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## The Utility Costs of Anonymization

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### Agenda

**Objective: Reducing Uncertainty in the Anonymization of Health Care** Data

- 1. Problem Definition
- 2. Anonymization
  - 1. Crucial Considerations
  - 2. Configuration of a Clinical Case Study
- 3. Utility Evaluation
  - 1. Broad Utility and Reproducibility Metrics
  - 2. Results of the Clinical Case Study
- 4. Conclusions



### Problem Definition



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### **Privacy Concerns are Major Barriers to Access Health Data**



Privacy is considered the most prominent issue in big data research.

A. Ferretti et al. "The Challenges of Big Data for Research Ethics Committees: A Qualitative Swiss Study," J Empir Res Hum Res Ethics, vol. 17, no. 1–2, pp. 129–143, Feb. 2022, doi: 10.1177/15562646211053538

Privacy concerns act as a barrier to sharing of health data.

• K. B. Read et al. "Data-sharing practices in publications funded by the Canadian Institutes of Health Research: a descriptive analysis," Canadian Medical Association Open Access Journal, vol. 9, no. 4, pp. E980–E987, Oct. 2021, doi: 10.9778/cmajo.20200303

• R. Trestian et al., "Privacy in a Time of COVID-19: How Concerned Are You?," IEEE Secur. Privacy, vol. 19, no. 5, pp. 26–35, Sep. 2021, doi: 10.1109/MSEC.2021.3092607

## Privacy concerns act as a barrier to seeking health care.

 Pool J, Akhlaghpour S, Fatehi F, Gray LC. Data privacy concerns and use of telehealth in the aged care context: An integrative review and research agenda. Int J Med Inform. 2022;160:104707. doi:10.1016/j.ijmedinf.2022.104707



#### **Exploring Privacy Concerns in Theory**

#### 1. Linking

- Voter registration list for Cambridge Massachusetts \$20
- Group Insurance Commission (GIC) in Massachusetts \$0
- 2. Uniqueness
  - William Weld (former governor of Massachusetts)

## 87% of Americans are probably unique by the combination of 5-digit zip code, sex and birth date.

L. Sweeney. k-anonymity: a model for protecting privacy. International Journal on Uncertainty, Fuzziness and Knowledge-based Systems, 10 (5), 2002; 557-570

#### Most re-identification attacks are on improperly anonymized data.

K. El Emam et al. A systematic review of re-identification attacks on health data [published correction appears in PLoS One. 2015;10(4):e0126772]. *PLoS One*. 2011;6(12):e28071. doi:10.1371/journal.pone.0028071



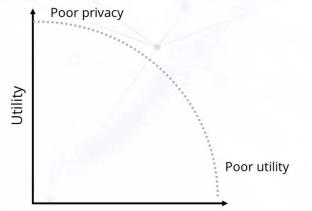
#### **Mitigating Privacy Concerns**

- Controlled (remote/on-site) access
- Remote execution
- Remote queries
- Secure Computation



#### Anonymization

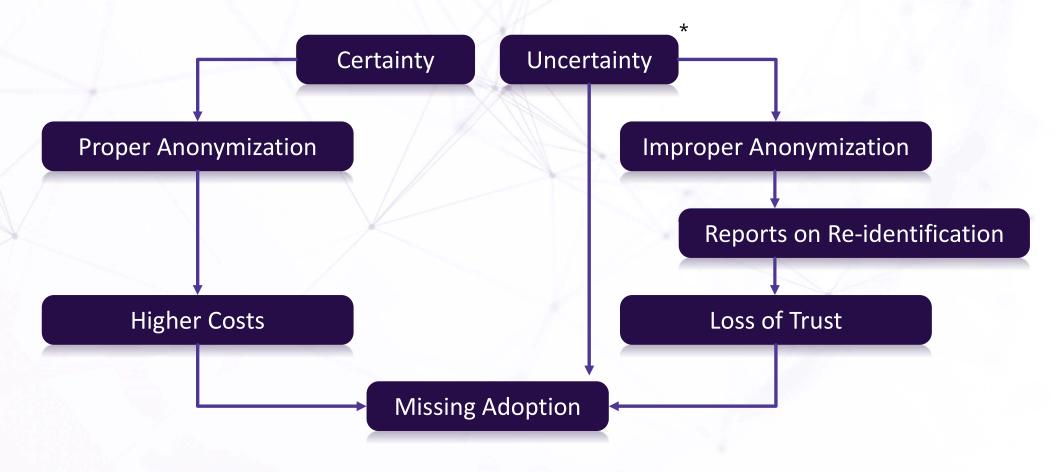
• Synthetic Data Generation



Privacy



### **Missing Adoption of Anonymization**



\* technical but also regulatory uncertainty

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## Reducing Uncertainty in the Anonymization of Health Care Data

