REAL-WORLD AND POLICY APPLICATIONS OF THE **“SOCIAL DETERMINANTS OF DATA”**

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INTRODUCTION: DEFINING THE SOCIAL DETERMINANTS OF DATA

The Social Determinants of Data (SDOD) is a concept I introduced (Francis, 2025) that draws analogy from the social determinants of health. It posits that data quality, completeness, and representation are not merely technical issues but are shaped by systemic, institutional, and social forces. Just as social determinants of health influence health outcomes, SDOD influence how data are collected, categorized, and even rendered missing, particularly for marginalized populations. For example, my critical analysis of North Carolina's 2020 Latino COVID-19 mortality data found that missing ethnicity information was not random but rooted in bureaucratic inefficiencies, inconsistent reporting practices, and institutional neglect (Francis, 2025). In other words, the same structural inequalities that drive health disparities also drive "data disparities", causing certain communities to be undercounted or misrepresented in data. This report explores five domains where the Social Determinants of Data concept can be applied: (1) public health data systems and mortality reporting; (2) data equity frameworks and policy; (3) government data collection practices; (4) data governance (training, accountability, community engagement); and (5) advocacy, activism, and community empowerment. In each area, I highlight existing initiatives aligning with SDOD, gaps in current systems, and opportunities for integrating this concept into policy and practice.

1. PUBLIC HEALTH DATA SYSTEMS AND MORTALITY REPORTING

Public health surveillance and vital statistics systems rely on accurate, complete data to inform interventions and policy. Applying the Social Determinants of Data lens reveals that data gaps – such as missing race/ethnicity in mortality records – often stem from structural issues in how data are collected and reported. In my case study of COVID-19 deaths, the absence of ethnicity data was traced to system-level failures like inadequate training for those filling out death certificates, lack of prioritization for capturing ethnicity, and neglect of minority data needs (Francis, 2025). These factors made Latino decedents invisible in official statistics and thus in public health planning. Notably, this problem is not isolated to one state or one pandemic. Nationally, analyses by the CDC have found that racial misclassification on death certificates is persistently high for certain groups. For example, about 40% of American Indian or Alaska Native decedents were recorded as the wrong race or "unknown" in one large study (Arias et al., 2016). Such misclassification leads to underestimation of mortality rates and health needs in these communities. By contrast, reporting was highly accurate for White and Black decedents, underscoring how minority populations suffer data quality disparities (Arias et al., 2016). Even during COVID-19, many jurisdictions struggled with incomplete race/ethnicity data for cases and deaths, reflecting systemic barriers in data collection streams (Beaulieu, 2022). These omissions are not simply technical errors – they mirror social context (e.g. histories of mistrust, language barriers, under-resourced institutions) and thus are manifestations of SDOD in public health data systems (Francis, 2025).

Existing initiatives/models: Recognizing these issues, some health agencies and researchers have begun implementing practices to improve data completeness by addressing root causes. For instance, several states have used data linkage techniques to correct racial misclassification in mortality data – linking death records with other databases (like tribal registries or healthcare records) to more accurately identify decedents' race/ethnicity (Arias et al., 2016; Gartner et al., 2023). The U.S. CDC's State and Territorial Epidemiologists have also highlighted the need to explore "systemic factors contributing to gaps in race and ethnicity data" and document solutions across the data reporting pipeline (Beaulieu, 2022). These solutions include: (a) **Standardized training** for data collectors – e.g. Considering mandating culturally responsive (Francis et al., 2021) training for funeral directors and registrars on how to properly ask about and record ethnicity, avoiding assumptions based on appearance or surname; (b) **Technology improvements** – such as upgrading Electronic Death Registration Systems (EDRS) to require an entry for ethnicity (disallowing "unknown" without documented attempts to obtain it) and integrating multilingual prompts for informants; and (c) **Community partnership in data collection** – for example, embedding trusted bilingual community health workers ("promotores") into the death reporting process to help families provided information and underscore why these data matter. All these steps align with the SDOD perspective by intervening on the social and institutional determinants of data quality (training, trust, resource constraints).

