

COMMENTS ON SELECTED SLIDES FROM A CONSUMER LISTENING VIA ZOOM

STAKEHOLDER ADVISORY COMMITTEE MEETING OF JUNE 23 2022

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DXF slides

(4) Permitted, Required, and Prohibited Purposes... continued

3. Responding to State Restrictions on Essential Services: Commenters expressed concern that the DSA could force providers to provide HSSI to third parties that may seek to limit or penalize access to abortion, mental health care, and gender-affirming services.

- **Response:** Added a provision stating that Participants shall not access, use, or disclose HSSI through the DSA with the intention to deny or limit access to medical services, including but not limited to contraception, abortion, mental health care, and gender-affirming care.
- Please add: "...intention to deny or limit access to medical services, OR TO PURSUE OR PROSECUTE USE OF MEDICAL SERVICES, including but not limited to..." The EU is now grappling with concern that sharing info EU-wide could enable indiv countries to pursue or punish, e.g. for abortion.

7) Individual Access Services

Requires Participants to provide Individual Users or their Personal Representatives access to the Individual User's PHI or PII.

1. Processing Individual Access Services: Commenters noted that existing law imposes limitations on the individual right of access. Commenters also noted that certain provisions in the Policy are based on HIPAA language that is likely to change.

- **Response:** Revised the Policy to require Participants to process Individual Access Services requests in accordance with Applicable Law. Revised the Policy to provide that if a Participant does not maintain the PHI/PII that is the subject of an individual access request, the Participant will direct the patient to the appropriate Participant (if known). Revised the Policy to provide that if the Policy conflicts with a legally-enforceable

Business Associate Agreement, the terms of the Business Associate Agreement will control.

- This implies to this layperson that if a provider does not wish to share with patient and chooses to use an intermediary in order not to maintain PHI/PII, provider could write the contract to make access so laborious that patient will never get any data and that said contract will rule. Surely this isn't what you mean to happen. Shouldn't state law and all flowing therefrom ALWAYS rule? PI don't say say no lawyer in CA would allow my interpretation into a contract. Lawyers elsewhere, lawyers paid enough, etc. are a loophole that must be anticipated.

2. Data Exchange Framework Guiding Principles

- Core expectations or “rules of the road” that guide the design and implementation of the DxF, DSA, and P&Ps.

1. Support for Principles & Suggestions for Additional Considerations:

Commenters offered support for the Principles and suggestions for a variety of considerations for certain providers (e.g., smaller providers, human service, long-term care, and public health) and individuals (e.g., older adults and caregivers and historically marginalized populations).

- **Response:** The Section was modified to add income and age to the list of data elements that should be collected, exchanged, and used to identify gaps in care and health disparities and support quality improvement under *Principle 1: Advance Health Equity*
- Delete “income.” Maybe unless provider has reason to believe pt lacks resources (must use Gravity codes to record this) and that resources might be available to help. Unless that rationale is present, “income” appearing in a shareable record is intrusive beyond justification.

Strategy for Digital Identities Slides

Permitted Uses: Discussion of the permitted purposes to be embodied in the DSA / P&Ps

12. Allow secondary uses: Prohibition increases effort to obtain demographics; may limit valuable contributions to public good

- **Response:** Retained restriction as aligned with Purpose of person matching, record linking and limit statewide data repository to minimum necessary for Purpose; added language that permitted purposes should be regularly reviewed
- Statewide data depository...is this required by SB 133? If not, what is it doing here at all? Makes my teeth chatter. Surely this cannot be envisioned. I think Rim said there was support for this, I don't recollect who from. I certainly do not.