Connecting for Better Health

June 9, 2022

John Ohanian, Chief Data Officer and Director, Center for Data Insights and Innovation
California Health and Human Services Agency
1660 Ninth Street, Room 460
Sacramento, CA 95814

Re: Data Exchange Framework Strategy for Digital Identities

Dear Director Ohanian:

On behalf of the Connecting for Better Health coalition, we write to thank you for the opportunity to comment on the draft Strategy for Digital Identities (Strategy), part of the Data Exchange Framework (DxF). Connecting for Better Health is a coalition representing diverse health care organizations and leaders including consumers, providers, and health plans, that supports the advancement of health data exchange policy in California. Our vision is that every Californian and their care team have the information and insights they need to make health care seamless, high quality, and affordable.

We are excited by the state's pursuit of the DxF and associated Strategy under A.B. 133. We agree that there is urgency behind this work and believe the Strategy will propel California forward to help realize more meaningful, real-time data sharing across the state. Please find below our collective feedback and recommendations:

Stakeholder Representation and Strategy Development

There is minimal background available regarding those consulted in the development of the strategy through focus groups and other input, and the perspectives they shared. We recommend that CalHHS include the extensive list of stakeholders consulted in an appendix in the Strategy to show stakeholders the breadth of individuals included in this work. Additionally, based on feedback from our coalition participants who were involved in several of the input sessions, there is concern that some perspectives may be underrepresented, especially those of social care and services organizations. It would be helpful if CalHHS published a summary of the feedback shared and how this input was incorporated into the strategy design and recommendations.

Purpose

The strategy defines the purpose of the digital identity as follows: "The purpose and use case for digital identities is to associate accessed or exchanged health and social services information with the correct real person." The coalition agrees with this purpose. However, the references to 'patient matching' and 'person resolution' on page 11 are confusing and should *not* be referenced as synonymous with "record linking," but rather included and defined separately. CalHHS should recognize in example that record linkage happens between data sets from different systems and that resolution or authentication typically occurs at the points someone accesses a system.

Statewide Person Index

The strongest utility for the statewide person index proposed in the Strategy is to simplify how DSA Participants, including providers, HIOs and health plans, query for patient information through various networks. Currently, many organizations perform a broadcast query within a geography to identify other organizations that might have information on the individual. This approach is burdensome, given that organizations receive millions of these queries every month for individuals for whom they may not have information in their records.

Creating an index of all medical records numbers and their associated providers and health plans would simplify this process. Organizations would be able to directly request information from organizations known to have records for an individual, reducing the burden of handling and responding to queries. This would also allow providers to compile more complete records for their patients.

Our comments reflect the utility and merit of a statewide person index that serves as a record locator service (RLS). We agree that a RLS would be of great value to the state given the current health information exchange landscape and the robust patient matching capabilities that exist within health systems, health plans, and health information organizations. A statewide person index that is readily available to direct data queries will make immediate improvements to statewide health data sharing and support the integration of social care data required for CalAIM. Given that there is a higher level of complexity to cross-domain identity resolution due to several factors, including lack of integrity and variance in attributes, CalHHS should consider leveraging proven approaches instead of developing something from scratch. For more insight it would be useful for the state to compare the query process for entities using Carequality, which does not have an RLS, with the process for entities using CommonWell, which does.

Public-Private Participation

The DxF and Strategy should be viewed as collective assets for public and private organizations that benefit all Californians. The draft strategy does not recognize the essential role that state agencies and local health jurisdictions play as organizations that have a business need to identity patients, and as contributors and recipients of data. Moreover, the strategy does not account for existing and/or planned patient matching infrastructure maintained by the state or its partners such as the California Department of Health Care Services (DHCS) Statewide Client Index (SCI); California's All-Payer Claims Database (APCD); the DHCS Population Health Management (PHM) Service; the Department of Justice (DOJ) Controlled Substance Utilization Review and Evaluation System (CURES); the forthcoming California Emergency Medical Services (EMSA) Physician Order for Life Sustaining Treatment (POLST) registry; and the California Department of Public Health (CDPH) immunization, birth and death, and other disease registries. We recommend a statewide review of person indexing capabilities and services to identify how the state can better leverage and consolidate these services for its own record marching use, or potentially harness them for private use. In addition, we recommend that the strategy includes input from the Department of Veterans Health Affairs and the

Department of Defense who may also benefit and/or can contribute to the statewide patient indexing effort.