Gaps and opportunities: Significant gaps remain in public health data systems. Many jurisdictions still lack consistent training, accountability, and incentives for complete reporting. As I note in my paper, over half of funeral directors receive no formal training in death certification and many physicians lack training as well, leaving data accuracy "vulnerable to human error, assumptions, or neglect." Additionally, there is often little transparency or feedback on data quality – counties may not even know their performance on completeness. One opportunity is to implement data quality report cards and benchmarks: for example, North Carolina's State Center for Health Statistics could publish quarterly dashboards showing each county's percentage of missing ethnicity data (analogous to how immunization rates are tracked). Publicizing these metrics, coupled with technical assistance for low-performing areas, would create accountability and motivate local improvements. Another gap is the burden of grieving families to supply data at the time of death. SDOD thinking invites creative solutions, such as pre-populating death records with race/ethnicity from other sources (driver's license, medical records) to reduce stress on informants and improve accuracy. In summary, applying the Social Determinants of Data in mortality reporting means going beyond fixing forms – it calls for reforming the surrounding system (training people, building trust, improving tools and policy mandates) so that marginalized deaths are fully counted and appropriately recorded. This ensures that public health interventions and resource allocations truly reflect the needs of all communities, rather than skewed data that omit those most at risk (Francis, 2025).

2. DATA EQUITY FRAMEWORKS AND POLICY

The concept of SDOD is inherently linked to data equity – the principle that health equity requires equity in the data itself (Ponce et al., 2023). In recent years, policy experts have recognized that incomplete or biased data perpetuate inequity by rendering some groups invisible in evidence-based decision making. As one policy analysis put it, despite decades of documenting health disparities, "health equity goals remain largely unfulfilled" in part because we have not applied an equity lens to data systems from collection through interpretation (Ponce et al., 2023). The Social Determinants of Data framework contributes to data equity by identifying how power imbalances and social biases enter at each stage of the data lifecycle. For example, standard data systems often rely on broad racial/ethnic categories that mask important subgroup differences, effectively erasing smaller communities. Ponce et al. (Ponce et al., 2023) describe this as grouping people in ways that make them "statistically invisible" – a form of systemic bias in measurement (Gilburg, 2023). Data equity frameworks emerging from academia and policy institutes are increasingly focused on making the invisible visible. They emphasize disaggregating data to uncover hidden disparities, partnering with communities to decide what data to collect, and treating missing data not as a technical glitch but as a sign of exclusion (Gilburg, 2023; Ponce et al., 2023). Notably, the Biden Administration convened an Equitable Data Working Group in 2021-2022 precisely to address these issues. The Working Group's report (2022) called for "making disaggregated data the norm," building capacity for "robust equity assessments," and improving community access and input in federal data efforts (Gilburg, 2023; Ponce et al., 2023). Such recommendations align strongly with the SDOD perspective: they acknowledge that historically underserved populations have been either lumped together or left out of datasets, and that correcting this requires intentional policy changes to how data are collected, categorized, and shared.

Existing initiatives/models: Several models illustrate data equity in practice. One is the effort to reform federal data standards for race/ethnicity. After decades of advocacy (especially from Arab American and Hispanic communities), the U.S. Office of Management and Budget (OMB) in 2023-2024 revised its Statistical Policy Directive No.15 – the guiding standards for federal data on race/ethnicity. The updated standards will add a new "Middle Eastern or North African (MENA)" category (ending the practice of classifying MENA individuals as white) and treat "Hispanic or Latino" as a distinct category in a single race/ethnicity question (Orvis, 2024). It also requires collecting more detailed subgroup data (beyond minimum categories) wherever possible (Orvis, 2024). This change, due to be implemented across federal surveys and forms in coming years, directly addresses a long-standing categorical gap that left certain groups uncounted. It exemplifies policy-driven data equity: acknowledging that prior data categories were products of social-historical biases and updating them to better reflect the population. Another example is the proliferation of data equity assessment tools and frameworks by public health organizations. For instance, the Milbank Memorial Fund's Data Equity insights highlight priority areas like increasing use of disaggregated data, forging partnerships with marginalized communities in data work, and ensuring data accountability to the public (Ponce et al., 2023). Likewise, the CDC Foundation and others have published principles for using public health data to drive equity, which call for community engagement, transparency, and intersectional analysis in data practices (RWJF, 2025). On the ground, some health departments are adopting "equity checklists" for data projects – e.g. asking who is missing from the data, examining how data collection methods might inadvertently exclude certain groups, and involving community representatives to interpret results. All these efforts are in harmony with the Social Determinants of Data idea that social context and power dynamics must be considered at every step for data to be truly equitable.

