Sensitive But Business Critical Operationalizing Sensitive Data Consents





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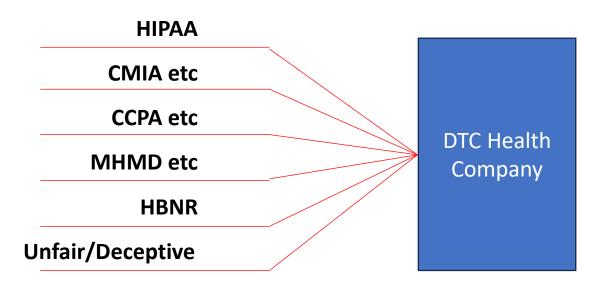


What we're talking about.

- Why does it matter?
- The current regulatory landscape.
- Defining sensitive data: where is it, and what is it?
- When to ask for consent and when not to.
- How to ask for consent.

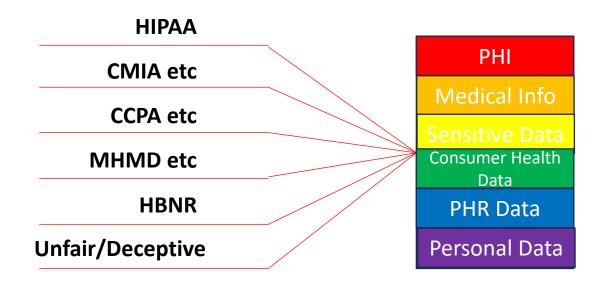


Operating in sensitive data areas is becoming increasingly complicated (especially in healthcare).



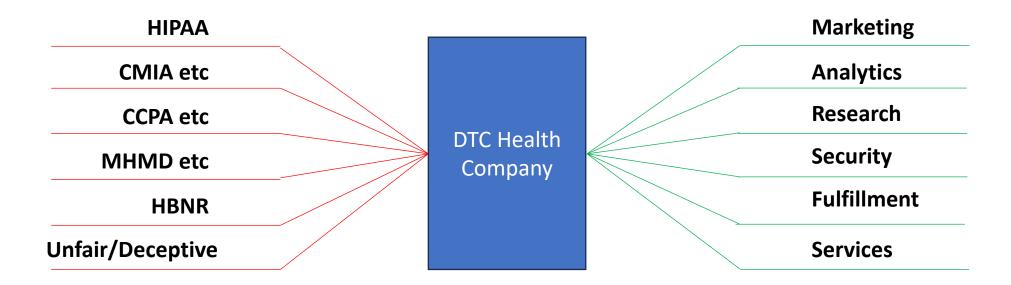


Companies dealing with sensitive data must account for a wide range of laws that apply to different sets of data, at different times, with variations across states.



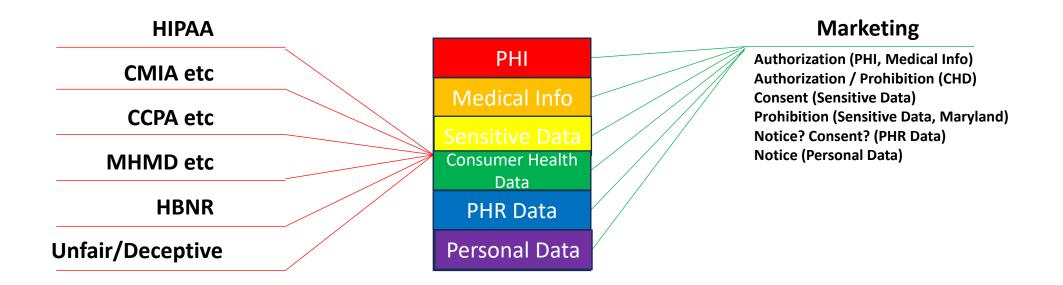


It's more difficult for businesses – especially small and medium businesses – to perform basic functions without overwhelming regulatory burdens.



