opt-in, their utility diminishes greatly for individuals juggling choices among many providers and provider types and complex sets of health and non-health data.
- 22 See *2023 Data Book*, *supra* note 1, at 35, Ex. 6.
- 23 See, e.g., KAREN AHO, IMMIGR. IMPACT, AMID A SEVERE SHORTAGE OF HOME HEALTH AIDES, IMMIGRANTS HELP CARE FOR OUR SENIORS (Jan. 26, 2023), <https://immigrationimpact.com/2023/01/26/shortage-home-health-aides-immigrants/>. Diversity characterizes the entire health care work force. For example, 29% of physicians in the United States are foreign born. Yash M. Patel et al., *Proportion of Non-US-Born and Noncitizen Health Care Professionals in the United States in 2016*, 320 JAMA 2265, 2265 (2018), <https://jamanetwork.com/journals/jama/fullarticle/2717463>.
- 24 See 42 U.S.C. § 18116(a). The rulemaking is found in Nondiscrimination in Health Programs and Activities, 87 Fed. Reg. 47824, 47857-60 (proposed Aug. 4, 2022) (to be codified at 45 C.F.R. § 92.101).
- 25 87 Fed. Reg. at 47850-52.
- 26 The regulations for grievance procedures for Medicare managed care plans are found at 42 C.F.R. § 422.564. For the most recent detailed guidance on grievance procedures, see CTRS. FOR MEDICARE & MEDICAID SERVS. (CMS), U.S. DEP’T OF HEALTH & HUM. SERVS., PARTS C & D ENROLLEE GRIEVANCES, ORGANIZATION/COVERAGE DETERMINATION, AND APPEALS GUIDANCE (Aug. 3, 2022), <https://www.cms.gov/medicare/appeals-and-grievances/mmcag/downloads/parts-c-and-d-enrollee-grievances-organization-coverage-determinations-and-appeals-guidance.pdf>.
- 27 See OFF. OF THE NAT’L COORDINATOR FOR HEALTH INFO. TECH. (ONC) & OFF. OF CIV. RTS., U.S. DEP’T OF HEALTH & HUM. SERVS., PERMITTED USES AND DISCLOSURES: EXCHANGE FOR TREATMENT (Jan. 2016), https://www.hhs.gov/sites/default/files/exchange_treatment.pdf.
- 28 42 C.F.R. § 422.118.
- 29 The HHS OCR website provides options to file by mail, fax, email or by using the OCR online portal. See U.S. DEP’T OF HEALTH & HUM. SERVS., FILING A CIVIL RIGHTS COMPLAINT, <https://www.hhs.gov/civil-rights/filing-a-complaint/index.html> (last visited Mar. 29, 2023).
- 30 42 U.S.C. § 2000d et seq.
- 31 42 U.S.C. § 6101-6107.
- 32 29 U.S.C. § 794.
- 33 42 U.S.C. § 12101 et seq.