Potential Opportunities:

Data Exchange Standards, Provider Identity Management, and Consumer Data Access

Note: Red text indicates the revisions that were made through February 15, 2022, in response to stakeholder comments submitted during and after the January 25, 2022, Data Exchange Framework Stakeholder Advisory Group meeting. Discussion questions have been deleted without tracking.

Gaps: Standards and Consumer Access

1. **Human Service Data Exchange Standards and Capacity.** National and federally recognized human service data exchange standards are nascent, and the standardized collection, exchange, and use of SDOH and other human service information remains limited; national networks, HIOs, and EHRs generally have limited capabilities to exchange structured and standardized SDOH and other human service data.

2. **Demographic Data.** Race, ethnicity, languages (spoken/written), sexual orientation, gender identity and other demographic data necessary to support population health and to identify and address disparities and inequities are often missing, incomplete, or are not collected or shared, and multiple standardized terminologies exist and regulations conflict on which must be supported.

3. **Provider Identity Management.** Robust provider, care team, and social service organization directories are not available or accessible to health and human service organizations across California.

4. **Consumer Data Access.** Individuals consistently face challenges in accessing and contributing to their health and human service records - directly or through selected third parties - in a manner that is convenient, timely and compliant with federal access requirements.

(Covered by Digital Identity Strategy) **Person Identity Management.** *Robust person identity matching services are not available or accessible to health and human service organizations across California.*

Gaps and Opportunities

1. **Human Service and Demographic Data Exchange Standards and Capacity***

   ➢ **Opportunity 1a:** <u>SDOH</u> data collection and use standards, requirements, and incentives

   ➢ **Opportunity 1b:** <u>Demographic</u> data collection and use standards, requirements, and incentives

   ➢ **Opportunity 1c:** Enhance cross-state agency data sharing efforts to support the exchange of program enrollment data and consumer demographic and SDOH information to support cross-program service coordination and whole person care

   ➢ **Opportunity 1d:** Advance recommendations to federal government to improve demographic data collection nationally

2. **Provider Identity Management****

   ➢ **Opportunity 2a:** Expand upon the provider directory API Requirements in CMS's Interoperability and Patient Access Final Rule.

   ➢ **Opportunity 2b:** Require qualifying HIOs to participate in a federated provider identity management service

3. **Consumer Data Access**

   ➢ **Opportunity 3a:** Adopt policies to ensure consumers have meaningful access to their longitudinal health information across all health care organizations subject to AB-133, allowing them to make informed health care decisions

   ➢ **Opportunity 3b:** Adopt policies to ensure consumers understand how their health information may be used and trust in the systems in place that govern its use

*Combines two previously identified gaps for solutioning purposes
**Previously identified "Person Identity Management" is being addressed through the Digital Identity Strategy process

Gap #1: **Human Service and Demographic Data Exchange Standards and Capacity** (1 of 2)

Gap #1a: National and federally recognized human service data exchange standards are nascent, and the standardized collection, exchange, and use of Social Determinants of Health (SDOH) and other human service information remains limited; national networks, HIOs, and EHRs generally have limited capabilities to exchange structured and standardized SDOH and other human service data.

Relevant AB 133 Provision(s): *Identify ways to incorporate data related to social determinants of health, such as housing and food insecurity, into shared health information. [§130290(c)(3)(C)]*

Key Considerations:

- SDOH data collection efforts remain largely nascent, though are developing to allow health care organizations to better understand and support individuals' whole person care needs. SDOH – the conditions in the environments where people are born, live, learn, work, play, worship, and age – are estimated to account for up to 80% of health outcomes; understanding and addressing these factors is central to improving the health and wellbeing of all Californians. DHCS' CalAIM program focuses on addressing SDOH (link).

- SDOH data may be collected:
  - **Directly** from interactions with an individual (e.g., patient screening, observed conditions noted in clinical records or on claims).
  - **Indirectly** from changes in an individual's engagement with the human service system (e.g., SNAP enrollment/food insecurity, HMIS identification/housing insecurity, jail and prison data to support care transitions).

- SDOH data **directly** collected from interactions with an individual and recorded in:
  - Screenings or in clinical records that are often not collected in alignment with federal standards and definitions, such as the USCDI v2 (released by ONC in July 2021 and available here), as health care organizations sought to collect information prior to federal or national standards being widely disseminated.
  - Claims/encounters using the ICD-10-CM codes (primarily Z55-65 under *Factors influencing health status and contact with health services*, described here) remain limited (link), as health care organizations frequently do not have financial incentives or training to accelerate use.