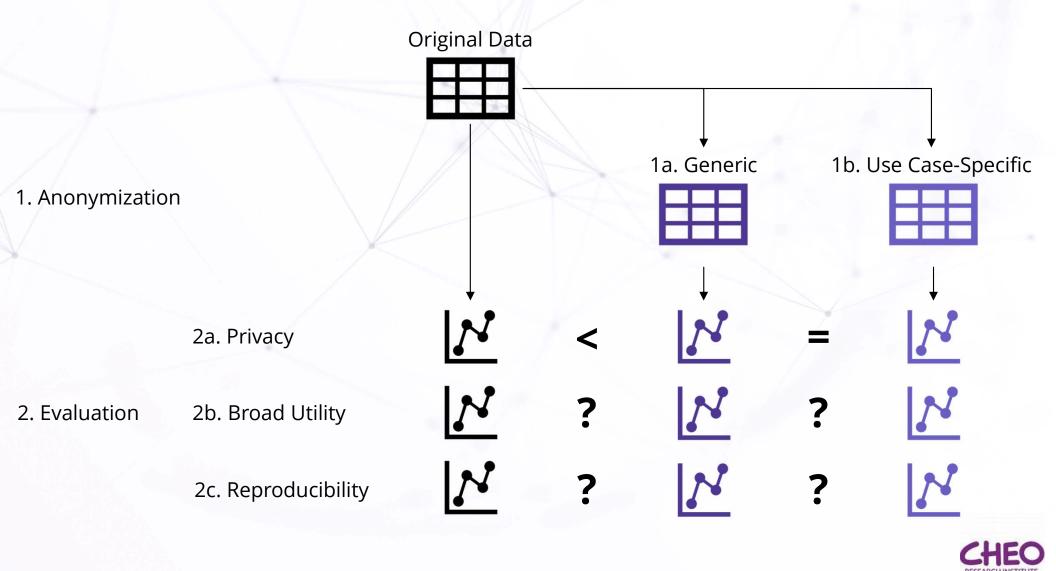


#### **Research Questions**

- 1. Can we reproduce scientific results in health research with anonymized data?
- 2. How relevant is use case-specific anonymization for reproducibility?
- 3. Do broad utility metrics reflect reproducibility?



#### **Case Study Using Clinical Data**



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## Anonymization



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## **Equivalence Classes are Defined by Quasi-Identifiers**

Age (years)	Gender	ВМІ	Pulse (bpm)	Obstructive nephropathy				
63	Female	23.5	87	Yes				
67	Female	30.0	65	Yes				
55	Male	35.5	100	Yes				
72	Female	27.8	96	No				

Quasi-Identifiers (QI)



### **Re-identification Probability is Based on Equivalence Classes**

Birth year	Gender			
1950-1960	Female	Risk: 1/1		
1960-1970	Male	Risk: 1/1		
1960-1970	Female	Risk: 1/1		
1950-1960	Male	Risk: 1/1		

Maximum Risk: 1/1 = 1.00 Average Risk: 1/4 \* (1/1 + 1/1 + 1/1 + 1/1) = 1.00



### **Re-identification Probability is Based on Equivalence Classes**

Birth year	Gender	/
1950-1960	Female	F
1960-1970	Female	F
1960-1970	Female	F
1950-1960	Male	F

Risk: 1/1 Risk: 1/2 Risk: 1/2 Risk: 1/1

Maximum Risk: 1/1 = 1.00 Average Risk: 1/4 \* (1/1 + 1/2 + 1/2 + 1/1) = 0.75



#### **Re-identification Probability is Based on Equivalence Classes**

Birth year	Gender	1
1950-1960	Female	Ri
1960-1970	Female	Ri
1960-1970	Female	Ri
1950-1960	Female	Ri

Risk: 1/2 Risk: 1/2 Risk: 1/2 Risk: 1/2 k-anonymity Maximum Risk: 1/2 = 0.5 Average Risk: 1/4 \* (1/2 + 1/2 + 1/2 + 1/2) = 0.5

