



### 2020 ANNUAL REPORT

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### **About FPF**



# The Leading Experts and Conveners in the Privacy Landscape

The Future of Privacy Forum is a non-profit organization that serves as a catalyst for privacy leadership and scholarship, advancing principled data practices in support of emerging technologies.

#### We Bring Key Stakeholders Together so that Responsible Data Use is Prioritized in all Areas of Society

FPF brings together a range of voices from industry, academia, and civil society to support collaboration and ensure the diversity of ideas necessary to advance principled data practices in support of emerging technologies.

We value the guidance and contributions of a wide range of supporters and stakeholders. We believe varied perspectives contribute to a comprehensive understanding of the risks and opportunities of new technologies and data uses, and their impact on society, now and in the future.

Composed of leaders from industry, academia, and civil society, FPF's Advisory Board and our Board of Directors guide our work and mission. Their input ensures that FPF's work is expert and independent of any single stakeholder or stakeholder group.

Through research, publications, educational meetings, expert testimony, and other related activities, FPF works with organizations and governments to shape best practices and policies, in the United States and globally.

FPF's work has a real-world impact, sharing research and insights through reports, briefings, and roundtables. FPF provides expert testimony and comments to Congress, federal agencies, Congressionally-chartered commissions, and legislatures around the world. Globally, FPF helps regulators, policymakers, and staff at data protection authorities better understand the technologies involved in today's economy.





### **FPF's Expert Workstreams include:**

- Ad Tech
- ► Al & Machine Learning
- Biometrics
- De-Identification
- **Ethics**
- Europe

- **▶** Global
- Health
- Mobility & Location
- Research
- Smart Communities
- Youth & Education Privacy

### Leadership Letter

It is a great pleasure to present the Future of Privacy Forum's 2020 Annual Report.

We are celebrating a dozen years of bringing together academics, advocates, government officials, and industry to evaluate the utility of data uses, the effectiveness of safeguards, and strategies to mitigate risks.

Technology and data underlie every modern activity, from education to healthcare to transportation. Our mission is to understand and convey how different services and systems need data, and how data can be used ethically and legally.

Since our founding, we have been a centrist, independent organization that creates a space for thoughtful discourse among diverse stakeholders. We are optimists who believe technology and data can benefit society and improve lives if the right policies, protections, and rules are in place.

During a year marked by the onset of COVID-19, FPF committed itself to provide updated, pertinent information through our Privacy & Pandemics series. The information we compiled has helped policymakers and practitioners alike think clearly about what personal information they will collect or disclose, to whom, and under what conditions. We are incredibly proud of the work our staff has done throughout this unusual year to continue providing up-to-date, important guidance.

Throughout 2020, FPF continued to serve as a forum for a diverse range of views and voices and provided a thorough analysis on a variety of state and federal privacy legislation. FPF maintained its commitment to helping privacy leaders learn from peers and other experts, and presented the inaugural Award for Research Data Stewardship to recognize leadership in research data sharing. FPF has trained corporate leaders and policymakers through the creation of formal programs such as the Digital Data Flows Masterclass, and has continued to serve as a hub of valuable information for complex tech and legal issues, both domestic and international, clearly explained through a variety of methods.