- SDOH data that may be **indirectly** collected from changes in an individual's engagement with human service programs may not always be accessible in a timely manner to health care organizations that could use it to inform an individual's care and/or connect individuals with needed supports due to various legal, operational, and technical barriers to data exchange.

Gap #1: **Human Service and Demographic Data Exchange Standards and Capacity** (2 of 2)

Gap #1b: Race, ethnicity, languages (spoken/written), sexual orientation, gender identity and other demographic data necessary to support population health and to identify and address disparities and inequities are often missing, incomplete, or are not collected or shared.

Relevant AB 133 Provision(s): *Identify ways to incorporate data related to underserved or underrepresented populations, including, but not limited to, data regarding sexual orientation and gender identity and racial and ethnic minorities.* *[§130290(c)(3)(D)]*

Key Considerations:

- Demographic data collection completeness and consistency across health and human service programs varies significantly by data type.
  - "Gender" data are almost universally collected against a consistent – though outdated – male/female classification schema.
  - "Sexual Orientation" and "Gender Identity" data are rarely collected at present, and when collected, are captured against varying local or industry standards.
  - "Race", "Ethnicity", and "Language" (preferred spoken/written) data are almost universally voluntarily solicited by programs from individuals, but frequently left blank, and collected against varying federal, state, local, and industry standards.
  - Current inadequacies in data elements can have serious implications for clinical decision support, quality of care, and health disparities.
- Health disparities in California are pervasive, and reflective of structural racism in our society and inequities in our systems of health. For example, Black Californians are expected to live 11 years less than Asian Californians, and experience the highest death rates from breast, cervical, colorectal, lung, and prostate cancer among all racial and ethnic groups (CHCF Brief); while nationally – according to data from the Trevor Project – 42% of LGBTQ youth seriously considered attempting suicide in 2021. Understanding Californians' unique diversity and the barriers specific groups may face in accessing and receiving health care is essential for ensuring their long-term health and wellbeing.
- Demographic data are ideally collected directly from an individual against standardized definitions. However, many individuals are hesitant to volunteer such information for fear of discrimination. Health care organizations may "fill in" missing demographic data with "indirect" data matched from other data sources or through statistical imputation (i.e., approximations based on other individual information). There are no systemic operational/technical methods in the health care ecosystem to maintain a "hierarchy of truth" (i.e., member data vs. indirect data).
- Demographic data collection, curation, and use will benefit from data standards, protocols, and practices that may not presently be in place across the health care data ecosystem – or nascent in implementation. For example, the Gravity Project is working to incorporate both source and method of collecting certain demographic data alongside the value itself. In addition, federal HRSA and UCSDI demographic data standards conflict and may cause confusion in the market.

Opportunity #1: **Improving SDOH and Demographic Data Collection and Use to Identify and Address Health Disparities** (1 of 4)

(1a): Consider establishing SDOH data collection and use standards, requirements, and incentives. CalHHS should adopt the US Core Data for Interoperability (USCDI) Version 2 standards to facilitate ~~the collection of~~ consumer SDOH data collection, in addition to consumer race, ethnicity, language, sexual orientation, gender identity, social and behavioral risk information (see Opportunity #2a). Standards may be paired with common data collection, data quality and performance reporting requirements and incentives through public and private payers to support system change. Data collectors and users may also require technical assistance to support new data collection and use practices.

California DHCS has prioritized identifying and addressing SDOH through CalAIM, which builds upon its Whole Person Care (WPC) pilot program that promoted coordinated care – physical, behavioral, and social – for high-risk, high-utilizing Medi-Cal enrollees by increasing service integration and SDOH data sharing and use among counties, plans, and CBOs. Successful WPC pilots – including Alameda County Care Connect, LA County WPC, Marin County WPC, and San Francisco DPH WPC – each established new data sharing protocols to support the exchange of SDOH related information. More broadly, CMS has encouraged state Medicaid and CHIP programs to adopt strategies that address SDOH, including instituting new data collection and reporting requirements, investing in systems capable of exchanging SDOH data, and programs that can put such data to meaningful use. Many states already incorporate SDOH screening and/or referral requirements in their Medicaid MCO contracts; and use quality reporting requirements and incentive payments to monitor and reward SDOH progress (KFF overview).