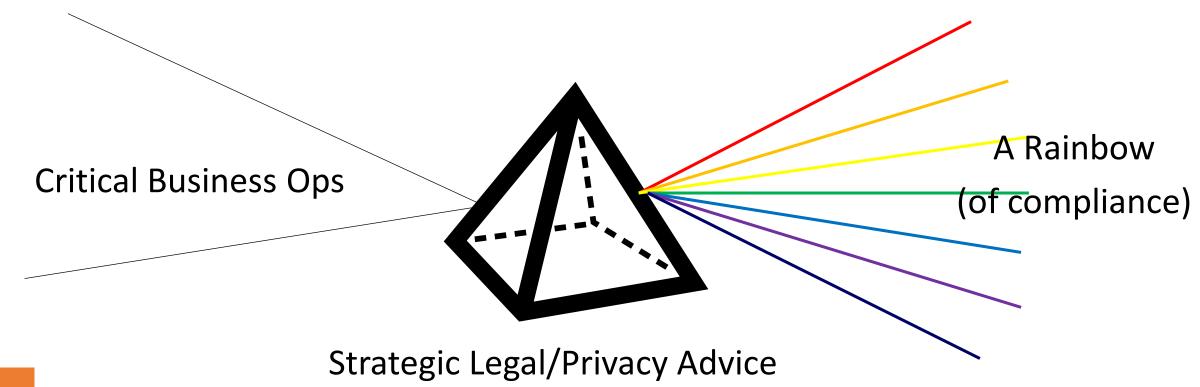


Especially when single functions can be regulated by several laws, which vary across states.



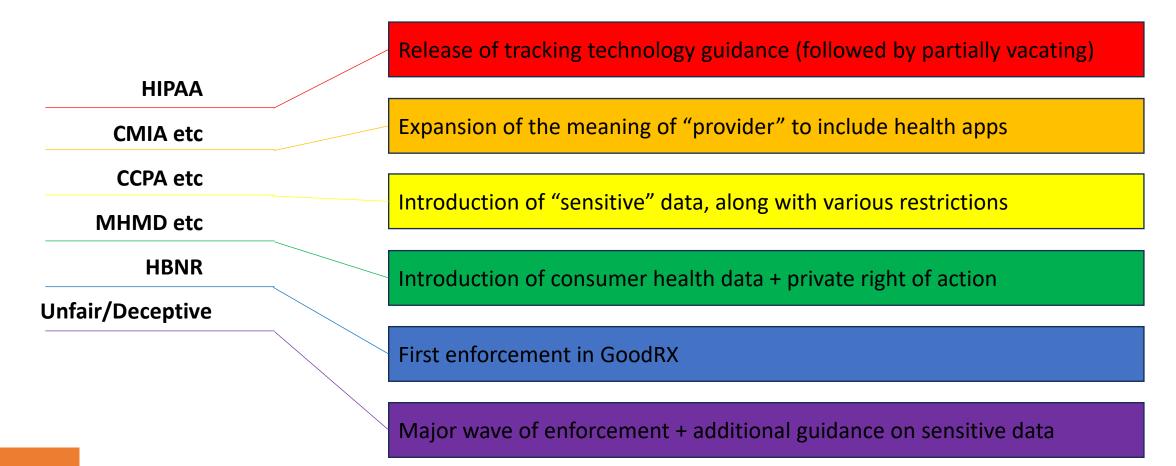


So the question is: how do we support business partners in performing their functions—while complying with the law?





The regulatory landscape is evolving (quickly).





The risks are high – but getting it right can be an advantage.

- 1. Sensitive data can be anywhere.
- 2. Regulators have signaled that appropriate use and handling of sensitive data is a priority area.
- 3. Aligning on a strategic approach to good data governance, while still empowering business functions, is critical and challenging.



Three key operational considerations:

How do I identify and classify my data?

When do I need to obtain consent?



Virginia: Personal data revealing racial or ethnic origin, religious beliefs, mental or physical health <u>diagnosis</u>, sexual orientation, or citizenship or immigration status

California: Personal data revealing racial or ethnic origin, religious beliefs, a mental or physical health <u>condition or diagnosis</u>, sex life or sexual orientation, or citizenship or citizenship status

Washington: Personal information that is <u>linked or reasonably linkable</u> to a consumer and that identifies the consumer's <u>past, present, or future</u> <u>physical or mental health status</u>.



