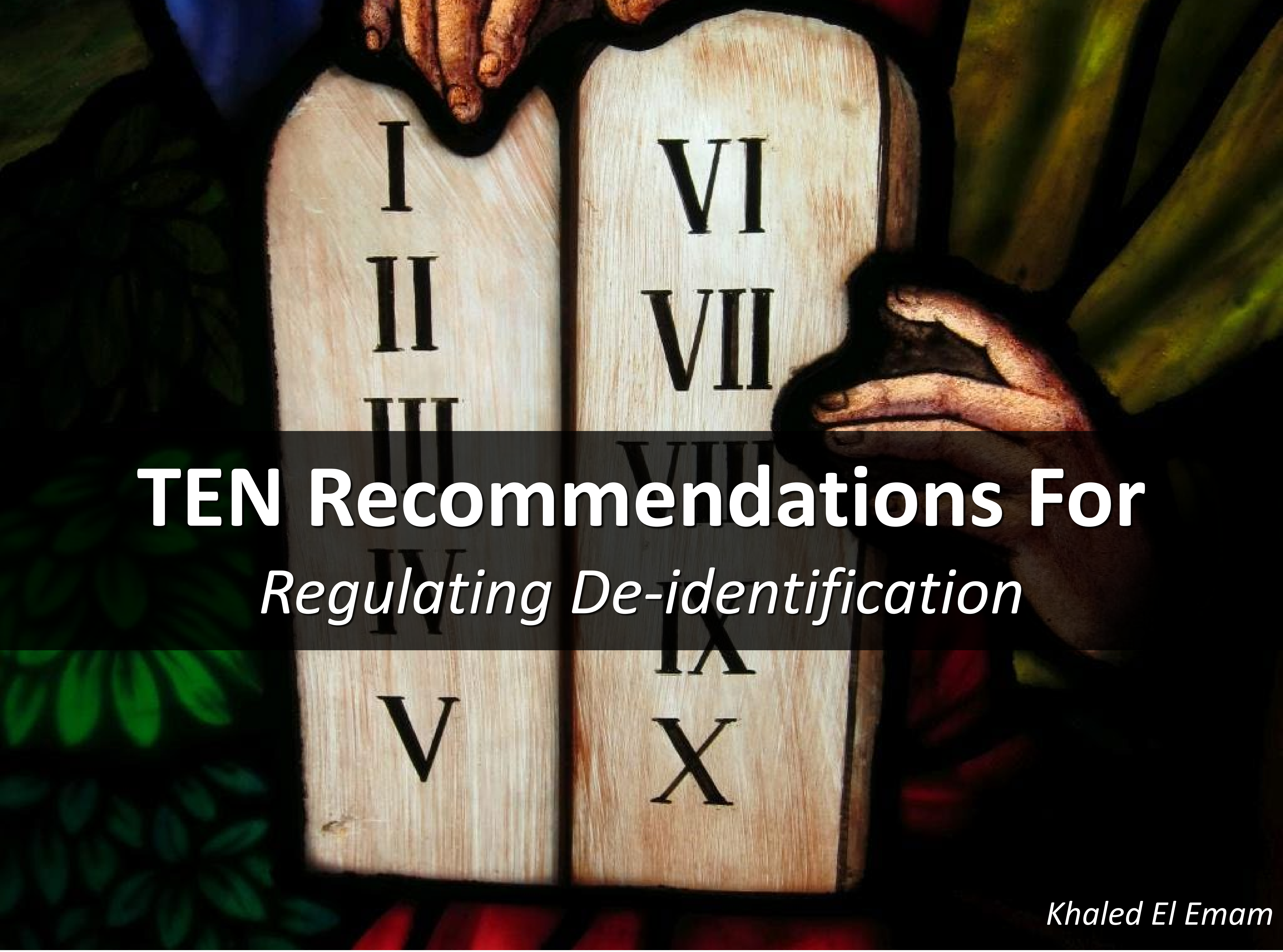

TEN Recommendations For

Regulating De-identification

Khaled El Emam

Main Drivers

- There are many efforts going on globally in privacy law reform, or there are new privacy laws taking effect, and these need to address the concept of identifiability
- Multiple guidelines, standards, and opinions are being developed or updated on how to generate non-identifiable data
- There has been extensive experience with generating and using non-identifiable data over the last decade within existing regimes and following existing standards and guidelines
- We wanted to capture key learnings and summarize them as input into all of these processes

