

**Northwestern University
Office for Research**

Supplemental Privacy Statement - PIPL

This Privacy Statement (the “**Statement**”) applies to the handling of Personal Information (as defined herein), by Northwestern University (“**Northwestern**,” “**University**,” “**we**,” “**our**,” or “**us**”) subject to the Personal Information Protection Law of the People’s Republic of China (“**China**”), through research activities performed at or with Northwestern (the “**Services**”).

This Statement describes how we collect, use, disclose, retain, transfer, and protect such Personal Information, your rights and choices with respect to your Personal Information, how this Statement will be updated, and how you can contact us if you have any questions or concerns. For the purposes of this Statement, “China” refers to the continental landmass under the direct control of the People’s Republic of China, including the islands of Hainan Province and five major autonomous regions (i.e., Tibet, Inner Mongolia, Xinjiang, Ningxia, and Guangxi), but excluding the Hong Kong Special Autonomous Region (SAR), Macao SAR and Taiwan.

We understand the importance of Personal Information to you and will do our best to ensure the security and reliability of your Personal Information. We are committed to maintaining your trust in us and sticking to the following principles to protect your Personal Information: consistency between rights and responsibilities, clear purpose, optional consent, minimum necessary, security assurance, subject participation, and openness and transparency. We will take security measures to protect your Personal Information according to mature standards of the industry.

Please carefully read and understand this Statement before using our Services and contact us using the details at the bottom of this Statement if you have any doubts, comments, or suggestions.

1. Scope of this Statement

This Statement applies to you if you are a natural person, not a corporation, partnership, or other legal entity and if Northwestern Handles your Personal Information obtained in the course of research activities in the following ways:

- Handling Inside China: You are physically located anywhere in the world, and Northwestern Handles your Personal Information within the borders of the PRC; or
- Handling Outside China: You are physically located in China, and Northwestern Handles your Personal Information outside the borders of China in order to 1) perform research and provide you associated goods or services such as compensation for your participation, 2) analyze or assess your activities when you participate in a research project, or 3) comply with other circumstances as provided by Chinese laws or administrative regulations, including the Civil Code of the People's Republic of China, the Cybersecurity Law of the People's Republic of China, the Data Security Law of the People's Republic of China, the Personal Information Protection Law of the People's Republic of China, the Provisions on Standard Contracts for Personal Information outbound Transfer and other laws, regulations and departmental rules of the People's Republic of China.

If you are located outside China and you provide your Personal Information to Northwestern outside China, this Statement does not apply to that information.

2. Personal Information We Collect and Handle

In this Statement, “**Personal Information**” means any information, recorded by electronic or other means, relating to an identified or identifiable individual and does not include information that underwent anonymization. We may collect Personal Information about you from various sources described below. “**Handle**” or “**Handling**” as used in this Statement means any operation or set of operations performed on Personal Information or on sets of Personal Information, whether or not by automated means, and includes the collection, storage, use, processing, transmission, provision, publication, and erasure of Personal Information.

General categories of Personal Information Northwestern Handles in the context of research include but are not limited to the following: name, email address, study identification number, date of birth, gender, ethnicity, nationality, medical information, occupation, and location information. Research study participants are notified of the specific categories of Personal Information to be collected from them prior to participating in a research study.

Such information may be collected by Northwestern in the following manners:

Information Provided by You

- **Research Participation.** Northwestern may receive Personal Information from individuals directly, for example, when such individuals fill out an online survey, or participate in a University research protocol. 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.
- **Communications.** When you contact us via a contact form, email, or other means, you provide us with Personal Information, such as your name and contact details, and the content, date, and time of our communications.
- **Sensitive Personal Information.** Research study participants are notified of the specific categories of sensitive Personal Information to be collected from them prior to participating in a research study; such categories may include but are not limited to the following: ethnicity, medical information, location information, and information relating to minors under the age of 14.

Where applicable, we may indicate whether and why you must provide us with your Personal Information as well as the consequences of failing to do so. For example, it may be necessary for you to disclose certain Personal Information in order for us to provide the Services to you.

Information Collected from Other Sources

- **Third Parties.** Northwestern may 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 one of our research programs, the names of which we will provide when we provide Services to you, and other entities. This information may include names, contact information, interests, location data, etc. and other similar information.

Information Collected by Automated Means

- **Cookies.** The University collects Personal Information through automated processes (e.g., cookies) that provide information about how users interact with its 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](#).

3. How We Use Personal Information

We may use the Personal Information we collect for the purposes stated in OR's Privacy Statement, including without limitation for the following purposes:

- **Communications.** including to contact you for administrative purposes (e.g., to respond to comments and questions).
- **University Research,** including to allow and facilitate individuals to perform research at or with the University, or to utilize individuals as participants of research performed at or through the University, and to perform activities related to such research.
- **Administrative and Legal,** such as to address administrative issues or to defend our legal rights and to comply with our legal obligations and internal policies as required by state and federal laws, and as permitted by Chinese law.
- **Sensitive Personal Information.** We may use the sensitive Personal Information collected in connection with research activities and to support advancing Northwestern's mission.
- **Providing Other Services,** including to operate, maintain, support, and provide our Services.