Adopt a universal, internal definition of sensitive data	Train your workforce (actually)	Know your tech – and empower your people	Build or adopt tools	Classify and control data
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- Multi-tiered system vs "least common denominator"?
- State by state or nationwide?
- Track to legal definition or "one size fits all"?





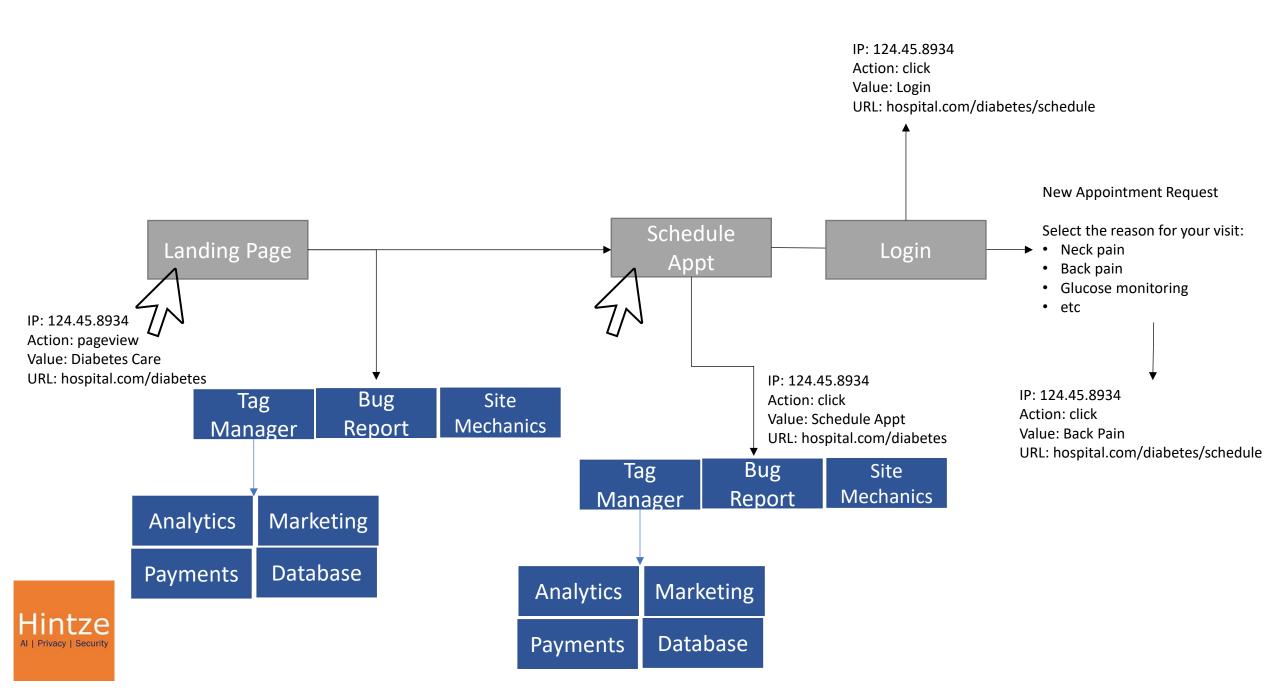
- Using a common lexicon is critical
- Make materials accessible and therefore usable





- Bridge the gap between engineering and legal
- Speak the same language and ask the right questions
- Do some self-learning, and don't be afraid to ask (again and again)
- The responsibility is not just yours







- Tools are your friend
- Perfection vs operationalization
- Stay with the market