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Context for generating non-identifiable data

- The assumption is that data will be used for a secondary purposes
- This secondary purpose is different than the purposes that the data subjects had originally consented to (primary purpose)
- Secondary purposes can involve training AI or machine learning models
- The non-identifiable data may be disclosed to third parties
- No assumptions are made about the technology that is used to generate non-identifiable data
- Pseudonymous data is not non-identifiable data

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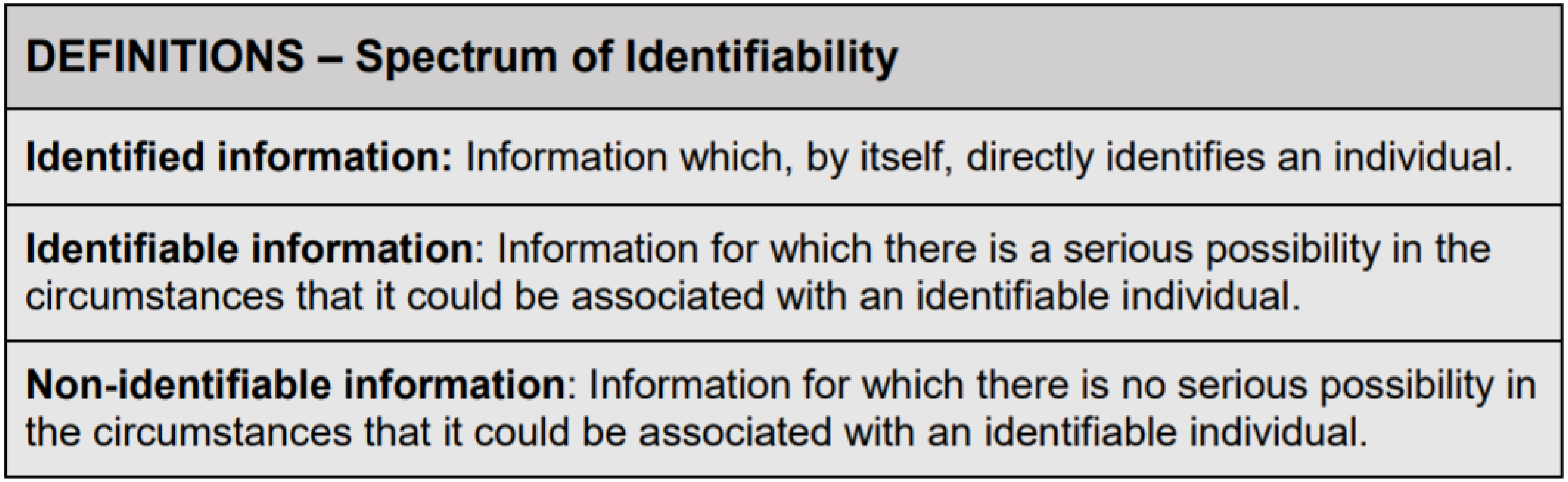
Definitions

We will use the definitions from CANON (Canadian Anonymization Network)



DEFINITIONS – Spectrum of Identifiability
Identified information: Information which, by itself, directly identifies an individual.
Identifiable information: Information for which there is a serious possibility in the circumstances that it could be associated with an identifiable individual.
Non-identifiable information: Information for which there is no serious possibility in the circumstances that it could be associated with an identifiable individual.

