Savage & Savage LLC

December 23, 2021

<u>*By electronic submission*</u>

Mr. John Ohanian
Chief Data Officer, California Health and Human Services Agency
Director, Center for Data Insights and Innovation
1215 O Street, 11th Floor MS-08,
Sacramento, California 95814

re: Requested comment on draft Data Exchange Framework Guiding Principles (v4) and draft HIT Gaps and Opportunities

Dear Director Ohanian:

Thank you very much for the opportunity to provide comment and expertise regarding the draft Data Exchange Framework Guiding Principles (v4), dated December 17, 2021, and the draft gaps and opportunities to realize the short- and long-term goals and objectives of AB-133, presented December 14, 2021.

Draft Data Exchange Framework Guiding Principles (v4)

Regarding the draft Principles, I attach a copy of version 4 with suggested changes and comments explaining those changes. I appreciate and wholeheartedly agree with the decision to restore, not delete, Principle 8 on accountability. These principles are not just words on paper.

I also renew critical recommendations on patient access, bidirectional exchange, and health equity.

a. Principle 4 on patient access should explicitly call out **Californians' access to their longitudinal health record** across all providers through the state health information exchange, just like providers, payers, public health, and other authorized members of the care team. The California Legislature stated just that in AB 133: "patient access to personalized, longitudinal health records." AB 133 leverages national standards, and Congress mandated that, too, in the 21st Century Cures Act: "offering patients access to their electronic health information in a single, longitudinal format that is easy to understand, secure, and may be updated automatically." California's patients need access to their longitudinal health information as much as any participant for shared care planning, whole person care, consolidated medication and immunization lists, and much more.

b. As COVID-19 has highlighted, the need for **bidirectional and multidirectional exchange** covers far more than the state and local public agencies targeted in Principle 2. Patients need to contribute patient-generated health data, patient-reported outcomes, and remote monitoring data missing from their health records so their doctors have access. Community and social service organizations need to be able to contribute screening, diagnosis, and intervention data for a complete record before and after a referral. Public health agencies need multidirectional exchange in real time to manage public health emergencies. And we need multidirectional exchange of care plan updates among all care team members for dynamic, longitudinal shared care planning and coordination.

c. Social and environmental determinants of health, such as food and housing insecurity, account for 80-90 percent of an individual's health status. Clinical care only accounts for 10-20 percent of one's health status. As COVID-19 has highlighted repeatedly, this is true at both individual and community or population health levels. Thus, **integrating social determinants of health (SDOH) data is critical for both whole-person care and for advancing health equity**, and I urge that it be included in Principle 1 on health equity in addition to the current mention in Principle 3 on whole-person care.

The attachment interlineates these recommendations and includes other recommendations and explanations as well.

Draft HIT Gaps and Opportunities

The presentation to the Stakeholder Advisory Group on December 14 identified four gaps and opportunities for consideration: improve EHR adoption, improve data exchange capacity of health care and human service organizations, improve event notifications to providers, and improve intra- and inter-sector data exchange capabilities. While these gaps and opportunities are real, it is striking that the current draft includes no patient-facing gaps and opportunities. I suggest at least three for consideration.

Many key gaps and opportunities for patients revolve around ready electronic access to their longitudinal health record. As mentioned above, California's patients need access to their longitudinal health information as much as any stakeholder group for understanding their health status, for shared care planning and whole-person care, even for such basics as consolidated medication and immunization lists, sharing with family caregivers, and much more. The opportunity: Develop policies that promote patients' access to and use of their longitudinal health records, beginning with the state HIE.

Other key gaps and opportunities for patients revolve around the disconnect between clinical care (the 10-20 percent of health status) and care or services provided by community-based organizations and social service agencies to address social and environmental determinants of health in underserved communities (the other 80-90 percent of health status). The Gravity Project and its nationwide collaborative

community of stakeholders have done much done much to build standardized terminology and FHIR-based exchange of SDOH data end-to-end, including providers, payers, vendors, community-based organizations, referral or coordination platforms, and patients using smartphone applications. On July 9, 2021, the Office of the National Coordinator included the Gravity Project's SDOH data elements in the U.S. Core Data for Interoperability, version 2, for nationwide interoperability and use.[1] The opportunity: Develop policies that promote integration and use of social and environmental determinants of health data so that—as COVID-19 has demonstrated—patients and underserved communities can get better care and better health with better value for all. To some degree, this gap and opportunity may overlap with gaps and opportunities listed under "data exchange capacity of health care and human service organizations" and "intra- and inter-sector data exchange capabilities."

Health inequities and disparities present a huge gap and opportunity. The literature documenting this gap and opportunity is legion. The opportunity: Develop policies that identify and reduce health disparities and advance health equity. For example, the Consumer Partnership for eHealth—a coalition of more than 50 consumer, patient, and labor organizations working at the national, state, and local levels to advance private and secure health information technology—cataloged key opportunities, grounded in evidence and the literature, in its Disparities Action Plan.

This is hardly an exhaustive list of gaps and opportunities, but I hope it provides you with significant opportunities worth considering.

Thank you again for the opportunity to share these thoughts and expertise. If you have any questions, or if I can provide any further help, please contact me at MarkSavage.eHealth@pacbell.net.

Very truly yours,

Mark Savage
Managing Director,
Digital Health Strategy & Policy

attachment

cc: Secretary Mark Ghaly
       Jonah Frohlich

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[1] I am the Gravity Project's SDOH Policy Lead and can provide further information if needed.