

Northwestern University Office for Research Privacy Statement

Purpose

Northwestern University's Office for Research ("OR") is committed to protecting and respecting the privacy rights of all individuals who engage in research activities with the University. This OR Privacy Statement ("ORPS") provides a general description of the personal information that Northwestern University ("Northwestern" or "University") collects and uses as part of its research activities and explains how such personal information is collected, handled and the rights of personal information subjects. For a description of the personal information that Northwestern, as a whole, collects and uses, please read [Northwestern University's Privacy Statement](#). For the purposes of this ORPS, the term "**Personal Information**" includes both personal information and sensitive personal information as defined below; the term does not include fully "**Anonymized Information**". While this ORPS applies only to Personal Information collected in the context of research activities, this ORPS also contains links to other Northwestern privacy notices and policies that are applicable in the context of research activities and more broadly.

Scope

This ORPS covers all individuals who are natural persons (not a corporation, partnership, or other legal entity) and Northwestern handles their Personal Information solely in the context of research activities. This ORPS applies to all members of the Northwestern community including all faculty, staff, students, third-party contractors, vendors, volunteers, and agents and members of the public who are engaged in University research activities and/or have access to Personal Information obtained as part of University research activities.

Definitions

"Anonymization" means the process of processing personal information to make it impossible to identify specific natural persons and impossible to restore.

"Anonymized Information" means information that has fully undergone Anonymization.

"Personal Information Subject" means an individual to whom the Personal Information relates.

"Handle," "Handling," "Handles," and "Handled" means any operation or set of operations performed on Personal Information or Sensitive Personal Information, whether or not by automated means. This includes, but is not limited to, collection, recording, organization, structuring, storage, adaptation or alteration, retrieval, consultation, use, processing, transmission, provision, publishing or otherwise making available, alignment or combination, restriction, and deletion.

"Personal Information" means any information, recorded by electronic or other means that relates to an identified or identifiable individual. Personal Information does not include fully Anonymized Information. General categories of Personal Information includes, but are not limited to the following: names; addresses; telephone numbers; email addresses; identification numbers including but not limited to social security numbers, Resident Identity Cards, driver's license numbers, University identification numbers; date of birth; demographic information; education history; financial information including but not limited to credit and debit card numbers, tax

information, tax identification numbers (TINs); transaction histories; passport and visa information; work histories; medical histories; insurance information; military service; IP addresses; location information; metadata; education records; demographic, health, political and religious views, biometric and other information related to research activities.

“Sensitive Personal Information” means Personal Information which, if inappropriately disclosed or illegally used, would likely cause harm to the dignity of an individual or grave harm to persons or property. Sensitive Personal Information includes information on racial or ethnic origin; political opinions; biometrics; genetics, if handled for the purpose of uniquely identifying a natural person; religious or philosophical beliefs; trade union membership; specially-designated status; health, including medical health status; a natural person’s sex life or sexual orientation; financial accounts; individual location tracking; and personal information about children under the age of 14.

Collection of Personal Information

Northwestern may collect Personal Information from various sources as described below in the course of research activities. Northwestern will take all reasonable and practical measures to ensure that unnecessary Personal Information is not collected.

Direct Collection

Northwestern may receive Personal Information from the University’s researchers who collect Personal Information from individuals directly, for example, when such individuals fill out an online survey, or participate in a University research protocol. Northwestern may receive such Personal Information collected from research collaborators, research participants and others who participate in research activities. Personal Information collected directly may include, but is not limited to, your name, email address, mailing address, telephone numbers, social network identifiers, and demographic information.

Third Parties

Northwestern may receive Personal Information from the University’s researchers who obtain Personal Information about you from third parties including public and private databases or companies or institutions that may sponsor or facilitate your participation in a research project. This information may include names, contact information, interests, location data, and other similar information.

Automated Collection

The University collects Personal Information through automated processes (e.g., cookies) that provide information about how users interact with its websites, including OR websites. For more details on the use of cookies and how to control or opt-out of the cookies that are set on a computer or mobile device, please see the University’s [Cookie Information Page](#).