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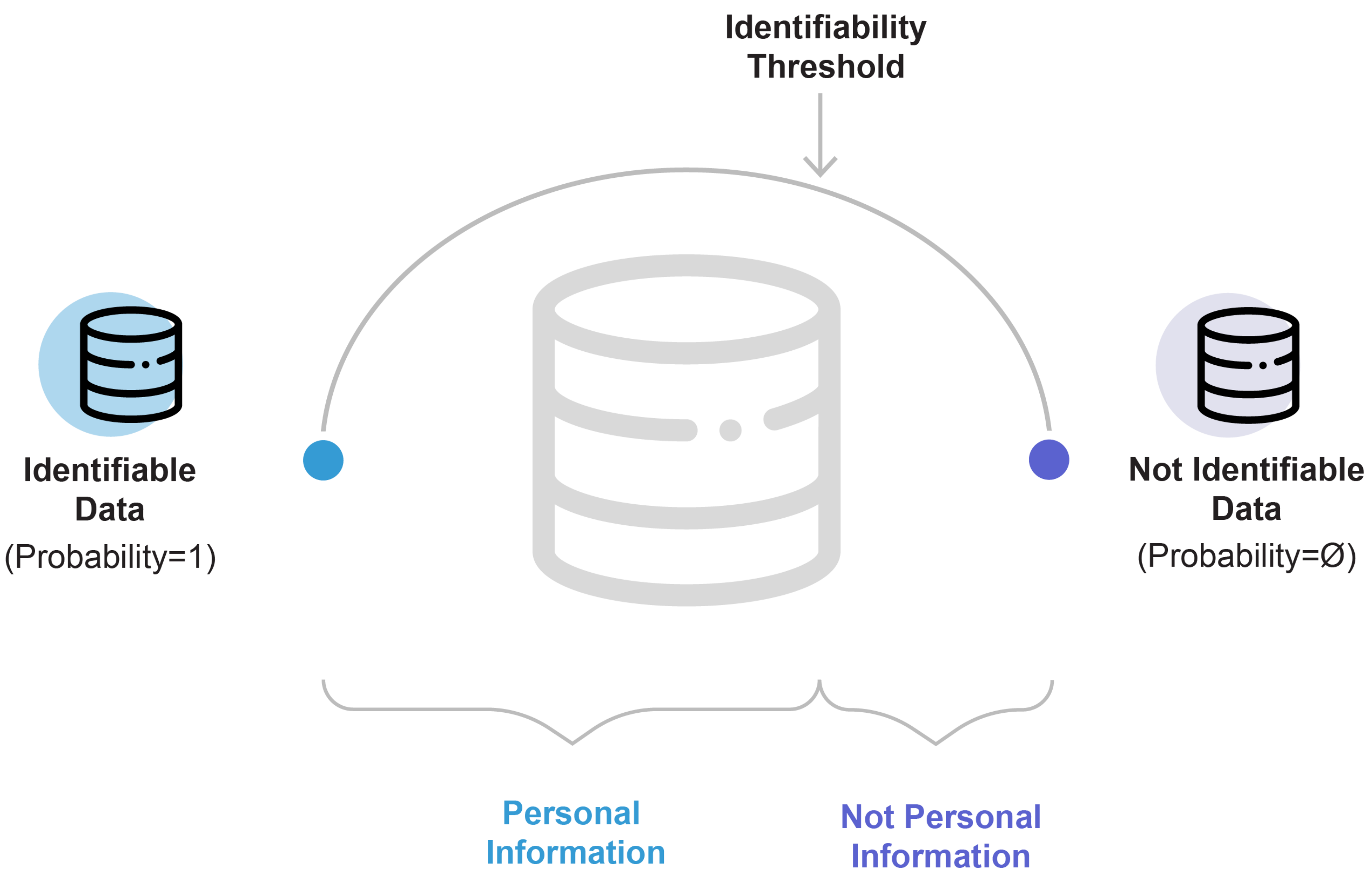
Identifiability spectrum and risk thresholds



Identifiability Threshold

Identifiable Data

(Probability=1)

Not Identifiable Data

(Probability=Ø)

Personal Information

Not Personal Information

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Recommendations

- The recommendations consist of:
- Principles (3):
  - General considerations that apply across the board
- Practices (7):
  - Specific practices that have not worked well, or that should be followed