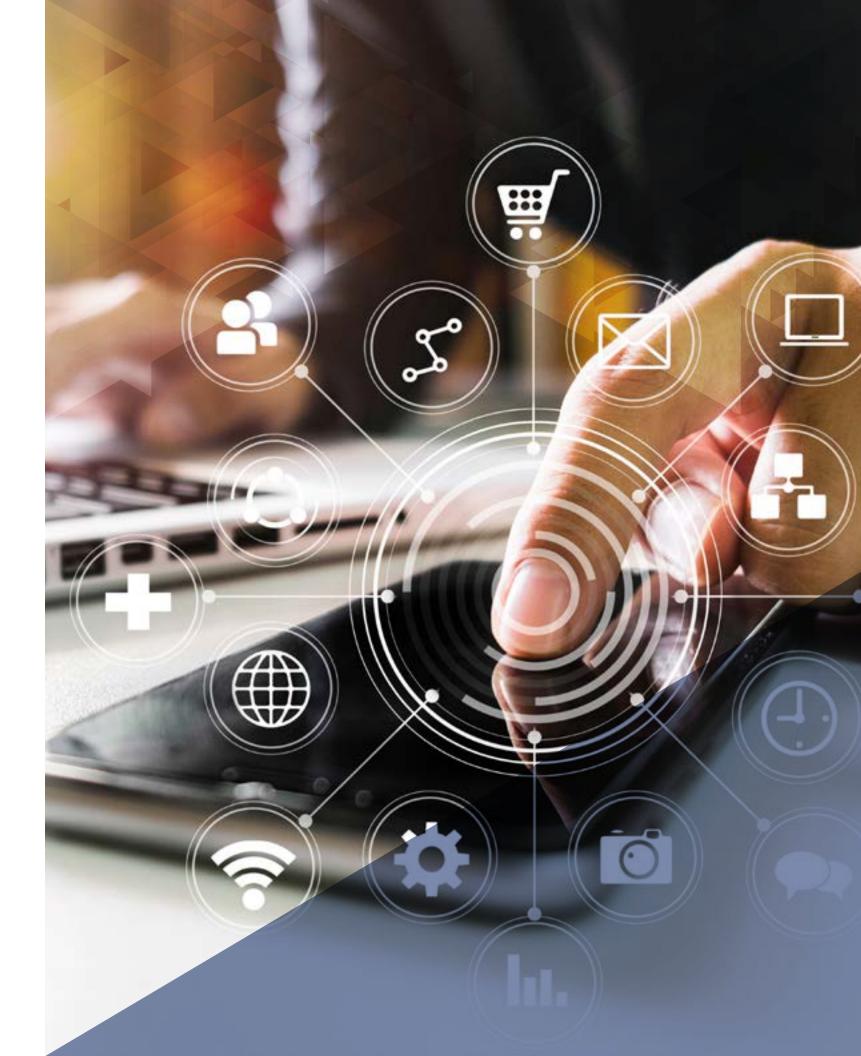
We could not do this work without the committed stakeholders on our board, advisory board, and corporate and foundation supporters. Thank you for your continued partnership and support during this truly unique year. We remain confident in the power of collaboration to integrate privacy protections with responsible data use that will improve people's lives.



Jules Polonetsky **Chief Executive Officer** 



**Christopher Wolf Board Chair** 



# **Privacy & Pandemics**



# Responding to an Unparalleled Global Crisis

y March of 2020, it was clear that COVID-19 would have us readjusting how we set our priorities for years to come. FPF moved quickly to respond and re-assess our immediate priorities. FPF launched Privacy and Pandemics, a collection of resources published throughout the year that addressed challenges posed by COVID-19 to ethical, privacy, and data protection frameworks.

This resource also sought to provide information and guidance to governments, companies, academics, and civil society organizations interested in responsible data sharing to support the public health response.

FPF assembled a comprehensive online depository of U.S. and International COVID-19 privacy and data protection resources.

fpf.org/covid-19-resources

### FPF's Privacy & Pandemics work includes:

In 2020, FPF was awarded a grant from the Robert Wood Johnson Foundation to dissect and determine strategies to address how COVID-19 digital contact tracing efforts (DCTT), informed by digital exposure notifications, can be designed and implemented with equity, fairness, and privacy in mind. This work continues into 2021 and includes expert working groups and a comprehensive suite of resources in 5 different languages on how organizations can execute digital contact tracing while keeping the privacy of at-risk and marginalized groups at the forefront. FPF will continue to develop and make these recommendations available to partners who will sign on to align their work to the principles highlighted in the program.