OR’s website contains links to and from various Northwestern and third-party websites. When following a link to any of these websites, please note that these websites may have their own privacy statements. OR does not accept any responsibility or liability for policies of third-party websites; please check these policies before submitting any personal information to third-party websites.

Use of Personal Information

Northwestern uses certain Personal Information to allow and facilitate research performed at or with the University, to allow individuals to participate in research performed at or through the University, and to perform activities related to such research.

Northwestern will only collect, store, access, use or otherwise handle Personal Information when permitted or required by applicable law and there is a legitimate reason and legal basis for doing so. In most cases, the legal basis is individual consent or when the University has a legal obligation to fulfill statutory duties or responsibilities, for example to comply with state and federal obligations. All Personal Information collection and use will comply with all applicable law and University policies, including the University's [Data Classification Policy](#). Where the legal basis is individual consent, collection and use will be consistent with the consent that was provided. Only the minimum amount of Personal Information needed to conduct the research activity will be collected, stored, accessed, used, or otherwise handled.

Disclosure and Sharing of Personal Information

When Personal Information is required or permitted to be disclosed, OR will disclose the least amount of Personal Information reasonably necessary to fulfill the relevant obligations or to achieve the relevant goals. OR may disclose Personal Information about you in the following circumstances:

Internal and Related Organization Use

Northwestern shares Personal Information with employees, including faculty, researchers, institutional review board (IRB) members, OR staff, and others associated with the University and affiliated institutions in order to carry out research activities in furtherance of its mission.

Third Parties

Northwestern does not rent, sell, or trade Personal Information to third parties. Northwestern may share Personal Information with third parties that provide services or products, support operations, or otherwise help the University carry out activities in furtherance of its research mission. Northwestern signs confidentiality agreements with these third parties, which bind them to processing your Personal Information in accordance with the University's requirements, and other relevant confidentiality and security measures. Examples include partner institutions, service providers, and vendors. The University will reasonably assess the third parties' privacy and data security practices prior to sharing Personal Information with them. To the extent applicable law requires Northwestern to obtain individual consent and/or provide notice to Personal Information Subjects prior to sharing Personal Information, Northwestern will obtain the necessary individual consent and/or provide the necessary notice in accordance with applicable law and prior to sharing. Any sharing of Personal Information will be consistent with this consent and notice.

Law Enforcement and Government Agencies

Northwestern may share Personal Information with law enforcement agencies when required to do so by law, court order, or other legal process, or when required to exercise the University's legal rights or to establish or defend legal claims. Northwestern may also share Personal Information with government agencies in order to comply with regulations.

Anonymized Information

Northwestern may provide Anonymized Information developed from Personal Information to third parties. Such Anonymized Information, which cannot identify specific natural persons and is impossible to restore, is outside the scope of this ORPS.

Public Disclosure

Northwestern will only publicly disclose Personal Information after Northwestern obtains explicit consent, or when applicable laws or regulations require Northwestern to publicly disclose Personal Information.

Cross-Border Transfer

Northwestern may conduct cross-border transfers of Personal Information to and from the United States of America, where data protection laws may differ from those of the Personal Information Subject's home country. In the event of a cross-border transfer, the University will do so in a manner consistent with applicable data protection laws regarding the protection of Personal Information.

PIPL Privacy Statement

The OR Supplemental Privacy Statement - PIPL ("Supplemental Statement - PIPL") also supplements this ORPS. The Supplemental Statement - PIPL applies generally to the provision of Personal Information by individuals in the People's Republic of China who are participating in University research. The Supplemental Statement - PIPL explains how Northwestern meets its obligations under the Personal Information Protection Law ("PIPL") with respect to such information solely in the context of Northwestern research activities.