- Technical vs operational controls
- People are the last line of defense



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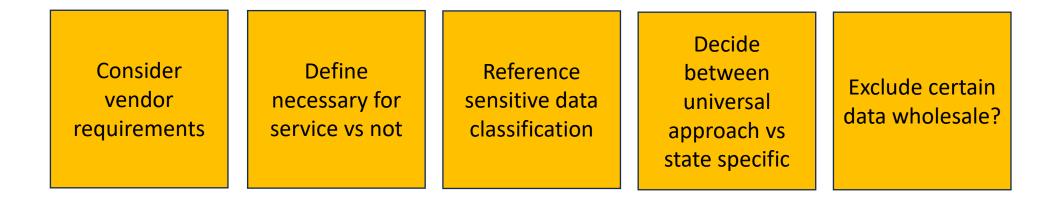
Virginia: A controller shall not process sensitive data concerning a consumer without obtaining the consumer's consent

But: Nothing in this chapter shall be construed to restrict a controller's or processor's ability to provide a product or service specifically requested by a consumer

Washington: A regulated entity or a small business may not collect any consumer health data except:(i) With consent from the consumer for such collection for a specified purpose; or (ii) To the extent necessary to provide a product or service that the consumer to whom such consumer health data relates has requested from such regulated entity or small business.

FTC: Consent required for disclosure of sensitive data?



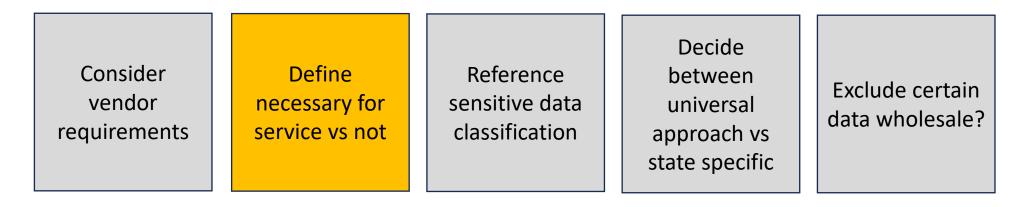






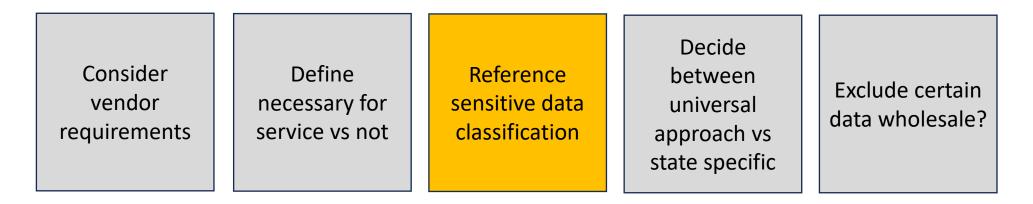
- Do vendors define sensitive data the same way you do?
- Disclosure vs use?





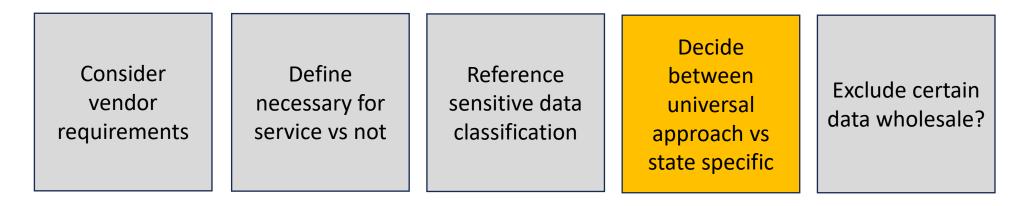
- Take a position and be clear about your risk tolerance
- Is something "necessary" in one state, but not in the other?





- Account for all sensitive data
- Make sure all data elements are tied to a consent (or otherwise "necessary" for service)





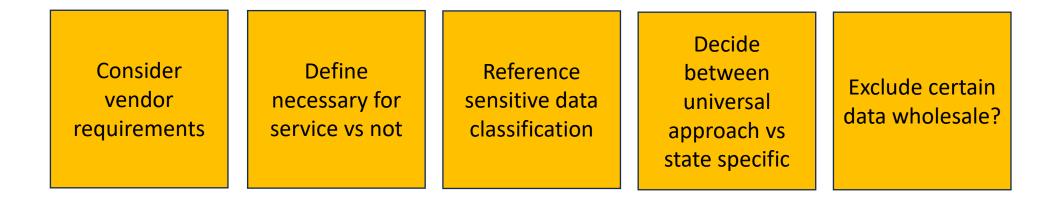
- Operational simplicity vs potential business loss
- Should some states be excluded wholesale for certain functions?





