

University of California Irvine – Lumos Labs Task Switching Project FPF Award for Research Data Stewardship

WASHINGTON, DC (May 19, 2020) - The Future of Privacy Forum (FPF) recently announced that Professor Mark Steyvers, University of California-Irvine Department of Cognitive Sciences, and Lumos Labs are the winners of the first-ever FPF Award for Research Data Stewardship. Nominees for the Award for Research Data Stewardship were judged by a panel of expert reviewers based on their adherence to privacy protection in the data sharing process, the quality of the data handling process, and the company's commitment to supporting academic research.

About the Research Project: The partnership between Prof. Steyvers and Lumos Labs, makers of the Lumosity brain games, explored the ability of people to flexibly and efficiently adapt behavior in response to changing contexts, otherwise known as task switching, and the impact of practice on task switching ability. To study task switching behaviors, de-identified response time and accuracy data were drawn from players' interaction records from one Lumosity game and provided to the academic researchers in a secure environment. The research concluded that practice improves task-switching capability across all age groups, but has an even greater effect on older adults, with extensive practice making some older individuals functionally similar to less-practiced younger individuals. The co-authored research, entitled "A Large-Scale Analysis of Task Switching Practice Effects Across the Lifespan", was published in Proceedings of the National Academy of Sciences (PNAS), the official journal of the National Academy of Sciences (NAS).

About the Human Cognition Project: The Human Cognition Project (HCP) is an online research platform created by Lumos Labs to facilitate large-scale, collaborative research studies led by independent academic and clinical researchers. Through the HCP, Lumos Labs provides researchers with free access to its software and relevant portions of its de-identified data based on the researchers' needs, enabling types of analysis that would be impossible through traditional, laboratory, or clinical studies. In the last ten years, the HCP has supported collaborations with over 100 universities and organizations, including Harvard University, Stanford University, UC San Francisco, the United States Department of Veterans Affairs, and more, resulting in more than 40 peer-reviewed publications.

Data Protection Procedures and Processes in the Lumos Labs – Prof. Steyvers Collaboration:

- A Focused Request for Data. Prof. Steyvers was interested in data from games that are
 adaptations of tasks commonly used in the lab or clinic, particularly those related to task
 switching. Lumos Labs and Prof. Steyvers collaborated to define the nature and scope of the data
 that would be most valuable for the research project. For this specific project, the collaborators
 settled on response time and accuracy data, as well as user age data, from individuals who had
 trained extensively on the game.
- 2. A Written Agreement with Prohibitions on Further Sharing. Prof. Steyvers then signed a binding data licensing agreement that defined restrictions and conditions for accessing and using the data from Lumos Labs. The restrictions included a prohibition on selling or licensing the data to a third party, an emphasis that data uses must stay within legal bounds, and a commitment that Prof. Steyvers would not attempt to re-identify the de-identified data that Lumos Labs would provide.

- 3. A De-Identified Data Set. Once the type of data to be shared had been identified and limits agreed upon, Lumos Labs set about de-identifying the data set. In order to enforce the appropriate use of the data, Lumos Labs pulled and prepared the data in accordance with its Information Security Policy, which governs the classification of confidential information, systems and device management, access controls, training, systems and network security, and facility access control.
- 4. **Following HIPAA Guidelines for De-Identification.** Lumos Labs de-identified the data in accordance with the Department of Health and Human Services' Safe Harbor <u>de-identification</u> <u>guidelines</u> for protected health information in a manner that is in line with the Health Insurance Portability and Accountability Act (HIPAA). The Safe Harbor method requires the removal of specific types of identifiers, including names, telephone numbers, email addresses, social security numbers, and more.
- 5. **Close Collaboration on Privacy.** Over the course of the research collaboration, the parties kept regular contact to ensure they maintained alignment on the uses of data, answer questions, and provide feedback. By communicating frequently, the parties made sure that the de-identified data remained private, the uses of the data remained acceptable, and expectations were met.

Lessons for Future Data-Sharing Projects

The data sharing partnership between Professor Steyvers and Lumos Labs highlights a number of valuable lessons that companies and academic institutions may apply to future data sharing collaborations.

- Companies should be sure to understand how their data sets relate to the needs of the
 researcher. It is essential that companies and their research partners engage in frequent, open
 discussions about the project at hand and the types of data that would be most useful for the
 research. Otherwise, data that may not be applicable may be shared, unnecessarily exposing
 individuals included in the data set to privacy risks.
- Researchers should propose a well-designed, focused study. Researchers seeking personal data
 from companies should bring clear, methodologically sound study proposals to their potential
 partners that could result in publishable research that is high-quality and embodies the
 principles of research integrity.
- **Establish clear boundaries.** Agreeing to terms and data uses in advance engenders trust and creates confidence that the data will be accessed, shared, and used in an acceptable manner.
- Companies should follow internal guidelines when engaging in research partnerships. The
 Lumos Labs Information Security Policy represented a robust, established framework for
 handling and processing company data, making it easier to share their data with independent
 researchers in a privacy-protective manner.
- Research partners should follow guidelines for de-identifying and aggregating data. Federal
 agencies and other organizations often publish guidelines for de-identifying protected personal
 information, which should guide the processing of data for corporate-academic data sharing
 projects.

•	Be transparent. Regular communication between collaborators helps ensure that expectations are met and trust is built, easing future collaborations. Additionally, establishing clear, public-facing company guidelines for data sharing for research helps maintain public trust.