Gaps and opportunities: While momentum for data equity is building, gaps persist in institutionalizing these practices. A major gap is the disconnect between high-level policy intentions and on-the-ground implementation. For example, although federal standards now mandate better race/ethnicity data, local agencies may lack resources or will to fully implement them (e.g. upgrading IT systems to capture the new categories or training staff to ask multi-part questions sensitively). There is an opportunity for capacity-building and funding to accompany data equity mandates – much as the Equitable Data Working Group recommended investing in statistical and data science expertise to use disaggregated data appropriately (Equitable Data Working Group, 2022). Another gap lies in data usage and interpretation. Even when more granular data are collected, they must be analyzed and communicated with an equity lens. This means, for instance, not just publishing data by subgroup but actively using those insights to allocate resources or change programs. It also means guarding against misinterpretation – ensuring that data on disparities are framed as evidence of structural inequities, not as inherent traits of communities (Beaulieu, 2022). One opportunity here is integrating SDOD concepts into data governance policies (see next section) – formalizing practices like community review of data publications or equity impact assessments whenever data inform policy. Additionally, policy frameworks could require accountability for data equity: for instance, government could tie funding to demonstrated efforts in improving data inclusivity or require agencies to report on how they are closing data gaps for underrepresented groups. In summary, applying the Social Determinants of Data in the policy realm means treating equitable data as a moral and practical imperative, not an afterthought (Francis, 2025; Ponce et al., 2023). By doing so, policies and programs can be built on a foundation of data that truly represents all constituents, thereby driving more effective and just outcomes.

3. GOVERNMENT DATA COLLECTION PRACTICES (VITAL STATISTICS, CENSUS, ETC.)

Government data collection – from the decennial census to vital records (births, deaths) and administrative data – provides the backbone for public policy and resource distribution. Here, the Social Determinants of Data concept spotlights how systemic biases and institutional practices influence who gets counted and how. Historically, many government data systems have undercounted or miscategorized marginalized communities due to factors like hard-to-reach populations, distrust in authorities, language barriers, and rigid categorization schemes. The U.S. Census offers a clear example: the 2020 Census experience significant undercounts of Black, Latino, and Native populations (e.g. an estimated 3.3% undercount for African Americans and 4.99% undercount for Hispanics) (U.S. Census Bureau, 2022), even as Whites were overcounted. These patterns are not random – they reflect structural issues such as unequal access to internet (for online census forms), immigration fears amid policy crackdowns, and chronic underfunding of outreach in minority communities. In vital statistics, as discussed earlier, lack of uniform training and standards can lead to higher rates of missing data for minority groups, effectively erasing them from health statistics. Applying SDOD to government data practices means first acknowledging these disparities as products of underlying social determinants and then reforming practices to mitigate them.

Existing initiatives/models: Beyond the aforementioned OMB Directive 15 revisions (which directly address categorical inclusivity), there are other notable efforts: The Biden Administration’s Equitable Data Working Group (EDWG) in 2022 mapped out a strategy for making federal data more inclusive. It emphasized things like “underutilized data” (linking administrative records to fill gaps where surveys undercount), and ensuring intersecting identities can be analyzed (so that people at the margins of multiple categories aren’t lost in averages) (Equitable Data Working Group, 2022). The EDWG also highlighted the need for engaging underserved communities in data design, leading to recommendations for more community consultations and partnerships in federal data programs (Equitable Data Working Group, 2022). At the operational level, some agencies have piloted improvements: for instance, the National Center for Health Statistics (NCHS) has worked with states to enhance death certificate data by promoting use of electronic systems, providing guidance on collecting race/ethnicity, and even linking with other databases (Medicare, Indian Health Service) to improve accuracy (Anderson et al., 2014; Arias et al., 2016). The Census Bureau, learning from 2020, is planning to invest in trusted messenger outreach and translation services to reduce undercounts in future counts – a reflection of addressing social determinants (like language and trust) in a data collection context. Another model is the “Count Me In” style campaigns led by community organizations alongside government. For example, the grassroots coalition “Yalla Count MENA In!” has been actively working to ensure people of Middle Eastern/North African descent identify on forms in ways that will be captured, and their advocacy was instrumental in pushing the federal government to create a MENA category (AAI, 2025; Wang, 2023). Similarly, tribal governments and Native advocacy groups have been collaborating with the Census Bureau to improve American Indian/Alaska Native census response by incorporating indigenous leadership in the process. These initiatives recognize that when communities see the value and safety in being counted, data completeness improves – a clear alignment with SDOD principles.

