RE: Comments regarding Data Exchange Framework DSA Draft

Sir John,

On behalf of SacValley MedShare, I am submitting the following recommendations regarding the Data Exchange DSA Draft. I appreciate the opportunity to provide you feedback and respect the efforts required to achieve the extremely complex initiatives outlined in AB133. It is my hope that together we can make a tremendous impact in Californian’s lives.

I recommend the inclusion of the following text to the Definitions section (Section 3) of the DSA: Qualified Health Information Organizations ‘Qualified HIos’ shall refer to data exchange intermediaries approved by the California Health and Human Services Agency (CalHHS) to facilitate data exchange between Participants. CalHHS shall establish a rigorous process to evaluate and approve Qualified HIos. Baseline requirements include: status as a non-profit organization or local government agency based in California; openness to participation by any provider or health plan in their service region; and the ability to facilitate data exchange between Participants for all Required Purposes and using all Standards set forth by the DSA, within timeframes established by CalHHS. Qualified HIos shall sign the DSA and meet its terms and conditions, as well as be subject to all Policies and Procedures associated with the DSA, and to any special amendments to the DSA specific to Qualified HIos as determined by CalHHS. Qualified HIos shall exchange data with each other to create a statewide data exchange network, in a manner and timeframe to be determined by CalHHS as it conforms to the legislative requirements outlined in AB133.

Edit Section 7 as follows:

Each Participant shall engage in the exchange of Health and Social Services Information for at least all Required Purposes as set forth in the Policies and Procedures, either through execution of an Agreement with a Qualified HIO or through use of their own technology. If Participants use their own technology, rather than joining a Qualified HIO, they must meet Minimum Requirements as set forth in the Policies and Procedures so that exchange with other Participants and with Qualified HIos is efficient and scalable, and meets the required timelines and oversight standards.
Include, in an appropriate section of the Policies and Procedures, the following requirements for Participants that elect to use their own technology for data exchange rather than join a Qualified HIO:

Minimum Requirements for Participants that elect to use their own technology for data exchange rather than joining a Qualified HIO

- Hospitals shall be required to proactively share ADT notifications and discharge summaries with all Qualified HIOs by establishing HL7 V2 ADT feeds and HL7 V2 ORU feeds (sharing lab data and discharge summaries) with each of these entities;
- Providers and hospitals shall be required to share CDAs through eHealth Exchange or Carequality in response to queries from Qualified HIOs for any Required Purpose;
- Health plans shall be required to share Minimum Required data elements including but not limited to claims with Qualified HIOs through flat files or designated formats for any Required Purpose.

California’s HIOs form the core infrastructure for a successful DxF that equitably meets state goals, as seen in other large states such as New York and Michigan. Our HIOs serve diverse communities of providers, linking community health centers and small practices with commercial payers and health systems. They share a history of not only meeting local needs, but of responding to and advancing state data exchange initiatives in California – including public health COVID response, the Cal-HOP program, EMSA initiatives and CalAIM. In contrast, other types of organizations seemingly being considered as “data sharing intermediaries” for the DxF do not align with key DxF principles that stakeholders would expect of the state. For instance, for-profit software vendors do not possess the transparent governance or public service orientation required for public trust in this pivotal role.

Second, national networks such as Carequality and eHealthExchange follow their governance processes based in Washington, DC, with no clear mechanism to allow for pre-emptive state regulation, concerns or priorities. Furthermore, these networks do not support the full set of Required Purposes contemplated for the DxF and struggle with appropriate levels of patient matching. Their successful participants in California today are highly concentrated among large health systems with the internal resources to smooth out the clunky and challenging user workflows that render these networks unworkable for many smaller organizations.

In short, putting California’s HIOs at the heart of the DxF aligns with all of the principles established by the Stakeholder Advisory Group, whereas failing to do so makes a continued digital divide in the state’s health care system the most likely outcome.

I would like to recommend further discussion and review of the recommended oversight protocol for state wide data exchange. We believe that the principles of exchange can best be met through rigorous and continuous review of the policies and procedures as this complex endeavor is implemented. As such, the oversight, be it an independent advisory, a state agency, an advisory board or some combination requires further investigation to ensure the future of the program meets the legal ethical and stakeholder needs for improving care in our communities.
As the Executive Director of SacValley MedShare I seek to be a catalyst of sustained improvement in the lives of those I touch. Accurate, consolidated, deduplicated, and consumable health data is critical to efficient and effective care. This data includes but is not limited to: Allergies, Immunizations, Social histories, Vital signs, Laboratory tests, Diagnostic tests, Radiology tests, Diagnoses, Medications, Procedures, ADT. Other data needed specifically after an ER/Inpatient stay are: Discharge Summaries, Physicians’ notes, Nurses’ notes, Physical examination.

I truly believe that if we are to achieve the spirit and intent behind AB133 and the mission behind CalAIM through whole person care, then HIE’s/HIO’s are critical intermediaries that can partner with and support CalHHS in achieving a healthier, information rich, and outcomes driven California.

With regards to the governance model for California needs to clearly include all the key stakeholders that include HIE’s, Health Plans, Health Systems, Providers, Public Health, Behavioral Health, and State Government. Excluding any of these stakeholders will result in a less impactful Data Exchange Framework in my sincere humble opinion. I like the Stakeholder Advisory Group model for on-going evolution of this everchanging landscape and hope that it continues as a support arm of governance.

Some other key thoughts are:

- Alignment of state law with federal policy to reduce the complexity and challenges of sharing behavioral health, substance use treatment data, and HIV data.
- Registry of electronic endpoints such as Direct addresses for all Participants
- Standard criteria for query-based exchange based on a minimum set of USCDI version 2
- In cases where patient authorization is needed:
  - Standardized form for obtaining patient authorization
  - Electronic consent registry

Finally, it is imperative that California provide sustainable public funding to support the critical data infrastructure provided by our state’s HIOs. SVMS has joined the EQUITY coalition of more than 20 provider, health plan, and health information organizations requesting $95 million in 2022-23, and ongoing funding after, for data sharing incentives and HIO data infrastructure. I am hopeful the Governor’s May Revision includes this funding which is urgently needed to support California’s goals of improving equity and transforming Medi-Cal through whole person care.

Thank you for your leadership and inclusiveness in this critical ground level establishment of AB133. I standby ready to serve and achieve our common goals together.

Kindest Regards,