FPF partnered with BrightHive in developing the Responsible Data Use Playbook for Digital Contact Tracing. Responsible Data Use Playbook for Digital Contact Tracing provides considerations to stakeholders in setting up a digital contact tracing initiative while addressing privacy concerns raised by these technologies in an ethical, responsible manner. The privacy playbook was developed to assist coalitions of professionals invested in the development and deployment of trusted contact tracing. It provides a series of actionable steps that purposefully address the privacy concerns of DCTT and support the development of ethical and responsible digital contact tracing protocols. Its intent is to 1) ease tension between application providers, public health officials, and government authorities; 2) support "opt-in" models for individuals to share health and location data; and 3) support employers that are turning to internal contact tracing when their workplaces reopen.

In October 2020, FPF held a conference sponsored by the National Science Foundation on the responsible uses of personal data during times of crisis. "Privacy and Pandemics: Responsible Uses of Technology and Health **Data During Times of Crisis**" invited computer science, privacy law, public policy, social science, and health information experts from around the world to examine benefits, risks, and strategies for the collection and use of data in support of public health initiatives in response to COVID-19 and consideration of future crises. With additional support from Intel Corporation, Duke Sanford School of Public Policy, and Dublin City University's SFI ADAPT Research Centre, the workshop identified research priorities to improve data governance systems and structures in the context of the COVID-19 pandemic. Drawing on the expertise of workshop participant submissions and session discussions, FPF prepared a report submitted to the National Science Foundation (NSF) as part of its Convergence Accelerator 2021 workshops. This NSF program aims to speed the transition of convergence research into practice to address grand challenges of national importance. The final submitted workshop report is also available on the FPF website.

"Digital contact tracing technologies will play an instrumental role in localities' responses to the COVID-19 pandemic, but these technologies — if designed, developed, and deployed without thoughtful planning can raise privacy concerns and elevate disparities," said FPF CEO Jules Polonetsky. "Contact tracing initiatives should take a measured approach to location tracking, data sharing, purpose limitations and proportionality. If deployed hastily, these technologies risk exacerbating existing societal inequalities, including racial, socioeconomic, and digital divides."

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## **Privacy & Pandemics**

(continued)

#### **Protecting All Schoolchildren During Virtual Learning**

s COVID-19 swept across the U.S. and schools were forced to move to online learning to protect children, families, and communities, there was a need to ensure timely response to the unique concerns facing education stakeholders at both the K-12 and higher education levels. FPF immediately began formulating rapid-response privacy guidance. This suite of materials, including white papers, blogs, articles, webinars, and training initiatives, informed widely accepted best practices and guidance for student and educator privacy in virtual, in-person, and hybrid learning environments.

#### Some of the ways FPF responded to this unprecedented educational shift included:

Compiling and answering frequently asked questions (FAQs) from school districts. On March 20, 2020, we released *FAQs: Disclosing*Student Health Information

During the COVID-19 Pandemic, in partnership with AASA, the School Superintendents Association, with guidance, examples, and scenarios to educators and school staff.



To help school leaders prepare for a remote learning environment in fall 2020, FPF released *Privacy and Pandemics: Reopening Schools*, a new series of issue briefs on reopening schools. The series examined wearable technologies, location tracking, online monitoring, and other tools that districts might employ to mitigate the spread of COVID-19 in schools.



FPF joined 23 education, disability rights, civil rights, and privacy organizations in releasing *Education During a Pandemic: Principles for Student Data Privacy and Equity*, which features 10 principles aimed at helping schools to keep privacy and equity in mind as they seek to teach and protect students in-person and remotely during the pandemic.

# **Policymaker Education**



# Informing and Tracking State and Federal Privacy Legislation and Policies

s an independent non-profit that convenes advocates, academics, and corporate stakeholders, FPF stays on top of the latest in privacy legislation and policies in the U.S. Not only do we develop resources and guidance for policymakers who are leading these legislative efforts and building these policies, but our work in tracking legislation informs other privacy stakeholders.