Gaps and opportunities: One persistent gap in government data practices is the lack of routine evaluation and accountability for representation. For example, after each census or major survey, we often discover undercounts or biases (as in 2020), but there is less systematic follow-up to adjust funding formulas or make corrections in the interim. An opportunity would be to embed SDOD-informed accountability into data programs: e.g. require annual reporting of data quality by demographic subgroup for key programs (like how well did we track service uptake by various groups, who is missing?), and remedial plans when gaps are identified. Another gap is community trust and engagement. Many marginalized communities have valid historical reasons to be wary of government data collection (surveillance, misuse of data, lack of benefit). Embracing SDOD in government practice would mean investing in community-embedded data collection on a broader scale – not just during crises like a pandemic or census, but as an ongoing approach. This could involve hiring and training community members as enumerators or surveyors, forming community advisory boards to co-develop questions and data categories, and ensuring communities see the results and benefits of the data they contribute. There is also an opportunity to leverage technology thoughtfully: for instance, mobile data collection apps with multilingual support, or secure data-sharing that allows communities to access granular data about themselves for local advocacy. However, technology must be coupled with policy safeguards (to prevent reinforcing bias) – e.g. algorithms used in data analysis should be audited for bias, and data privacy must be protected to maintain trust. In essence, applying the Social Determinants of Data to government data collected pushes agencies to move from a mindset of “How do we get the data we need?” to “How do we create a data ecosystem that empowers everyone to be counted accurately, by addressing barriers and building trust?”. The result would be data that better reflect reality and thus lead to more equitable governance.

4. DATA GOVERNANCE: TRAINING, ACCOUNTABILITY, AND COMMUNITY-EMBEDDED PRACTICES

“Data governance” refers to policies, standards, and practices that ensure high-quality data management. Incorporating the Social Determinants of Data into data governance means explicitly accounting for the human and social context in those policies. Three critical aspects stand out: training, accountability, and community engagement.

- **Training**: Who collects data and how they are trained has a profound impact on data equity. If staff are not sensitized to the importance of certain data (e.g. ethnicity, disability status), those fields may be neglected. My study (Francis, 2025) revealed how a lack of formal training for funeral directors and physicians led to inconsistent ethnicity reporting. As a remedy, I propose standardized, culturally-responsive training modules – emphasizing why capturing data on marginalized groups is vital for public health, and how to do so respectfully. In a broader context, training in data governance should cover understanding implicit biases in data collection, proper handling of sensitive information, and protocols to avoid “erasing” identities (for example, not defaulting to “unknown” without effort). Some health agencies are moving toward certification requirements or continuous education for data stewards. For example, professional associations in vital statistics (like NAPHSIS) are considering training curricula that include modules on health equity and the social context of data. Training is a chance to instill the idea that collecting complete, accurate data on all groups is part of one’s professional duty, not an optional task.
- **Accountability**: Governance must include mechanisms to hold systems and people accountable for data quality and equity. This ties to earlier points about monitoring missing data and disparities. A practical model is creating data quality benchmarks – e.g. setting a target that no more that X% of

records should have missing race/ethnicity, and naming jurisdictions or departments that fall short. By publicly reporting such metrics (internally or externally), organizations create pressure to improve and also identify where additional support is needed. Another facet of accountability is clarifying roles and responsibilities in the data supply chain. For instance, if a certain hospital consistently submits incomplete data, governance policy might require that hospital to implement a correction plan. There are also emerging ideas of personal accountability in data work: some agencies have floated the idea of typing leadership performance evaluations to progress on data equity (for example, a health department director's success could be measured in part by improved community data representation). Data governance frameworks like "data stewardship charters" are being adopted wherein data collectors and managers formally commit to principles of completeness, accuracy, and fairness. The Social Determinants of Data approach would particularly stress accountability for representing marginalized communities – ensuring that their data are not systematically left out.

