

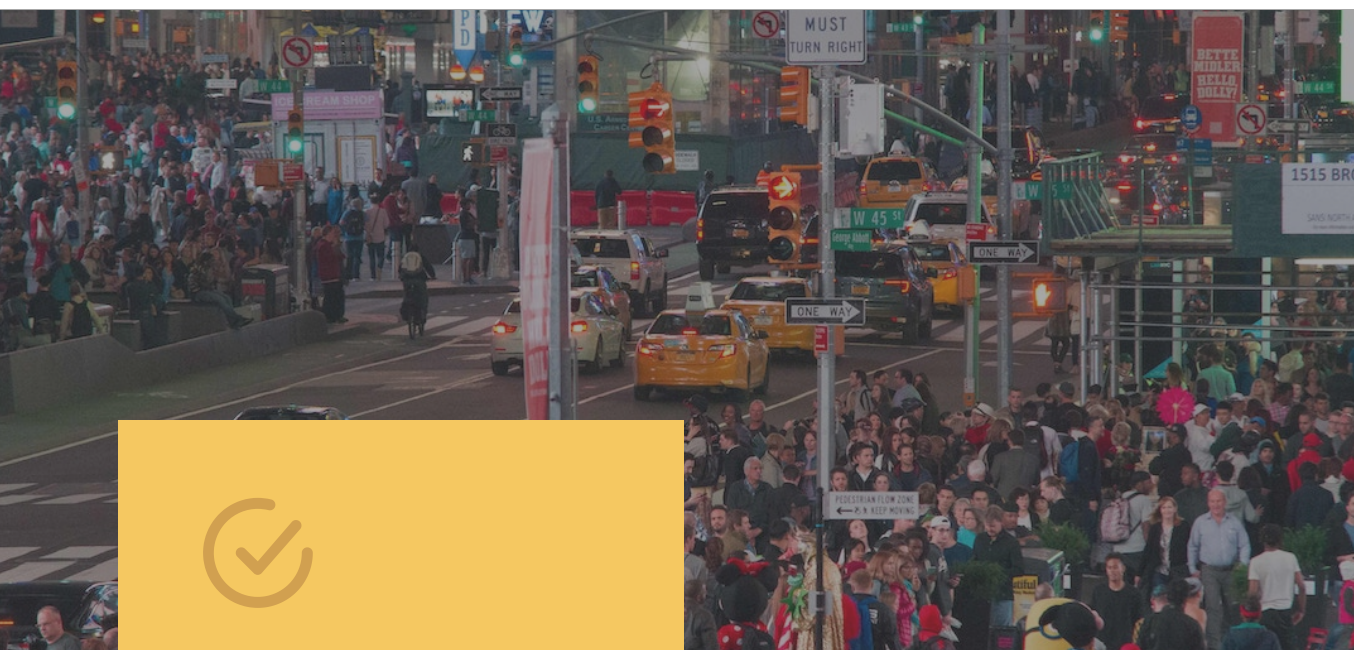
US-UK Privacy-Enhancing Technologies Prize Challenge Roundtable Executive Summary

Supporting Pandemic Response
and Healthcare with Privacy-
Enhancing Technologies:
Opportunities and Challenges

May 23rd, 2023
Council Room, The Royal Society, London

Privacy-Enhancing Technologies

This roundtable followed the successful completion of the US-UK privacy-enhancing technologies (PETs) prize challenges that aimed to develop innovative privacy-preserving federated learning solutions to support important societal applications. The workshop was a half-day meeting that brought together researchers, technologists, policy analysts, data regulators, and data ethicists to discuss ideas around PETs for pandemic preparedness and response, and healthcare data. This report includes comments from participants after the roundtable.



The goals of the roundtable included:

- ***Exploring and identifying priority research areas for PETs***
- ***Exploring possibilities to pilot PETs solutions***

The initial discussion focused on how data from various sources and modalities could be used to effectively support public health response during an evolving pandemic as well as general healthcare solutions. Participants then discussed the application of PETs to unlock data to support public health and healthcare research, as well as pandemic response efforts.

Participants identified broad challenges with privacy guarantees, identifying and accessing critical datasets, building an infrastructure to leverage the value of diverse datasets, and potential areas for future study and pilot solutions.