The draft Strategy references that “organizations would be strongly encouraged, but not required, to use the statewide person index” (page 21). The coalition recommends that all Data Sharing Agreement (DSA) participants, including state agencies and local health jurisdictions should be required to contribute to the development of a statewide person index. We recognize there are and should be clear distinctions between requiring contribution versus optional use within the participating organization(s).

Data Standardization

We agree the strategy should adhere to the United States Core Data for Interoperability (USCDI) version 1; however, stakeholders should readily prepare to adopt versions 2, 3 and subsequent versions. In addition, the coalition strongly supports the required use of Project US@ postal codes and close engagement and alignment with HL7’s Patient ID Workgroup and Security Patient ID Workgroups.

Notably, the coalition recognizes that there is a need for the state to ensure that its own agencies and local jurisdictions’ data sharing capabilities are updated and aligned. The strategy should contemplate a process that inventories and reconciles the state’s multiple health data collection standards and data dictionaries across state, county, and municipal agencies. Also, please note that social care and services organizations do not leverage USCDI in social services case management, nor are there nationally defined data standardization efforts for these organizations.

We also stress that data standardization is insufficient to achieve the goal of standardized documentation. CalHHS should connect the Strategy with mention in the DxF of the need for incentives to assist organizations with updating their data standardization practices, and a review process for continual improvement to ensure their data conforms.

Privacy and Security

The utility and integrity of a statewide patient index that serves as a RLS must maintain the source of the data collected, as provenance is an interoperability best practice. We recommend the Strategy reiterate the importance of provenance.

The coalition also recognizes the relevance of forming patient consent registries in tandem with a statewide person index. We agree that consent registries should be dynamic (versus static) and be localized (versus statewide). We recommend the Strategy state that the development of consent management registries should be developed in parallel with the statewide person index.

While tokenization is highlighted in the strategy, we recognize that tokenization is one of many approaches that may be used to preserve privacy and decentralize identity. We recommend that tokenization and other methods for privatization, such as Project Unify with the National

Information Collaborative (NIC) and Privacy Preservation to Promote Interoperability (PP2PI) be reviewed again when appropriate.

The strategy restricts secondary uses of the attributes comprising digital identities (page 17). The coalition is concerned that this directive may limit valuable contributions to the public good. We recommend that use and purpose of the patient identity service be reviewed, and that the strategy considers additional stakeholder input into current and future scenarios.

The strategy references that it will “[r]equire organizations to follow the same security, consent, minimum necessary, and audit requirements for digital identities as those afforded to health information by provisions in the Data Sharing Agreement” (page 18). The coalition questions the guidance that organizations should abide by a “minimum necessary” for the purposes to populate a person index. We recommend that the strategy replaces “Data Sharing Agreement” with “all applicable law,” which may include the DSA for signatories to that Agreement, should the final version have minimum necessary standards that diverge from those currently in state and federal law.

Lastly, the coalition strongly supports the exploration of patient/consumer-managed identity strategies and notes the national programmatic efforts such as the Pan-Canadian Trust Framework (PCTF) and eID wallets of the European Union (EU) as references to consider for California.

Funding and Governance

The coalition supports prioritizing immediate implementation of the statewide person index that can be used to facilitate patient data queries as discussed earlier. CalHHS should also prioritize and invest in governance. Active governance is required to oversee the development and management of a statewide public-private person index that contemplates authentication and use by individuals (page 21). In addition, governance will play an important role in standards management including advocating, tracking, aligning, and communicating updates to consumers and DSA participants.

To move forward without addressing sources of funding would be remiss. In addition to securing general funding for a statewide person index in the upcoming budget cycle, we recommend that the state explore where efficiencies may be made by planning and building the statewide person index with funds already committed to state-funded initiatives that aim to modernize data sharing infrastructure and/or build additional data sharing capacity (like the programs referenced in section Public-Private Participation above).

Conclusion

Thank you again for the opportunity to comment on this important and essential initiative. The DxF envisions robust health data sharing among multiple organizations across the state. A statewide person index that is stewarded by the state is essential to realizing this goal. The Connecting for Better Health coalition is available to answer questions and facilitate further dialogue and continued collaboration. We would be happy to contribute to the ongoing discussions.

Sincerely,

Robby Franceschini
Connecting for Better Health Coalition