

# A Public Deliberation on the Re-Use of Data

Background for Participants

May 2020

The Data Assembly is an initiative from <u>The GovLab</u> and the <u>Henry Luce Foundation</u> to solicit diverse, actionable public input on data re-use for crisis response in the United States.

The Data Assembly will engage with civil rights organizations, key data holders and policymakers working in the United States, vulnerable groups and the public. This work will be done through remote consultations and deliberative platforms. With a diverse network of stakeholders, we will co-design a responsible data re-use framework. This framework will inform if, when and how the re-use personal data can be aligned with people's expectations and societal values.

While the initial focus of the Data Assembly will be data re-use for COVID-19 measures in the United States, the framework created will be applicable to policymaking beyond this pandemic.

DATA RE-USE WILL BE A

DEFINING TOOL TO ADDRESS

COVID-19, YET WILL REQUIRE

CITIZEN'S INPUT TO BE

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While data re-use has the potential to <a href="improve disease treatment">improve disease treatment</a>, identify <a href="better ways to source supplies">better ways to source supplies</a>, monitor <a href="adherence to nonpharmaceutical restrictions">adherence to nonpharmaceutical restrictions</a>, and provide a range of <a href="other public benefits">other public benefits</a>, many organizations have expressed concern data sharing may enable <a href="surveillance and oppression">surveillance and oppression</a>.

- Today, policymakers do not have a clear understanding of the different, and sometimes contradictory, needs and values of various stakeholders when it comes to data re-use.
- Important voices are absent from today's discussions on data re-use and governance.

We are facilitating The Data Assembly to:

- Identify and document the varying concerns, opportunities and expectations surrounding data re-use for COVID-19;
- Source and co-design innovative solutions to remedy these challenges and concerns; and
- Co-create a responsible data re-use framework to inform decision makers on how best to re-use data to solve public problems, such as COVID-19.

# OVERSIGHT AND GUIDANCE - STEWARD COMMITTEE

A Steward Committee will be supporting The GovLab and the Henry Luce Foundation in the process of prioritizing use cases, designing the outreach strategy, curating participants and determining how the Data Assembly will operate. The Steward Committee will include experts in a variety of fields, such as privacy, technology, civil liberties and public health policy.

# PLAN FOR PARTICIPATION

The Data Assembly will progress through three main phases. This will allow for rapid and intensive remote deliberation. The deliberations will take place remotely and iteratively, with discussions and findings published shortly after the conclusion of each phase.

# PHASE 2

# PHASE 3

### **IDENTIFYING PROBLEMS** CREATING SOLUTIONS

In the first phase, through the use of online deliberations and surveys, the Data Assembly will seek to highlight existing problems, possible concerns, and benefits they associate with data re-use. At the end of this process, there will be a map of challenges and expectations curated and ranked by the Data Assembly.

In the second phase, the Data Assembly will collectively ideate and co-design solutions to the problems identified in Phase 1. This ideation process will take place through an online crowdsourcing tool, complemented with other outreach mechanisms, which will allow participants to post their own solutions, up-vote or down-vote ideas posted by others, and provide comments and build upon other participants' submissions.

# **FINAL REPORT**

At the end of the deliberations, The GovLab will publish a final report detailing the result of each engagement in an open, transparent fashion, as well as any challenges or issues of note raised by participants. This final document will include a governance framework for the re-use of data to address the COVID-19 pandemic, as well as recommendations on how to operationalize this framework.

# **OUTCOMES**

- Clear understanding of expectations from different stakeholders on the responsible reuse of data.
- Framework for the necessary conditions and institutions needed to mitigate the risks of data reuse for crisis management and policy making.
- A path forward for instilling trust among citizens that their data is being managed in an accountable, transparent, and safe manner.

# **HOW TO GET INVOLVED**

If you are interested in joining the Data Assembly, please email sverhulst@thegovlab.org. We will be sending background reading materials and participation guides in June 2020.

Additional information on the project will be published in the coming weeks. Interested parties are invited to subscribe to The GovLab's Data Stewards Newsletter or visit its website (http://datastewards.net).





# **About the Henry Luce Foundation**

The Henry Luce Foundation seeks to enrich public discourse by promoting innovative scholarship, cultivating new leaders, and fostering international understanding. The Foundation advances its mission through grantmaking and leadership programs in the fields of Asia, higher education, religion and theology, art, and public policy. Established in 1936 by Henry R. Luce, the co-founder and editor- in-chief of Time, Inc., the Foundation's earliest work honored his parents, missionary educators in China. The Foundation's programs today reflect the value Mr. Luce placed on learning, leadership, and long-term commitment in philanthropy.

## **About The GovLab**

The Governance Lab's mission is to improve people's lives by changing the way we govern. Our goal at The GovLab is to strengthen the ability of institutions — including but not limited to governments — and people to work more openly, collaboratively, effectively, and legitimately to make better decisions and solve public problems. We believe that increased availability and use of data, new ways to leverage the capacity, intelligence, and expertise of people in the problem-solving process, combined with new advances in technology and science, can transform governance. We approach each challenge and opportunity in an interdisciplinary, collaborative way, irrespective of the problem, sector, geography, and level of government. For more information, visit thegovlab.org.