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Reduce uncertainty

- Uncertainty = no decisions being made / “paralysis”
- Focus on the big issues (like the ones we cover here)
- Flexibility elsewhere is important

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Create incentives

- Organizations respond to incentives
- Removing incentives (or creating disincentives) for implementing good practices means very few organizations will implement them
- For example, if there is no clear benefit to creating and processing non-identifiable data then organizations will find other ways which may be less privacy protective
- Imposing unattainable standards is also a disincentive

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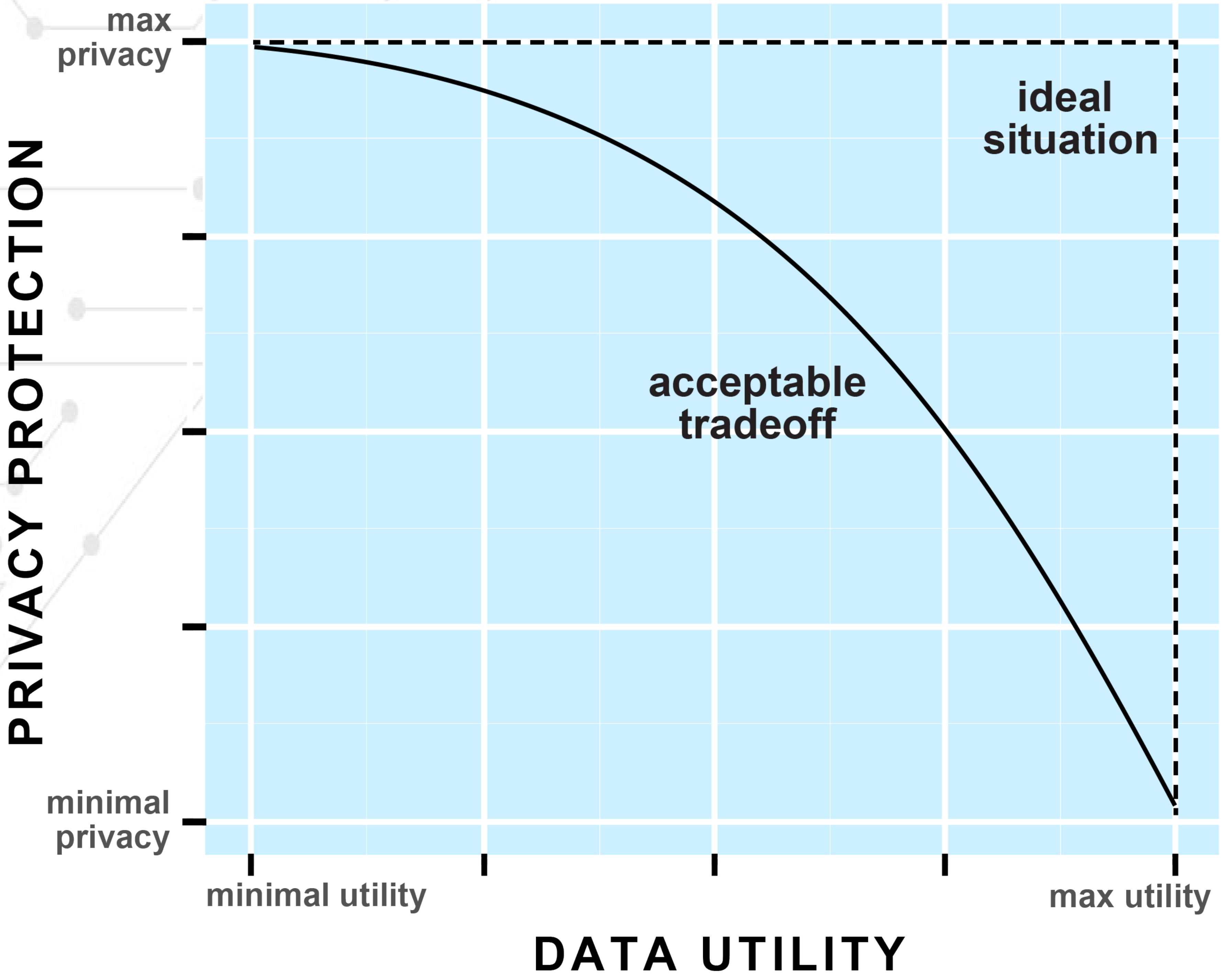
Ensuring sufficient data utility is an important incentive