• Certain data may just be untouchable for a given purpose (e.g., authorizations for marketing)







Virginia: "Consent" means a clear affirmative act signifying a consumer's freely given, specific, informed, and unambiguous agreement to process personal data relating to the consumer. Consent may include a written statement, including a statement written by electronic means, or any other unambiguous affirmative action.

Washington: "Consent" means a clear affirmative act that signifies a consumer's freely given, specific, informed, opt-in, voluntary, and unambiguous agreement, which may include written consent provided by electronic means.

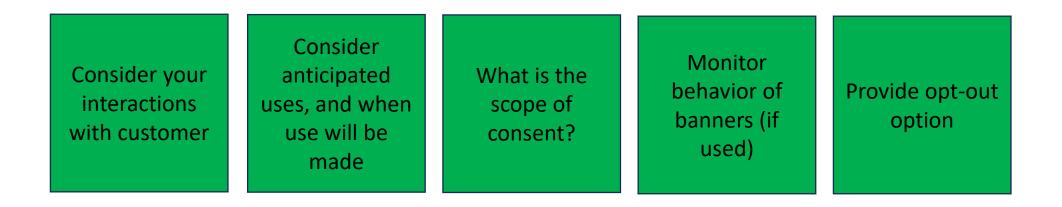
(b) "Consent" may not be obtained by:

(i) A consumer's acceptance of a general or broad terms of use agreement or a similar document that contains descriptions of personal data processing along with other unrelated information;

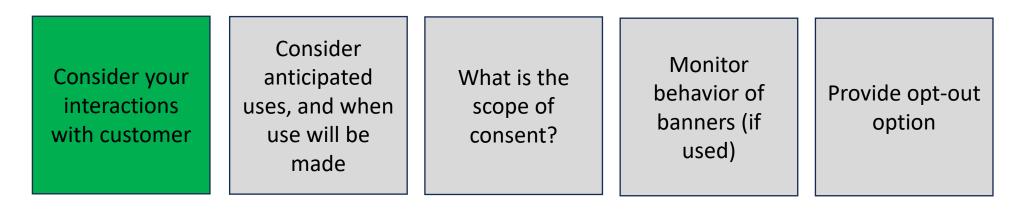
(ii) A consumer hovering over, muting, pausing, or closing a given piece of content; or

(iii) A consumer's agreement obtained through the use of deceptive designs.









- What's legally defensible, and what works best for the business?
- Registration flow vs pop-up?





- Collect now for necessary purpose and ask for consent later? Or ask now?
- What is the business need (e.g., marketing vs research)





- How broad can a consent be?
- Consider fatigue vs opportunity vs defensibility





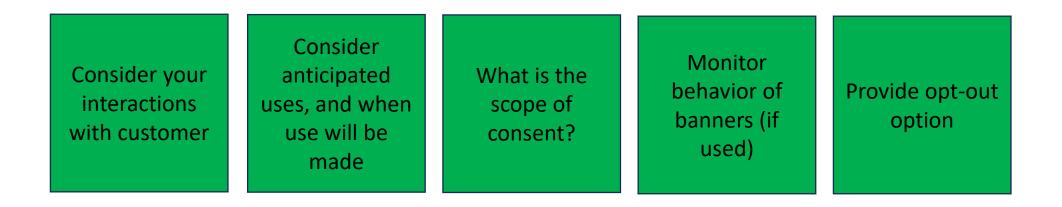
- Make sure a consent does what it says it does
- What is collection behavior prior to acceptance? If ignored?





 If you opt-in, don't forget the opt-out – and how that is operationalized







Unfortunately, no approach is universal.

- Limit use of sensitive information
- Maryland prohibition on use
- ... and whatever else is coming down the pipeline.



Thank you!