Rights and Choices

As provided under applicable law and subject to any limitations in such law, Personal Information Subjects may have the following rights:

- **Right to Know.** Personal Information Subjects have the right to know and make decisions about the processing of their Personal Information, and the right to restrict or refuse the handling of their Personal Information by others, unless otherwise provided for by laws or administrative regulations.

If the purpose or method of processing of an individual's Personal Information or the type of Personal Information or who has access to the Personal Information changes, if required the individual will be notified and/or asked to re-consent to the change(s).

- **Right to Access.** Personal Information Subjects may ask the University to confirm whether or not Personal Information are being handled; provide them with a copy of the Personal Information the University maintains about them; and request certain information about its handling.
- **Right to Consult and Copy.** Personal Information Subjects have the right to consult and copy their Personal Information, except when it is necessary for the University to maintain confidentiality or when otherwise provided for by applicable laws or administrative regulations.
- **Right to Correct or Supplement.** Personal Information Subjects have the right to request that the University correct any inaccurate Personal Information that it maintains about

them. Personal Information Subjects also have the right to request that the University complete any incomplete Personal Information that it maintains about them, which could be accomplished by incorporating a supplementary statement that the individual submits. To the extent that the University concurs that the Personal Information is incorrect or incomplete, the University will take steps to correct or complete it.

- Right to Transfer. In certain situations, Personal Information Subjects may ask the University to transfer their Personal Information to another organization.
- Right to Delete. In certain situations, Personal Information Subjects may ask to have their Personal Information anonymized or deleted without undue delay, as appropriate.
- Right to Withdraw. Personal Information Subjects may withdraw any consent they previously provided to University regarding the handling of their Personal Information at any time and free of charge by emailing privacy@northwestern.edu. This will not affect the lawfulness of the handling before the individual withdrew their consent.
- Right to Restrict Processing. Personal Information Subjects may ask Northwestern to suspend the Handling of their Personal Information.
- Right to Complain. Personal Information Subjects may lodge a complaint with a supervisory authority or regulatory institution.
- Right to Explanation. Personal Information Subjects have the right to request Northwestern to explain Northwestern's Personal Information Handling rules.

Individuals should direct any questions or comments about this ORPS, our privacy practices, or to exercise these rights by contacting the University using the contact details provided at the end of this ORPS. Note that applicable laws and regulations contain certain exceptions and limitations to each of these rights. The University may require requests to be submitted in writing and will also need to verify an individual's identity before the individual can exercise these rights to ensure that Personal Information is not inappropriately disclosed.

Data Protection and Retention

OR takes appropriate security measures according to industry standards including physical, managerial, organizational, and technical safeguards designed to protect your Personal Information and prevent unauthorized access to, disclosure, use, modification, damage or loss of information.

However, no method of transmission over the Internet or method of electronic storage is 100% secure. While OR strives to use commercially reasonable means to protect Personal Information, OR cannot guarantee its absolute security. More information regarding data protection is available under the University's [IT Policies, Guidelines, and Practices](#).

OR deletes or anonymizes Personal Information when it is no longer needed for the purposes for which it was collected, unless required or allowed by policy or law to keep it for a longer period. More information regarding data retention and disposal of Personal Information is provided in the University's [Retention of University Records Policy](#).

Illinois Biometric Privacy Act

The University uses biometric identification systems to increase security and control access to certain campus facilities. The University recognizes the sensitivity of biometric information and takes seriously its obligations to maintain the confidentiality and protect the security of data. Further information about the University's collection and use of biometric information is provided in the University's [Biometric Information Privacy Policy](#).

Contact Information

For further information about the University's collection or use of Personal Information, please contact **privacy@northwestern.edu** or in writing to:

Northwestern University
Attn: AVP Risk & Compliance
2020 Ridge Ave, 4th Floor
Evanston, Illinois 60208

Updates

OR may update this ORPS periodically to reflect changes in the University's privacy practices. Any changes become effective upon publication, and we will follow all applicable laws and regulations regarding notifications of such changes.

Last updated: March 8, 2023