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Recognize the broad benefits of non-identifiable data

- The starting point should be that the processing of non-identifiable data can be beneficial for society and beneficial economically, including by commercial actors and for commercial purposes
- The emphasis on, for example, the marketing and advertising uses of data or on a few actors distorts the trade-offs when developing guidance and standards

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Obtaining consent for generating non-identifiable data

- In some cases, generating non-identifiable data is treated explicitly as a permitted use (e.g., Ontario’s PHIPA)
- When this issue is left ambiguous it creates uncertainty
- If consent is required then an organization might as well obtain consent for the secondary purposes
- There is strong evidence of consent bias

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Anticipated adversary or all possible adversaries

- Many contemporary risk assessment methods need to make assumptions about the background knowledge of an adversary
- An “anticipated” adversary can be defined
- “Any adversary” makes it necessary to treat non-identifiable data as it if it is being publicly released
- This is a very high standard when data will be used or disclosed in a non-public manner

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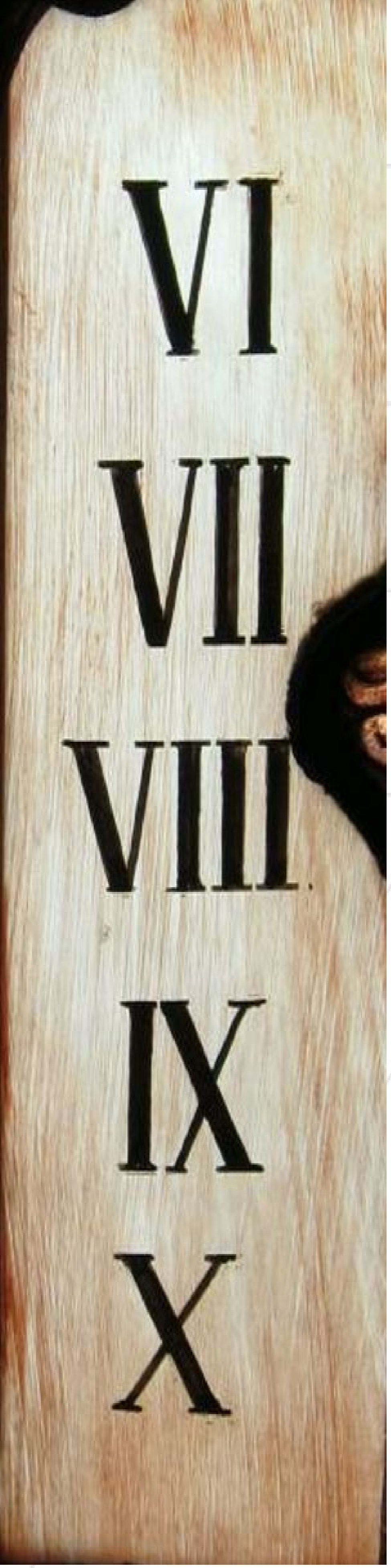

Destroying identifiable data

- Some regulatory guidelines have stated that if the original (identifiable) data exists then a dataset cannot be generated that is not non-identifiable
- The definition of “exists” is not clear
- This is a very high standard that would limit many beneficial uses of data (e.g., the ability to conduct health research)
- Reasonable steps can be defined to separate access to identifiable data from non-identifiable data, and these should be encouraged