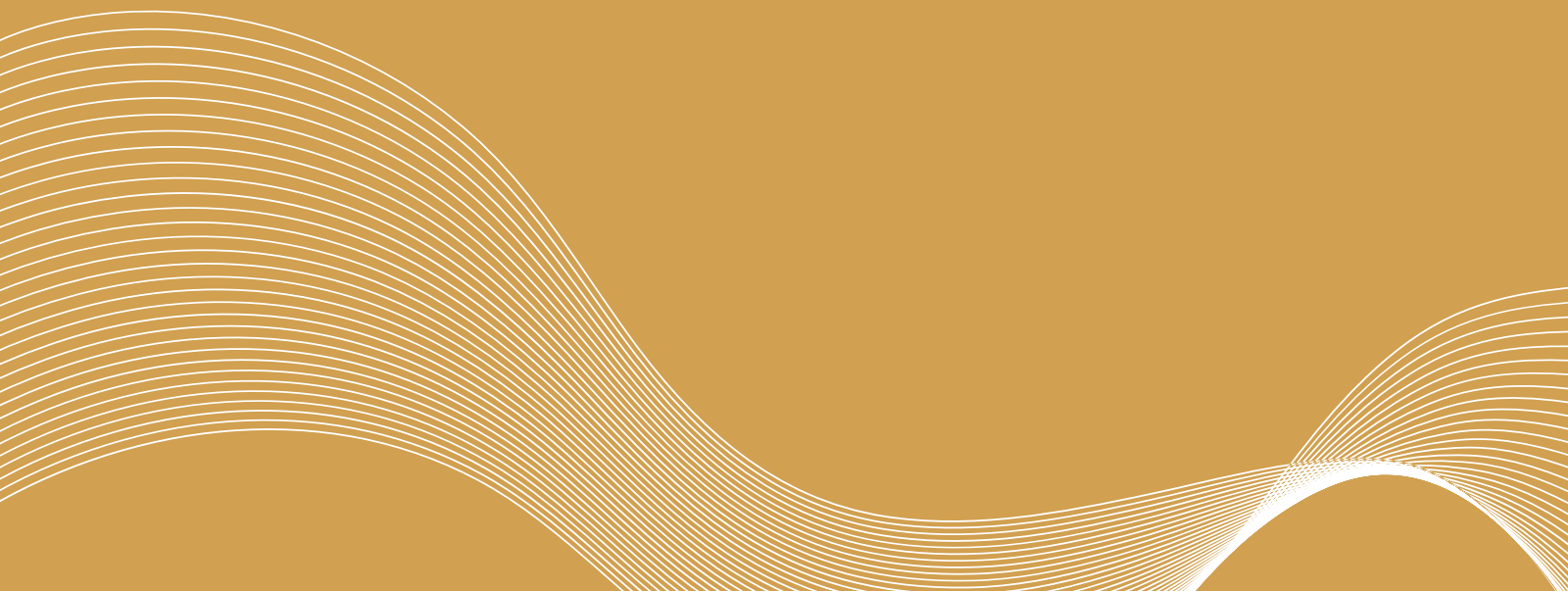
The discussion took place under the Chatham House rule

Challenge: Privacy guarantees

The complexity of privacy guarantees arises because the need to respect privacy must be balanced with the value of the information being shared. Current privacy models aim to protect the privacy of every individual, but fail to account for the fact that not all interactions are equal. A more nuanced contextual privacy model is necessary, one that can provide different types of guarantees based on the individuals involved. Privacy is not only an economic or political issue but also a matter of human rights and social concern. With privacy technology, it is crucial to prove that individual data is not shared, but rather broader insights are shared instead.

Challenge: Identifying what data is needed

The challenge of identifying the necessary data for meaningful analysis during a public health emergency is complex, especially when it comes to sensitive health data. The COVID-19 pandemic highlighted the importance of detailed information beyond simple statistics, such as co-morbidities, age, and gender. Epidemiologists require comprehensive individual data to gain deep insights into how the virus spreads and to inform policy decisions. However, the identification of mortalities through hospital locations raises concerns about data privacy and underscores the need for effective PETs.



Challenge: Data access

Data access in the context of a public health crisis is crucial for rapid response and informed decision-making. In some cases, federal public health agencies lack the appropriate authority to collect data from states/provinces, even in the setting of a public health emergency. Another example is a need to link clinical and sequencing data to enhance our understanding of a virus, but the legal implications of this are significant and regulations regarding this linkage need to be established.

One possible scenario to model or demonstrate PET utility is through data collected from local healthcare institutions. By harnessing the power of decentralized data from different institutions, we can achieve much better clinical utility through the creation of datasets focused on, for example, rare genetic childhood diseases, Alzheimer's, various clinical trials, diabetes, pharmaceutical sales, and operations.

Governments should optimize data access through designated routes, ensuring emergency-use privacy guarantees. Starting with a core set of baseline datasets for pandemic research is essential, while also having mechanisms in place to identify and access additional data as new questions arise.

Challenge: Building infrastructure

Building infrastructure for data sharing and interoperability requires the early involvement of the public sector. To incorporate PETs into existing infrastructures, procedural practices need to be adapted and anti-competitive behavior must be addressed. It is crucial for software platforms to communicate with each other to enable seamless data sharing. The question arises as to who will establish the standards that determine the trade-off between privacy and utility. There are also long-term challenges with implementing technical change in federal-level systems.

The phenomenon of the cycle of panic and neglect, where resources are abundantly allocated during crises but reallocated less rationally afterward, poses a challenge. Finding ways to operate within this landscape is crucial. Considering the value of network permission as a future utility, independent of specific infrastructure, is important. Integration into existing ecosystems should be carefully considered to ensure effective data sharing and interoperability.

Future directions

Before identifying potential use cases for this group to pursue, a solid first step is to identify organizations willing to share data and use their infrastructure as a prototype for other studies.

Cost of privacy. To gain a comprehensive understanding of the effectiveness of different pandemic response strategies implemented by countries during the SARS-CoV-2 pandemic, a comparative study across nations is needed. This study would assess case outcomes and determine the best approach. Evaluating the cost of privacy in terms of mortality is crucial for making informed decisions.

Leveraging mature technology. Matching data use cases to the privacy risk/threat model is essential in determining the appropriate PETs to employ, particularly for rare genetic childhood diseases. Mature technology in areas like diabetes can inform the development of PETs and systems in other health contexts.

Data linkage. Linking vertically partitioned patient data for a longitudinal view is critical but presents technical and systems research challenges. Additionally, the challenges posed by non-textual and multimodal data, as well as the integration of emerging technologies like telehealth, AR, and VR, must be addressed.

Systems and fundamental research. Scaling the research requires collaboration, standardization, and interoperability across data owners and providers. Systems research, incentives, and regulatory structures play a vital role in this endeavor, and the relationship between systems integration research and fundamental research should be acknowledged to ensure a comprehensive approach.



UK-US PETS PRIZE CHALLENGE 2023

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