



Holistic, innovative, culturally-rooted healthcare

Idea 24	Governmental transparency requirements and surveillance limitations
Proposal 24b	Better balance privacy with the need for data accessibility
Description	Create policy to better balance privacy with the need for data accessibility
How will the proposed action advance equitable health and well-being?	Having strict policies in place to not release information which can be traced back to an individual would protect people’s lives from being upended by privacy invasion. Information in aggregate can support important research in public health and community health and transparency efforts, without sharing personally identifiable information, which could negatively impact individuals. This reassurance would tamp down public fears of accessing publicly available benefits and decrease the amount of meaningless paperwork and administrative effort needed to access supports.
Is there work we can build on?	<p>The Census Bureau put in place extremely strong firewalls in the wake of the Japanese internment camps. The Census Bureau understands that it is core to their mission not to undermine public trust by sharing census data with law enforcement, while simultaneously assisting researchers and others. It is built into organizational DNA</p> <p>There is an analogous challenge in law enforcement; they need to be transparent in policies and procedures, but they cannot be freely release sensitive information.</p> <p>Healthcare could look to authentication in banking as a set of implemented processes.</p> <p>Enterprise Procurement for Interoperability offers an enterprise privacy approach to address issues in a more cohesive manner.</p>
Who would have to act? Who would be key partners?	<p>Those who hold data and who “the public” hold trust in</p> <p>Relevant local, state, and federal government institutions and agencies, including Human Services and social service providers</p> <p>Health systems and relevant local, state, an federal government institutions and agencies, including EMR/HER system providers and commercial players not covered by HIPAA</p>



<p>A few high-level action steps</p>	<ol style="list-style-type: none"> 1. Make it more accessible to readily enable consent. 2. Make the benefits of sharing information clear to key players and to the public. If people understood that the opacity of information in the system means they do not access all of the benefits they are eligible for, it would build public will. Convey how data can support coordination of services, facilitate the flow of information between systems, and (in aggregate) support health research. 3. Consider potential solutions: <ol style="list-style-type: none"> a. Impose rigid firewalls between data holders and those who could use data for nefarious purposes <p>Ban potentially nefarious actors from using any healthcare data (e.g., ban ICE from using data from any healthcare or social service entity in the same way that intelligence agencies are currently banned from doing so)</p>
<p>Other comments</p>	<ul style="list-style-type: none"> • Transparency vs privacy balance. • For whose benefit are we acting? Who are we protecting? • Decline in accessing public benefits due to fears, e.g., deportation • Real value of information-sharing framed as how do we enable coordination of care and social support through making data (in aggregate or as individual records) more accessible <ul style="list-style-type: none"> ○ Reframe as what individuals aren't getting that they're entitled to • Privacy about choosing what you do or don't reveal • Structure of integrated care in a siloed world doesn't really compute <p>Consider data as the fuel for healthcare; attempting to solve privacy issues in isolation from other interrelated issues just isn't going to cut it</p>