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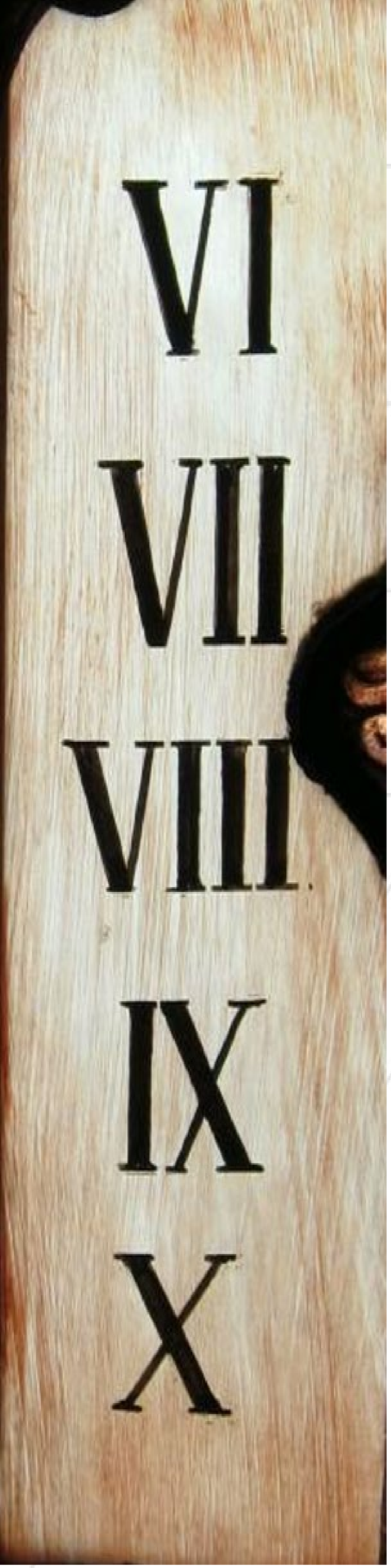

Threshold definitions need to be precise

- Terms such as “impossible” and “irreversible” imply zero risk, which is an unrealistic standard
- The qualitative terms that are often used to describe when data becomes non-identifiable are difficult to interpret in practice, especially as datasets are becoming more complex
- Example terms such as “reasonable”, reasonably likely”, “very low”, very small”, “serious possibility”, and “acceptably small”
- There are precise precedents that can be suggested

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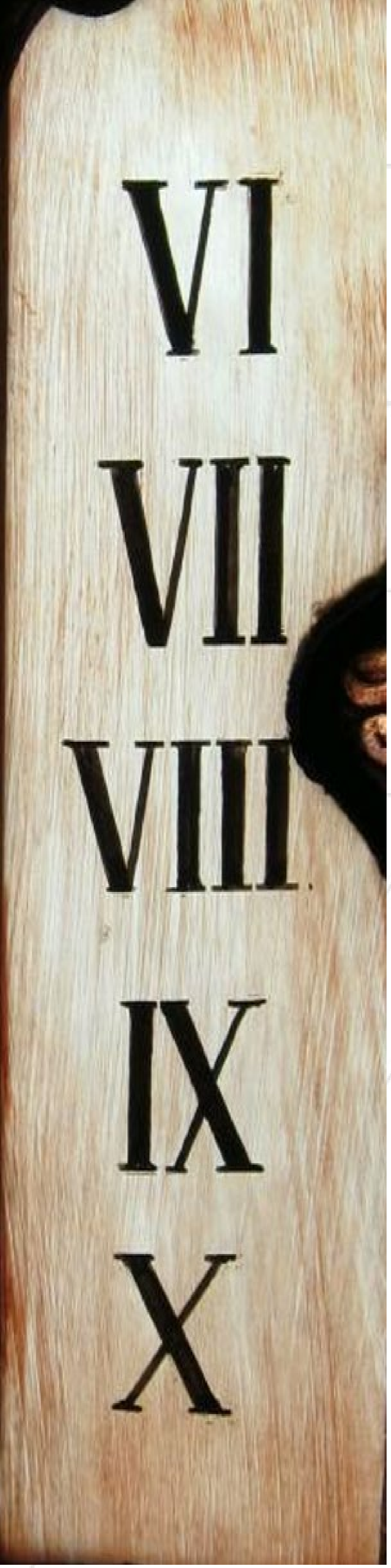