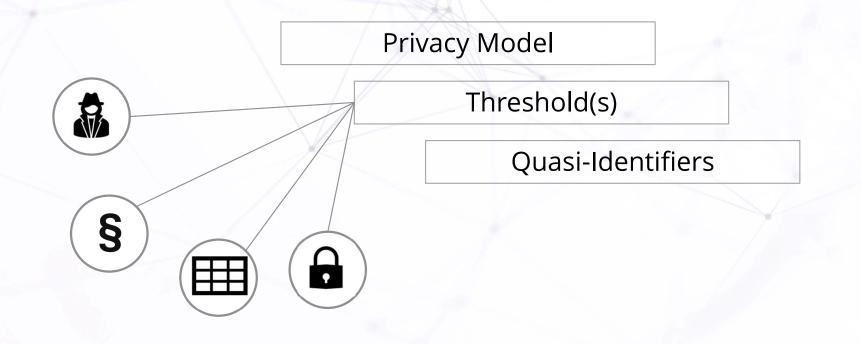
strict-average risk\*

\* combined with maximum risk (k-anonymity)



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#### **Threat Modeling**





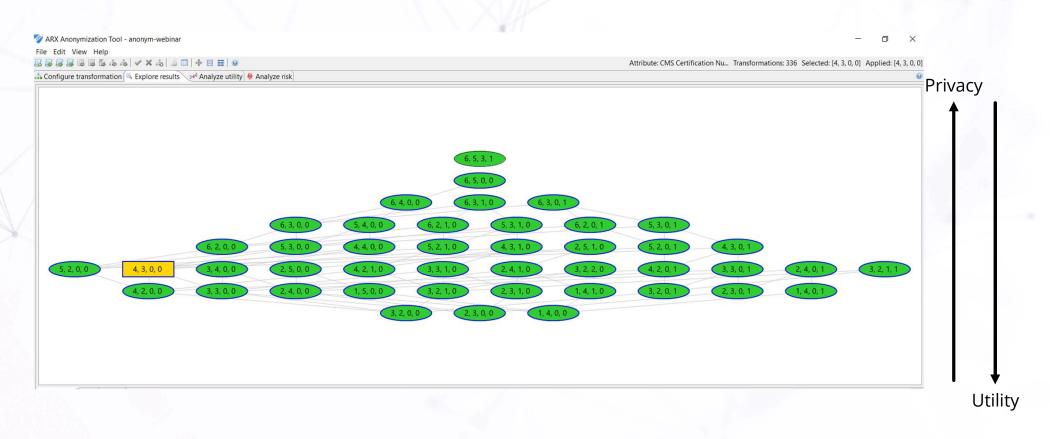
#### **Translating Concepts Into Tools**

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8	FMC Humacao D	402514	-	ROAD 3 KM 73.8	Humacao	PR	0										
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#### **Searching for the Optimal Solution**



Tool: Reference: Prasser F, Kohlmayer F, Lautenschläger R, Kuhn KA. ARX--A Comprehensive Tool for Anonymizing Biomedical Data. AMIA Annu Symp Proc. 2014;2014:984-993. Published 2014 Nov 14. <u>https://arx.deidentifier.org/</u>