- **Community-Embedded Practices**: Perhaps the most transformative element of SDOD-informed governance is bringing the community into the governance process. Traditional data governance has been top-down, but there is a shift toward participatory models. Community-embedded practices include involving community representatives in designing data collection forms (to ensure categories make sense and are inclusive), partnering with community organizations to collect data (as seen with *promotores* helping in death reporting), and even giving communities a say in how data about them are used and shared. One innovative example is the concept of Community Data Councils that some cities are exploring – multi stakeholder groups (including residents from marginalized neighborhoods) that advise on data priorities, flag concerns (like misuse or undercount), and co-create solutions. Another model is what the de Beaumont Foundation and RWJF are piloting through MADE for Health Justice initiative: in several cities, they are building local "data ecosystems" where community-based organizations collaborate with officials to generate and govern data that serves community goals (Porter et al., 2025). These MADE communities center anti-racism, equity, and community power in data efforts, creating shared values and accountability agreements among partners to ensure power imbalances are addressed (Porter et al., 2025). Such approaches treat community members not just as data subjects but as co-stewards of data – a key tenet of data justice.

Gaps and opportunities: Implementing training, accountability, and community engagement in data governance is challenging and many gaps exist. For one, training programs need scaling and standardization – currently, few jurisdictions mandate equity-oriented data training. An opportunity is for national bodies (CDC, public health associations) to develop and offer open-source training toolkits on SDOD and data equity, which states and localities could adopt and customize. For accountability, a gap is that we often lack real-time data quality tracking. Investing in better data audit tools – for instance, automatic flags in databases when certain fields (like ethnicity) are missing too often – could prompt quicker action. Additionally, enforcement levers are weak: even if policies exist on paper, without enforcement (or incentives), practices might not change. Governments could tie grant eligibility or funding bonuses to data completeness benchmarks as a carrot and use compliance reviews as a stick when necessary. With community engagement, a common challenge (gap) is sustaining engagement and avoiding tokenism. It's one thing to invite community members to a meeting; it's another to truly share power. Opportunities here include providing resources to community partners (paying them for their time, building their capacity) and establishing long-term forums for input rather than one-off consultations. Embracing SDOD in governance ultimately suggests a culture change: viewing communities as equal partners in knowledge production. When done right, this can lead to richer data (because people are more willing to participate and share when they trust the process) and to data products that are more relevant and actionable at the community level (RWJF, 2025). In summary, weaving the Social

Determinants of Data into governance ensures that the entire data system – from personnel to policies – is aligned with principles of equity, resulting in more trustworthy and just data.

5. ADVOCACY, ACTIVISM, AND COMMUNITY EMPOWERMENT INITIATIVES

Perhaps the most inspiring applications of the Social Determinants of Data concept are found in grassroots advocacy and community-driven data initiatives. Activists and community organizations have long understood that “data is power”, and that being left out of data is akin to being silenced in policy dialogues (Francis, 2025). Consequently, there is growing movement of data justice and data advocacy that echoes the SDOD message: that we must address systemic biases in data to achieve social justice.

Community data advocacy: Across the country, local groups are leveraging data to demand change and hold institutions accountable. For example, during the COVID-19 pandemic, Black and Latino civil rights organizations publicly pressured health departments to release race-disaggregated COVID data when initial reports omitted those details. Their slogan “#DataOrDeath” emphasized that lack of data on communities of color was obscuring life-and-death inequities. This activism led to many states publishing more granular COVID dashboards. Another sphere of advocacy is the push for participatory data practices: groups like Data for Black Lives have championed principles of “Nothing About Us Without Us” in data science – arguing that communities should co-create datasets and algorithms that impact them. Similarly, the Indigenous Data Sovereignty movement, led by Native scholars and leaders, fights for indigenous communities to have control over data about their people, asserting cultural values in data governance. All these efforts align with SDOD by confronting the power structures that decided what data is collected (or not) and for whose benefit.