Regulation of uses of non-identifiable data

- Prescribing or proscribing uses of non-identifiable data will be problematic because not all uses can be anticipated and “acceptable” uses will change over time
- A better option is to require ethics reviews on uses of data, models, and decision making from models; this is an approach that has worked well in other domains

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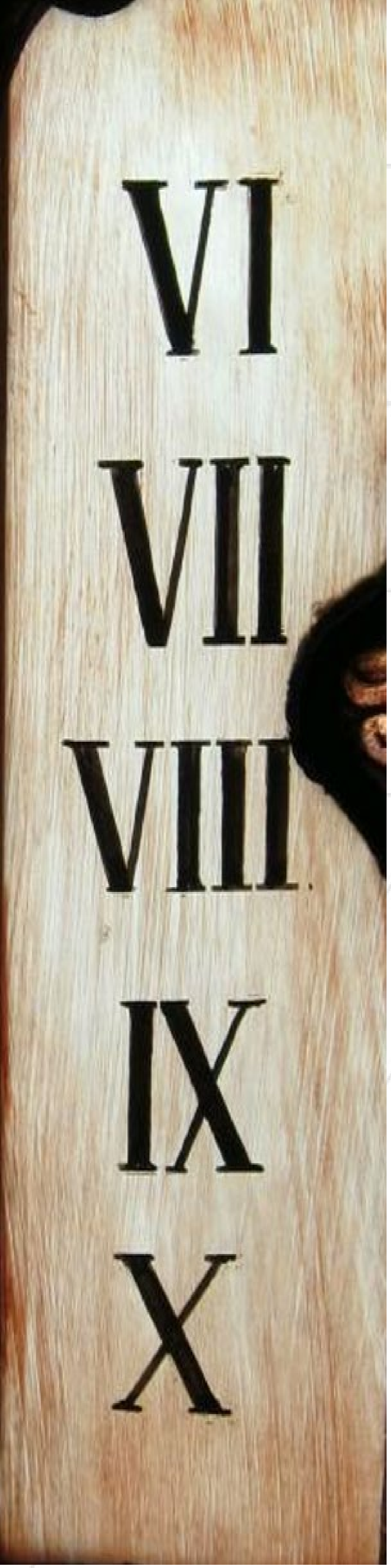

Consideration of context

- Many contemporary models for ensuring that the risk of re-identification is below some threshold use controls to manage residual risk (after applying data transformations)
- This approach can work well but it does need guard rails to ensure that it is implemented in a credible manner (e.g., there needs to be some oversight)

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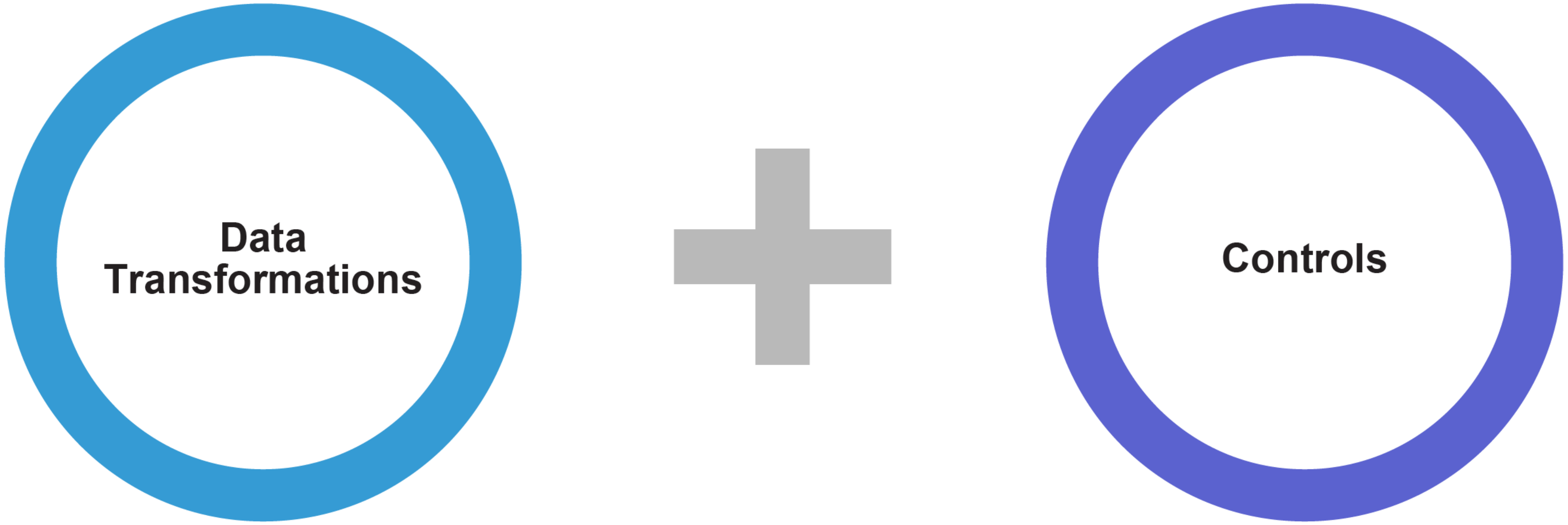
A common approach that has worked well in practice is risk-based anonymization