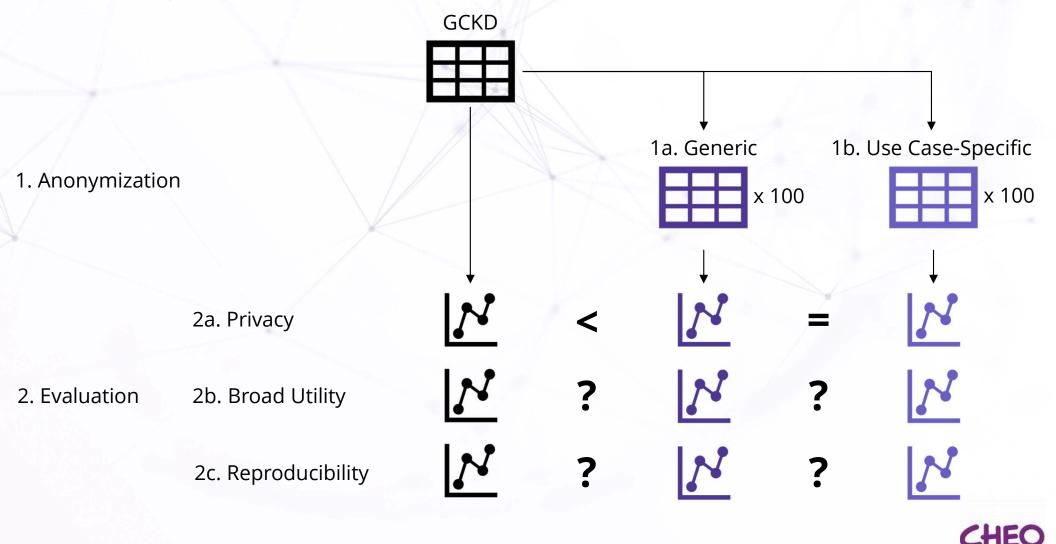


## **Configuring the Case Study Using Clinical Data**

- Original Data: German Chronic Kidney Disease (GCKD), n = 5,217
- Anonymization: generic scenario, use case-specific scenario
- Privacy models: k-anonymity, strict-average risk
- Thresholds: k between 1 and 50
- Quasi-Identifiers: age, gender, height, weight, BMI, history of renal biopsy
- Transformation models: generalization, suppression (MaxSup: 10%)
- Reproducibility: disease burden and risk profile of patients with CKD



#### Case Study Using Clinical Data: 100 Study Points Per Scenario



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### Utility Evaluation



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#### **Measuring Utility**

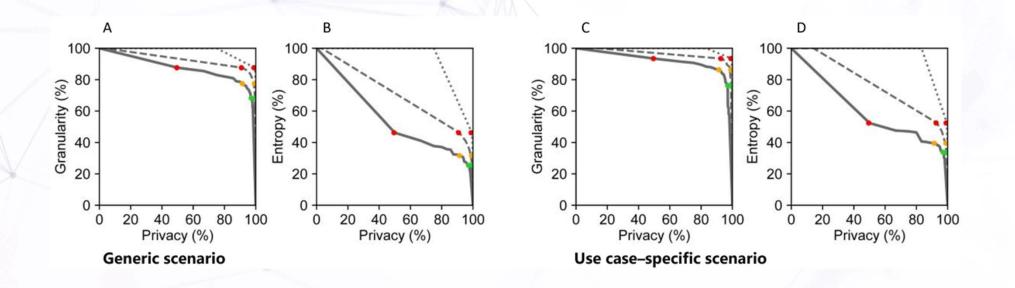
- Broad Utility
  - Granularity: coverage of the original value space
  - Entropy: differences in the distribution
- Reproducibility
  - Estimate agreement
  - 95% CI overlap

$$J_k = \frac{1}{2} \left[ \frac{U_{\text{over},k} - L_{\text{over},k}}{U_{\text{orig},k} - L_{\text{orig},k}} + \frac{U_{\text{over},k} - L_{\text{over},k}}{U_{\text{rel},k} - L_{\text{rel},k}} \right]$$

From: Karr AF, et al. A Framework for Evaluating the Utility of Data Altered to Protect Confidentiality. The American Statistician 2006, 60:3:224-232. doi: 10.1198/000313006X124640



# Utility loss was more pronounced for entropy than for granularity.

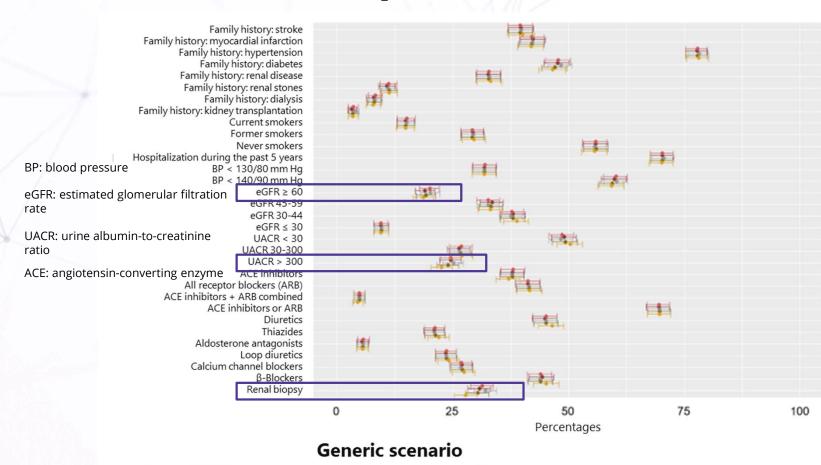


#### Privacy-utility curves based on general-purpose utility metrics.

From: Pilgram et al. The Costs of Anonymization: Case Study Using Clinical Data. J Med Internet Res (forthcoming). doi:10.2196/49445 http://dx.doi.org/10.2196/49445