Over the last year, FPF has tracked 150 state privacy bills, including both sectoral and comprehensive legislation. In addition, FPF staff were invited to testify or provide informational briefings for state legislators in California, Washington, and Virginia on the topics of comprehensive privacy legislation, facial recognition technology, COVID-19 & privacy, and genetic information privacy. We also provided federal testimony before congressional committees and the Federal Trade Commission on issues ranging from the privacy and ethical implications of the commercial use of facial recognition technology, enlisting big data in the fight against COVID-19, and data flows and portability, as well as submitted formal comments to Congressional subcommittees and task forces in the areas of artificial intelligence, privacy, and data protection.

### Policymaker Education and Resources in 2020 included:

Digital Data Flows Masterclass: Emerging Technologies — a series of 5 virtual events with leading academic instructors aimed at providing legislators and other policymakers with a better understanding of relevant data-driven technologies related to privacy and data protection.

Several new education infographics to help with visualization of highly technical topics such as geolocation data, data encryption, and crypto, and artificial intelligence to name a few.

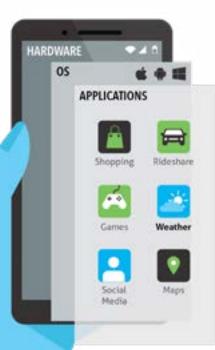
 Legislative webinars and policy briefs on topics such as commercial research, preemption, child privacy, and enforcement options for federal privacy law.

Supporting legislators responding to COVID-19 through a wide range of resources, on topics including digital contact tracing, location data, mobile apps in pandemic response, as well as analysis of newly released COVID-19 privacy bills.



FPF was featured in nearly
40 media articles in 2020
on the topic of privacy legislation.

FPF's team is dedicated to providing practical, educational resources on complex technical and legislative topics. As consumer privacy becomes even more of a focus for federal lawmakers, agency staff, and state policymakers, we will continue to expand on this important work.



Every year, FPF hosts its annual **Privacy Papers for Policymakers.** 

This past February 2020 was FPF's 10th annual event recognizing the year's leading privacy research and analytical work that is relevant for policymakers in the U.S. Congress, federal agencies, and international data protection. For 2020, FTC Commissioner Christine S. Wilson keynoted the event.

### Research



# Leading and Informing Ethical Data Sharing in Driving New Scientific Insights and Expanding Knowledge

PF is one of the few organizations that is leading the development of best practices and ensuring ethical use of data shared between stakeholders. This is a strategic and future priority for FPF as sharing of data can advance work in medicine, public health, education, social sciences, computer science, and many other fields. Meanwhile, access to data can be a challenge due to a range of barriers — including the need to connect with appropriate partners, protect privacy, address commercial concerns, maintain ethical standards, and comply with legal obligations.



In 2020, FPF has moved forward with initiatives that will continue to ensure ethical data sharing for research.
These initiatives include:

The Best Practices for Sharing Data with Academic Researchers were developed by the FPF Corporate-Academic Data Stewardship Research Alliance, a group of more than two dozen companies and organizations. The best practices favor academic independence and freedom over tightly controlled research and encourage broad publication and dissemination of research results while protecting the privacy of individual research subjects. In addition, FPF published Contract Guidelines for Data **Sharing Agreements Between Companies and** Academic Researchers. The guidelines cover best practices and sample language that can be used in contracts with companies that supply data to researchers for academic or scientific research purposes. FPF's Corporate Academic Data Stewardship Research Alliance and these resources were supported by the Alfred P. Sloan Foundation.

The FPF Award for Research Data Stewardship is a first-of-its-kind award recognizing a research partnership between a company that has shared data with an academic institution in a responsible, privacy-protective manner. The 2020 awardwinning partnership was between University for California, Irvine, Professor of Cognitive Science Dr. Mark Steyvers, and Lumos Labs. In an FPF virtual event on September 22, 2020, Professor Steyvers and Bob Schafer, General Manager at Lumosity, discussed their award-winning collaboration and lessons learned for future datasharing partnerships between companies and academic researchers. The inaugural FPF Award for Research Data Stewardship was supported by the Alfred P. Sloan Foundation.