Data Transformations

Controls

- Generalization
- Suppression
- Addition of noise
- Microaggregation

- Security controls
- Privacy controls
- Contractual controls

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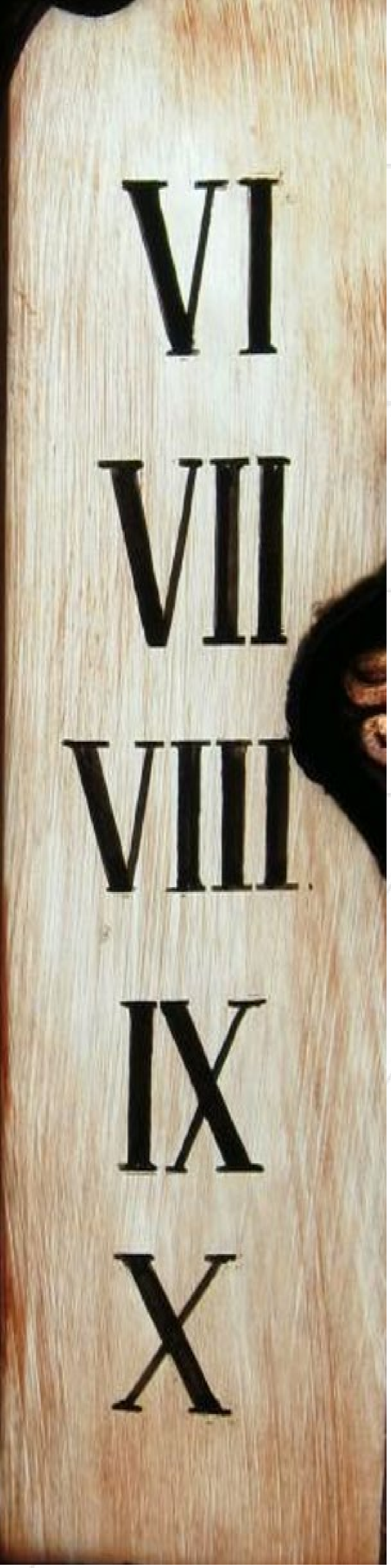

Consequences of re-identification attacks

- Making re-identification an offence under certain conditions is generally a good idea as it adds another layer of protection
- Allowances for legitimate re-identification is necessary
- Whit hat attacks need to go through ethics reviews, and there is a need for standards to ensure that they are reported accurately

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Thank you

- Replica Analytics develops the Replica Synthesis software – generator of privacy protective synthetic health data and simulator exchange
  - For more information on our synthetic data solutions:
    - Visit our website www.replica-analytics.com
    - Message us via the website contact page

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QUESTIONS

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