# A Conversation on Confidentiality & Privacy ... a barrier or an avenue to change?

## META insights

Is privacy a right or a privilege & who should decide?

How can we focus on what IS possible rather than what ISN'T?

How do we, as a very diverse group, sustain & join efforts to collectively push & govern progress on data sharing to improve human outcomes?

What will it take to build & support the will to do this?

Who benefits from the COMPLEXITY? (of privacy policies)

How can we learn from the international community & leverage successful protocols to share information & maintain privacy?

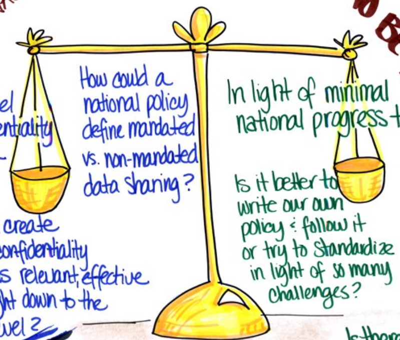
How do we reverse the question and spell out how to share data to help us?

How do we reverse the incentives that now inhibit data-sharing to encourage good practice while protecting privacy?

What is the disruptive innovation that will allow us to create a new paradigm for creating policy?

What data exists to persuade agencies/workers of the value of interoperability?

## NATIONAL PRIVACY POLICY: TO BE or NOT TO BE?



Is there a governance model that demonstrates cohesive, inter-capable rules & regulations?

Is there a group at the Federal level working on confidentiality policy in human services?

How could a national policy define mandated vs. non-mandated data sharing?

How can we create a national confidentiality policy that is relevant, effective & flexible right down to the individual level?

In light of minimal national progress to date...

Is it better to write our own policy & follow it or try to standardize in light of so many challenges?

Given the lack of nat'l. policy how do we effectively & efficiently share public health info across borders + jurisdictions, INCLUDING TRIBES?

Would a series of model statuates be a way to facilitate accommodations with existing statuates that obstruct information sharing?

Is there a generational divide on privacy concerns that current law & practice needs to accommodate?

SO LET'S SAY WE GET IT DEFINED... HOW DO WE **COMMUNICATE** IT IN A WAY THAT CAN BE EASILY GRASPED?

- How do we simplify?
- What are the good outcomes of sharing information that matter to the individual?
- How do we emphasize the benefits rather than the risks?
- How do we bridge the gap between Perception & Reality?

- How do policy makers raise consumer fluency re: privacy + security so they know what to ask?
- Is there primacy of confidentiality as human right? If so, can we achieve voluntary consent thru marketing compliance to get the end result of information sharing?
- How do we educate the public on the appropriate role of PRS in HIT?

WHAT ARE THE KEY PRINCIPLES THAT SHOULD DRIVE PRIVACY DECISIONS?

- Is it possible to protect individual rights without encroaching on the rights of others?
- What are the necessary elements to ensure informed consent with challenged clients? Does an "opt-out" policy satisfy this expectation?
  i.e. challenged - literacy, language, health, etc...
- How do we overcome the "adversarial" nature of our judicial system in order to provide the services needed?
- Is it possible to incorporate social services data into an EHR and the definition of "meaningful use"?

## Montgomery County, MARYLAND

Can we take Montgomery County experience to scale nationally?

If single authorization form works, why not more counties?

How do you define "treatment" to enable sharing of data?

## HIPAA

Where does accountability rest in the HIPAA self-reporting rule?

Will the new HIPAA changes bring data sharing progress to a halt? If so, how can we change that?