Opportunity #1: **Improving SDOH and Demographic Data Collection and Use to Identify and Address Health Disparities** (2 of 4)

(1b): Consider establishing demographic data collection and use standards, requirements, and incentives. Paired with Opportunity #1a, California may work with private health care organizations to establish and require demographic data collection and reporting (e.g., race, ethnicity, sexual orientation, gender identity, disability status, etc.) ~~against~~ in accordance with federal standards (e.g., CDC and OMB, USCDI v2.0), and ensure consistent and comprehensive demographic data collection across public and private entities (e.g., Connecticut SB-1). As indicated in Opportunity (1a), California should also have a process to evaluate relevant new federal standards as they are released in order to determine how they may be implemented. Standards may be paired with common collection and reporting requirements (e.g., MCP/provider quality/performance reporting) and incentives through public (e.g., Medi-Cal, CalPERs, and Covered California) and private payers to <u>use</u> data to identify and reduce disparities. Data collectors/users may require technical assistance to support new data collection and use practices.

DHCS analyzes Medi-Cal MCP quality data through its External Quality Review Organization (EQRO) process to assess potential differences in health outcomes between racial and ethnic population groups and shares those analyses with MCPs to guide interventions. DHCS also emphasizes increased data collection to reduce disparities and inequities through CalAIM. Covered California, meanwhile, continues to increase its race and ethnicity data reporting and use expectations for its QHPs. CDPH has also collected demographic and SDOH data to inform the state's response to COVID-19. More broadly, CMS has prioritized its expansion of the "collection, reporting and analysis of standardized data" – including race, ethnicity, language, sexual orientation, gender identity, and disability status - in its Medicare Equity Plan, as broader federal action in this area has been encouraged.

Opportunity #1: **Improving SDOH and Demographic Data Collection and Use to Identify and Address Health Disparities** (3 of 4)

(1c): Consider enhancing cross-state agency data sharing efforts to support the exchange of program enrollment data and consumer demographic and SDOH information to support cross-program service coordination and whole person care.
California may enhance its interagency data sharing efforts in accordance with the Framework's vision and goals to allow – in compliance with federal law – the sharing of individuals' public program information across agencies and departments, and with health and human service organizations and consumers, to support coordinated service delivery and improve the health and wellbeing of Californians. Data sharing may include program enrollment, demographic, service utilization, and/or health and human service needs information captured by agencies and departments including:

- DHCS/Medi-Cal, including enrollment and identified social needs (if captured on claims/encounters);
- DPSS/CalFresh, including enrollment and other food insecurity indicators;
- BCSH/Homeless Data Integration System (HDIS), including enrollment and other housing stability indicators;
- DOJ/Criminal Justice Statistics Center (CJSC), including justice involvement and probation events or transitions;
- DSS/Child Welfare Services/Case Management System (CWS/CMS), including intake, screening, and health/social needs data; and
- Covered CA and CalPERS, including enrollment and identified social needs (if captured on enrollment, screenings, and claims/encounters).

California may evaluate the feasibility and efficacy of incentivizing the connection to and expansion of health information exchanges, community information exchanges (CIEs), and other intermediaries to support cross-program and cross-sector exchange and use of SDOH and demographic data.

Under CalAIM, health care organizations will be expected to identify SDOH needs directly from individuals, if not available directly through state systems or regional community information exchanges (CIEs), such as San Diego CIE and Access Sonoma (see case examples).

DHCS could potentially leverage enhanced federal Medicaid matching funds for "state expenditures to design, develop, install, or enhance" interoperable systems capable of identifying individuals' SDOH needs and sharing that information with appropriate medical and social support services (CMS guidance).

Opportunity #1: **Improving SDOH and Demographic Data Collection and Use to Identify and Address Health Disparities** (4 of 4)

(1d): Consider advancing recommendations to federal government to improve demographic data collection nationally. Race and ethnicity data collection remain uneven across the health care data ecosystem, with applications limited for its use. And multiple federal standards also exist; HRSA for example does not align with USCDI v1 or v2. As such providers in HRSA(e.g., FQHCs) programs must now support both standards. Sexual orientation and gender identity data collection are also relative nascent, with federal standards only now emerging. Demographic data should accurately reflect the truth of the individual, though the technical systems and protocols for collection that presently exist do not always reflect this value – or collect/maintain needed meta information required to preserve that testimony (i.e., systems do not identify whether demographic information was provided directly by the member or collected through other sources).