Through its Applied Privacy Research Coordination Network, a project supported by the National Science Foundation. FPF continued in 2020 to introduce academic researchers to industry practitioners to develop working partnership opportunities and share best practices. This project builds on FPF's first NSFsupported Research Coordination Network established in 2019 to foster industry-academic collaboration on priority research issues and inform the public debate on privacy. These projects have provided ongoing support to FPF's Privacy Papers for Policymakers program which brings academic expertise to members of Congress and leaders of executive agencies and their staffs to better inform policy approaches to data protection issues.

In 2020, FPF and Actionable Intelligence for Social Policy (AISP) created the Nothing to Hide: Tools for Talking (and Listening) About Data Privacy for Integrated Data Systems toolkit to provide stakeholders with tools to lead privacy-sensitive, inclusive government Integrated Data Systems efforts using data that government agencies routinely collect in the course of delivering public services to shape local policy and practice.



As a featured part of the Privacy & Pandemics series, FPF's Corporate Data Sharing Workshop on March 26, 2020, convened ethicists, academic researchers, government officials, and corporate leaders to discuss best practices and policy recommendations for responsible data sharing.

FPF's October 2020 international tech and data conference, "Privacy and Pandemics: Responsible Uses of Technology and Health Data During Times of Crisis," presented in collaboration with the National Science Foundation, Duke Sanford School of Public Policy, SFI ADAPT Research Centre, Dublin City University, and Intel Corporation, produced a roadmap for research, practice improvements, and development of privacy-preserving products and services to further inform responses to COVID-19 and prepare for future pandemics and crises.

# **Convening Stakeholders**



One of FPF's main goals and one that ensures collaboration and expertise in advancing privacy alongside technology is to bring diverse stakeholders together to learn from each other. During 2020, that became more challenging as COVID-19 kept many of us apart physically, however, FPF was able to transition many of its expert events and convenings online.

ven in the midst of the COVID-19 pandemic, FPF hosted over 30 engaging and interactive events in 2020 with experts and working group meetings, bringing together corporate, academic, and civil society stakeholders. Attendees had the opportunity to hear from subject matter experts across a variety of disciplines and industries.

As the data privacy and protection landscape is always changing, FPF brings stakeholders together for an unplanned meeting or quick turnaround webinar to address the latest information and developments in the field. This is mostly to the credit of our policy team, who stay up to date on the newest developments and are committed to ensuring our supporters and stakeholders are able to use this information in their professional settings.

In 2020, FPF held

30
total virtual events.



### These virtual events and convenings included:

#### **Annual Meeting**

Every year, FPF gathers its Advisory Board to review the past year's accomplishments, discuss the pressing issues of the day, and help guide future FPF directions.

#### **Brussels Symposium**

The Brussels Privacy Symposium is an annual academic program jointly presented by the Brussels Privacy Hub of Vrije Universiteit Brussel and FPF and is a global convening of practical, applicable, substantive privacy research and scholarship.

On December 2, 2020, the fourth iteration of the Brussels Privacy Symposium, "Research and the Protection of Personal Data Under the GDPR", occurred as a virtual international meeting where industry privacy leaders, academic researchers, and regulators discussed the present and future of data protection in the context of scientific data-based research.

### Expert Working Group Meetings

FPF holds regular expert working group meetings in its various workstreams to keep privacy professionals abreast of the latest developments in the sector.

#### Masterclasses

Digital Data Flows Masterclass is an educational program designed for regulators, policymakers, and staff seeking to better understand data-driven technologies as they seek to regulate on and implement data protection law and policy. The program featured experts on machine learning, biometrics, connected cars, facial recognition, online advertising, encryption, and other emerging technologies.