# Most estimates in anonymized data had a 95% CI overlap of over 50%.

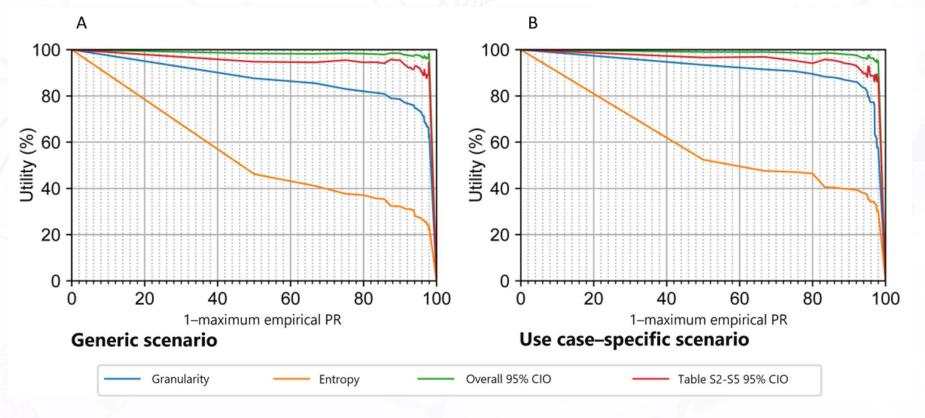


#### Proportion, CIs, and overlap in the interval lengths for descriptive analyses.

From: Pilgram et al. The Costs of Anonymization: Case Study Using Clinical Data. J Med Internet Res (forthcoming). doi:10.2196/49445 http://dx.doi.org/10.2196/49445



## There are differences between the applied utility metrics and scenarios.



#### Generic and use case-specific utility metrics.

From: Pilgram et al. The Costs of Anonymization: Case Study Using Clinical Data. J Med Internet Res (forthcoming). doi:10.2196/49445 http://dx.doi.org/10.2196/49445

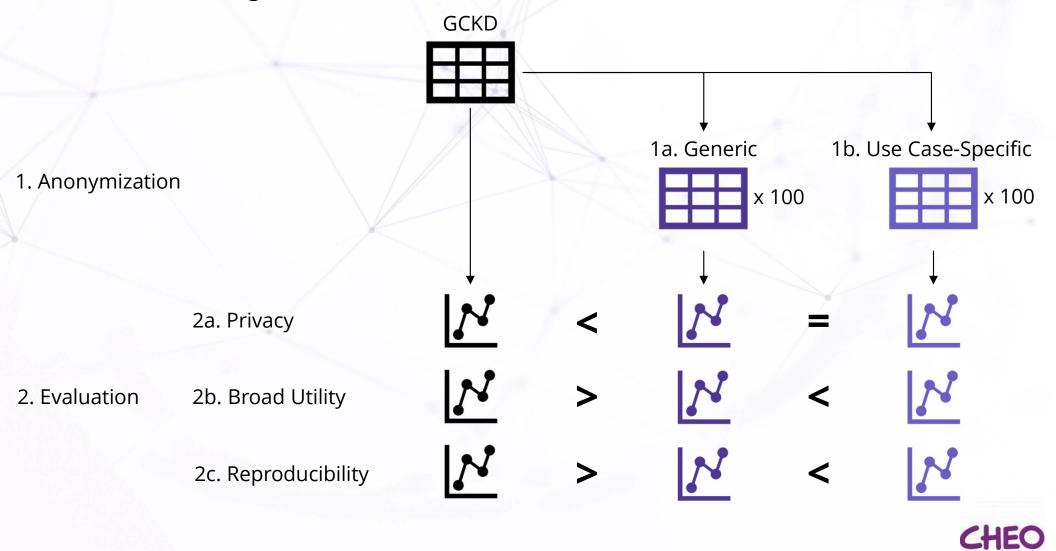


## Conclusions



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#### Case Study Using Clinical Data: Summary



#### **Research Questions: Key Findings**

1. Can we reproduce scientific results in health research with anonymized data?

Yes. Anonymization of data does not necessarily impair utility for downstream analyses.

#### 2. How relevant is use case-specific anonymization for reproducibility?

Use case-specific anonymization results in better utility for downstream analyses than generic one.

#### 3. Do broad utility metrics reflect reproducibility?

Not necessarily. Broad utility metrics treat all variables equally. Reproducibility might be worse or better than anticipated.



#### Conclusions

- → Specification of utility requirements should be an integral part of the anonymization process.
- → Anonymized data for multiple likely uses should indicate limitations when implications are drawn from their analyses.



#### Read more in

L. Pilgram, T. Meurers, B. Malin, GCKD Investigators, E. Schaeffner, K.-U. Eckardt, F. Prasser. The Costs of Anonymization: Case Study Using Clinical Data. J Med Internet Res (forthcoming). doi:10.2196/49445 http://dx.doi.org/10.2196/49445

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## **Questions?**