As California advances a Data Exchange Framework that prioritizes health equity, it should develop processes to identify both **misalignment** of national standards and **gaps** in our national data collection, curation, and use standards, including standards promulgated by HRSA, CMS, ONC, OCR, SAMHSA and other federal agencies that design and implemented new national standards. ~~to support the adoption of additional standards for the collection of disability (functional and cognitive) status and accommodation needs information~~ California should develop a process to advocate for and advance data standard that better align national standards and fill data standard gaps that are needed to advance state priorities. And California should develop processes to evaluate relevant new proposed federal SDOH standards and data collection, sharing and use regulations to determine whether and how they may be implemented and improved. For example, California could evaluate emerging draft USCDI Version 3 standards that support more consistent functional, cognitive and other disability status data collection, sharing, and use, and provide recommendations to the federal government to improve those standards before they are adopted.

Gap #2: **Provider Identity Management**

Gap #2: Robust provider, care team, and social service organization directories are not available or accessible to health and human service organizations across California.

Relevant AB 133 Provision(s): *Identify gaps, and propose solutions to gaps, in the life cycle of health information, incl. gaps in the: Linking, sharing, exchanging, and providing access to health information. [§130290(c)(3)(B)(iv)]*

Key Considerations:

- Provider identity management can be improved to support various objectives, including, but not limited to understanding bidrectional:
    - **Individual-to-provide**r relationships (i.e., attribution) to support care coordination;
    - **Provider-to-provider** data exchange addresses to ensure the appropriate and secure routing of individual information; and
    - **Provider-to-plan** data exchange (i.e., provider directories) to ensure plans maintain up-to-date network information to share with their members.
- California has invested significant public and private resources into improving **provider-to-plan** data exchange through Integrated Healthcare Association in California's Symphony project.
    - Other national provider directories include DirectTrust and the National Plan & Provider Enumeration System (NPPES) (National Provider Standard).
    - CMS's recent Interoperability and Patient Access Final Rule and California's SB-137 stipulate more rigorous requirements for certain plans to maintain up-to-date consumer-facing provider directories.
- While provider-to-provider address directories may be tied to provider directories, less progress has generally been made in ensuring their timeliness and reliability.
- Several challenges exist to developing robust provider identity management systems, including:
    - Many widely used identifiers have shortcomings for advancing the objectives above. For example, many billing providers have an NPI, but not all treating providers do. Further, both organizations and individual providers can have NPIs, potentially causing confusion.
    - Provider clinical, system affiliation, and technical/address information can often change, requiring updates to the systems of all organizations that depend upon it.
    - Provider identity management systems are most effective when they can be used across organizations and sectors; however, this requires transparent governance.
    - Social service providers often lack robust identity management processes that are compatible with identifiers and processes used in the health care sector. Some private sector organizations (such as kno2) offer solutions that facilitate data sharing between health and social service providers.

Opportunity #2: **Enhance Provider Directory Requirements to Incorporate Provider Address Information** (1 of 2)

(2a): Consider expanding upon the provider directory API Requirements in CMS's Interoperability and Patient Access Final Rule. California could require all signatories of the DxF DSA to maintain and update identity credentials. The requirement in CMS's Interoperability and Patient Access Final Rule (CMS-9115-F) that specified payers offer a public facing Provider Directory API using a FHIR-based API, specifically, the PDEX Payer Network Implementation Guide, could be expanded to include:

- All payers licensed in California, including Qualified Health Plans (QHPs); and

- DxF DSA signatories, such that all parties provide updated credentials to payers and to any qualifying health information exchange intermediaries with which they share data.

California could also consider building upon SB-137 to require the posting of NPI type 1 (organizational) and type 2 (individual provider) information to include other information including provider Endpoints.[1]

[1] *Endpoints provide a simple, secure, scalable, and standards-based way for participants to send authenticated, encrypted health information directly to known, trusted recipients over the Internet. In NPPES, providers can enter Endpoint information when they request new NPIs or when they update their NPI information. The Endpoint details can be entered on both Individual (Type 1) and Organization (Type 2) NPI applications. This information will be made available on NPI Registry , APIs, and Data Dissemination Files for users to receive and consume.*

Opportunity #2: **Enhance Provider Directory Requirements to Incorporate Provider Address Information** (2 of 2)

(2b): Consider requiring qualifying HIOs to participate in a federated provider identity management service. There is significant value in implementing identity and master data management as a shared service to reduce individual organizational burden. The DxF can establish a set of requirements for qualifying HIOs that they deploy master data management approaches to identity management that include technical systems, processes, governance, policies, and standards to establish a consistent reference identity for individuals, the data attributed to them, the identity of providers, provider membership in organizations, and patients attributed to them. (ONC's State Health IT Modular Functions for Value-based Payment Strategic Implementation Guide)

Gap #3: **Consumer Data Access**

Gap #3: Individuals consistently face challenges in accessing their health and human service records - directly or through selected third parties - in a manner that is convenient, timely and compliant with federal access requirements.