### Year-Round Expert Events with Partners

FPF hosts on average 30 educational events with leading organizations and companies.

#### **Civic Data Privacy Leaders Network**

This group, supported by the National Science Foundation, is comprised of over 80 members representing over 30 US cities and counties who convene to collaboratively address data privacy issues and principles.



### **Global**



# FPF Expands its Global Reach

PF continues to expand its influence and capabilities in Europe and globally. FPF's engagement helps regulators, policymakers, and staff at data protection authorities better understand the technologies at the forefront of data protection law. FPF also explains data protection and privacy law and the European Court of Human Rights legal framework to make them easily understandable for stakeholders in the U.S.

FPF closely follows developments internationally to keep stakeholders informed of relevant changes, caselaw, guidance, policies, and legal requirements, while also providing background and in-depth analysis in order to support them in being ahead of key developments globally. FPF will continue to expand in 2021 to include an expert presence in India, Brazil, and Singapore. FPF's global team is a vital bridge between European and U.S. privacy cultures, in addition to the global privacy ecosystem due to its interconnectedness. FPF strives and hopes to one day build a common data protection language spoken worldwide.

### Some European and Global highlights from 2020 include:

In 2020, the Future of Privacy Forum (FPF) and the Brussels Privacy Hub of Vrije Universiteit Brussel (VUB) hosted the Brussels Privacy Symposium 2020: Research and the protection of Personal Data Under the GDPR. The event, convened by FPF CEO Jules Polonetsky and Dr. Christopher Kuner, Co-Chair of the Brussels Privacy Hub, brought together industry privacy leaders, academic researchers, and regulators to discuss data protection in the context of scientific research under the European Union's General Data Protection Regulation (GDPR) from various policy and technical perspectives. The 2020 Brussels Privacy Symposium was the fourth annual academic program jointly presented by VUB and FPF. The event brought into focus recent developments in EU policymaking that may have significant effects on processing personal data for research purposes. One of the relevant legislative proposals recently introduced by the European Commission is the Data Governance Act (DGA), which "aims to foster the availability of data for use by increasing trust in data intermediaries and by strengthening data-sharing mechanisms across the EU." It also proposes to promote "data altruism," allowing researchers access to larger datasets for their research. Overall, the Symposium focused on striking a balance between the utility of research and privacy and data protection.



In November 2020, FPF and Data Privacy Brasil (DPB) co-hosted a landscape webinar exploring the relationship between Brazil's legal system and the implementation of Brazil's new data protection law, Lei Geral de Proteção de Dados (LGPD). This virtual event covered the various legal and regulatory institutions in Brazil that have authority over data protection, the implementation and outcomes of the LGPD, and the solutions to solve potential sources of conflict in the Brazilian legal system.

In July 2020, Dublin City University (DCU) and the Future of Privacy Forum (FPF) jointly organized the webinar "The Independent and Effective DPO: Legal and Policy Perspectives." The webinar was designed to help policymakers, regulators, and their staff better understand legal views concerning the position of the Data Protection Officer within an organization.

FPF participated in a <u>public workshop</u> held by the Federal Trade Commission, "Data To Go," examining the benefits and challenges of data portability frameworks for consumers and competition around the world. As a panelist during the first discussion, FPF's Dr. Gabriela Zanfir-Fortuna discussed how data portability operates in different commercial sectors; lessons learned from the GDPR and other global laws; and observations on the dual nature of data portability, as both a means to facilitate competition and a right of individuals to exercise control over their data.

In 2020, the FPF kicked off the Global Privacy blog series, which provides original content and hosts curated thought leadership that helps our stakeholders make sense of the profound developments in privacy and data protection legal regimes and policymaking around the world. From New Zealand to Singapore, Brazil, South Korea, or India — we have been keeping track of relevant changes and highlighted trends that should be in focus for privacy and data protection leaders.



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