Empowerment through community data projects: Beyond advocacy aimed at government, many communities are generating their own data to fill gaps. The Rober Wood Johnson Foundation’s “Local Data for Equitable Communities” program (2025) is funding nonprofit groups to collect and use data on issues they identify – recognizing that “all data are inherently shaped by purposes, assumptions, and biases of the people who create them” (RWJF, 2025). By putting the means of data production into community hands, these projects aim to correct biases and address questions that outsiders may overlook. The program also emphasizes building local capacity so that residents can analyze and interpret data themselves, rather than relying solely on outside experts (RWJF, 2025). Another example is the MADE for Health Justice initiative (mentioned earlier) which is essentially a coalition of community organizations in cities like Baltimore, Pittsburg, Portland, and Tucson, each working on community-led data ecosystem to advance equity in a specific domain (e.g. education, housing, climate justice, or Native American employment) (Porter et al., 2025). These ecosystems operate on shared values of anti-racism and have formal agreements to share power and ensure accountability among partners (Porter et al., 2025). They use tools like community storytelling and videos to keep the focus on human impacts, thus democratizing data in a very tangible way. Such models show the transformative potential of SDOD: when communities recognize how data injustice affects them, they can organize to collect their own data, redefine metrics of success, and compel public institutions to listen.

Gaps and opportunities: While community data initiatives are increasing, they often face hurdles such as limited funding, technical barriers, or resistance from established institutions. One gap is the access to data and tools – advocates sometimes struggle to obtain data held by governments or to afford analytic tools. Efforts like the Data Equity Hub and various open-data advocacy groups are working to bridge this by providing platforms and training for community use of data (Global Partnership for Sustainable

Development Data, 2025; Nesbitt, 2022). There is an opportunity for public agencies to actively support community data efforts by sharing data (with privacy safeguards) and co-developing community-friendly data portals. Another gap is sustainability: many grassroots data project are grant-funded and time-limited. To integrate SDOD into the fabric of how data is handled, these initiatives need to be scaled and sustained. Policymakers could create funding streams specifically for community data infrastructure – e.g. ongoing support for community data steward positions or for maintaining local data collaboratives. Education and empowerment are also key opportunities. Introducing the concepts of data justice and SDOD in schools and community workshops can build a broader base of residents who demand fair data practices. When more people recognize, for instance, that missing data on their community is a form of systemic neglect, they are likely to join in advocacy to change it. We are already seeing this awareness grow; as one data justice guide notes, the pursuit of data justice "must include the involvement of activists and advocates in civil society" (GPAI, 2022). In conclusion, advocacy and community empowerment operationalize the Social Determinants of Data by shifting power to the people whom the data is about. They highlight existing gaps (like whose stories are told by data) and seize opportunities to democratize data creation and governance. This not only leads to better data, but also to communities that are more informed and powerful in directing social change.

CONCLUSION

The "Social Determinants of Data" is a powerful framework that urges us to see data not as neural bits of information, but as reflections of our social structures and values. Applying this concept across public health systems, policy frameworks, government practices, governance processes, and community initiatives reveals a common theme: when data fail to fully represent marginalized people, it is a symptom of deeper inequities. The encouraging news is that many stakeholders – from federal agencies revising standards, to health departments improving data collection, to activists reclaiming data for their communities – are already moving in directions consistent with this philosophy. Still, much work remains to be done to institutionalize these changes. By integrating SDOD into policies (e.g. making disaggregated and community data the norm), into organizational cultures (e.g. training and accountability for equity in data), and into the public consciousness (e.g. treating inclusive data as a civil right), we can transform data systems to be more just. Ultimately, data justice and health equity go hand in hand. As my research showed, missing data can literally mean misdirected resources and lives not saved (Francis, 2025). Conversely, equitable data can illuminate need and drive action. In a world "dying to be counted", embracing the Social Determinants of Data in real-world applications is not just about better datasets – it is about affirming the dignity and visibility of every community in the decisions that affect their lives.

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