Relevant AB 133 Provision(s):
- *Identify gaps, and propose solutions to gaps, in the life cycle of health information, incl. gaps in the:*
  - *Linking, sharing, exchanging, and providing access to health information. [§130290(c)(3)(B)(iv)]*
- *Identify how all payers will be required to provide enrollees with electronic access to their health information, consistent with rules applicable to federal payer programs. [§130290(c)(3)(I)]*

Key Considerations:

- **Consumer Data Access and HIPAA.** Under, HIPAA, patients have a legal, enforceable right to access their health records maintained by a covered entity such as a provider or health plan. In reality, numerous barriers exist to accessing one's own health data including complex access requirements, consumer portals that are difficult to navigate, fragmented data, financial costs (e.g., printing fees), and often health care organization non-compliance. The Health Information Technology for Economic and Clinical Health Act (HITECH) of 2009 also requires that HIPAA-covered entities (physicians, payers, clearinghouses, and their business associates) who use EHRs must follow a direction from a patient to transmit the patient's PHI electronically to any person, entity, or application the patient chooses, such as a public health agency, a community-based service provider, and the patient's third-party health application.

- **Recent Regulations and Frameworks**. ONC's Cures Act Final Rule includes provisions that support consumer data access, including efforts to curtail information blocking. CMS's Interoperability and Patient Access Final Rule requires CMS-regulated payers to make patient data, including claims and encounter data, available to patients via a secure, standards-based API. TEFCA counts easy access to electronic health information for individuals and their authorized caregivers as one of its principles for trusted exchange.

- **Potential Opportunities.** Improving consumer data access will require an industry-wide effort with participation from both the public and private sectors.

Opportunity #3: **Ensure Consumer Access to their Health Information** (1 of 2)

(3a): Consider adopting policies to ensure consumers have meaningful access to their longitudinal health information across all health care organizations subject to AB-133, allowing them to make informed health care decisions. Potential policies and requirements to advance this objective may include:

- Expand federal information blocking and patient access API rules to <u>all</u> health care organizations subject to the DxF including:
    - All California licensed health plans and health care organizations listed in AB 133 subdivision (f)(1-6).
    - Requiring all health care organizations listed in AB 133 subdivision (f)(1-6) to implement and maintain a secure, standards-based (HL7 FHIR Release 4.0.1) API that allows patients to easily access their health information through third-party applications of their choice and made available electronically by the request of the individual.
- Evaluate where California law governs consumers access to their longitudinal health information (e.g., California Health and Safety Code 123110) since the federal Information Blocking and Patient Access Interoperability rules defer to state law.
- Provide consumers with bi-directional access to their health information maintained by health care organizations – including to add self-reported health information and correct inaccurate information to the extent allowed by law – in a manner that accommodates their preferred language, readability, disability access, and support access for those Californians who have limited access to technology or broadband and consider consumer health and IT literacy.
- Consumers should be provided with education and support by health care organizations on how to: access their health information; use their health information to inform their decision-making; and update their health information if inaccurate.

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Opportunity #3: **Ensure Consumer Access to their Health Information** (2 of 2)

(3b): Consider adopting policies to ensure consumers understand how their health information may be used and trust in the systems in place that govern its use. Potential policies and requirements to advance this objective may include:

- California should review its current Fair Information Practices, consider updates and develop stronger guidelines that can be linked with the state's Data Sharing Agreement and future State Policy Guidance. Guidelines may include transparency about data policies; limitations on health information collection, use, and disclosure; consent; data quality, integrity, and security protections; and ensuring accountability through appropriate audit trails and enforcement. Guidelines should be clear to consumers around how their health information will be shared and where they have the ability to provide consent or not prior for its exchange and use, in alignment with state and federal laws

- California should develop practices and policies to hold DSA participants accountable for participation in the appropriate exchange and use of consumer health information, including:
    - Monitoring and evaluating participation and adherence to policies regarding data sharing, safeguarding and use of health information;
    - Integrate explicit protections against misuse of health data;
    - Supporting health care organization training on consumer access to health information; and
    - Supporting consumer feedback mechanisms to improve data access.

- The U.S. HHS Office of Civil Rights' Individuals' Right under HIPAA to Access their Health Information 45 CFR § 164 and ONC's 2018 Model Privacy Notice provide examples of clear guidance to inform consumers about data access and privacy policies.

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