4. Legal Bases for the Handling of Personal Information

We rely on various legal bases to handle your Personal Information, including:

- **Consent.** You may have consented to the use of your Personal Information, for example participation in a research protocol. We will obtain your consent for the handling of sensitive Personal Information. You may withdraw your consent at any time by contacting us as described in Section 12 of this Statement.
- **Contract.** We need your Personal Information to provide you with our Services and to respond to your inquiries.
- **Legal.** We may have a legal obligation to handle your Personal Information when necessary to fulfill statutory duties and responsibilities or statutory obligations, for example to comply with state and federal obligations.
- **Public Interest.** We may also handle your Personal Information when necessary to respond to sudden public health incidents or protect individuals' lives and health, or the security of their property, under emergency conditions.

5. How We Use Children's Personal Information

A child should not provide us their Personal Information without consent of their parents or guardians. Children's Personal Information that is collected with their parents' or guardians' consent will only be used or publicly disclosed when it is permitted by applicable laws, explicitly consented to by their parents or guardians, or is essential to protecting the children. Although the definition of children varies in local laws and customs, we regard anyone below 18 years old as a child. If we find that a child's Personal Information has

been collected without their parents' or guardians' prior consent, we will delete relevant information as soon as possible.

6. How We Disclose Personal Information

We may disclose Personal Information about you in the following circumstances:

- **Group Entities.** We may disclose Personal Information about you to our affiliates.
- **Service Providers.** We work with third parties that provide services to facilitate some of our internal processes, such as workflow management, records management, and auditing of research study records. We sometimes refer to these partners and service providers as "entrusted parties." These third parties may have access to or handle your Personal Information as part of providing those services to us, but they are prohibited from using your Personal Information for their own purposes. The University 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.
- **Legal.** We may disclose your Personal Information when it is necessary to fulfill our duties and obligations under applicable law.
- **Anonymized Information.** Personal Information that has been processed to make it impossible to identify specific natural persons and impossible to restore. We may use and disclose anonymized information for any purpose unless we are prohibited from doing so under applicable law.
- **Research Partners.** We may share Personal Information such as name, address, and related data with our research partners and other related entities. We share Personal Information with our research partners in order to facilitate research, and for other related purposes. We will not share your Personal Information with any company, organization, or individual unless you provide explicit consent, except when applicable laws or regulations require us to share your information.
- **Public Disclosure.** We will only publicly disclose your Personal Information after we obtain your explicit consent, or when applicable laws or regulations require us to publicly disclose your Personal Information.

7. Your Rights and Choices

As provided under applicable Chinese law(s) and subject to any limitations in such law(s), you have the following rights, some or all which you may also exercise on behalf of a deceased person to whom you are the next of kin to the extent permissible under applicable law(s), for the sake of your own lawful and legitimate interests, except where the deceased has arranged otherwise before death:

- **Right to Know and Limit.** You have the right to know and make decisions about the processing of your Personal Information, and the right to limit or refuse the handling of your Personal Information by others, unless otherwise provided for by law.

If/when in the course of a research project, the purpose or method of processing your Personal Information or the type of Personal Information or who has access to your Personal Information changes, if required, you will be notified and asked to re-consent to the change(s).

- **Right to Access.** You may ask us to provide you with a copy of the Personal Information we maintain about you and request certain information about its handling.
- **Right to Consult and Copy.** You have the right to consult or copy your Personal Information, except when it is necessary for Northwestern to maintain confidentiality or when otherwise provided for by applicable law.
- **Right to Correct or Supplement.** You have the right to request that Northwestern correct any inaccurate Personal Information that it maintains about you. You also have the right to request that Northwestern complete any incomplete Personal Information that it maintains about you, which could be accomplished by incorporating a supplementary statement that you submit. To the extent that Northwestern concurs that the Personal Information is incorrect or incomplete, Northwestern will take steps to correct or complete it.
- **Right to Transfer.** You may request that Northwestern transfer your Personal Information to another Personal Information handler.
- **Right to Delete.** In certain situations, you may ask to have your Personal Information anonymized or deleted, as appropriate. You can submit a request to delete your Personal Information to us under the following circumstances:
 1. Our processing purposes have been achieved or cannot be achieved, or your Personal Information is no longer necessary for achieving the purposes of processing;
 2. If our processing of Personal Information violates applicable laws or regulations or if applicable laws or regulations require us to delete your Personal Information;
 3. If we collected and used your Personal Information without your consent;
 4. If you withdraw your consent, and there is no other legal basis for us to collect and use your Personal Information;
 5. If our processing of Personal Information breaches our agreement with you;
 6. If you no longer use our Services or you have cancelled your account;
 7. If we no longer provide you with our Services, or the retention period has expired.

When we decide to respond to your deletion request, we will also take steps to inform any known entity that acquired your Personal Information from us and ask it to delete your Personal Information without delay, unless otherwise specified in applicable laws and regulations, or the entity has acquired specific authorization from you.

When you delete Personal Information from our Services, we might not be able to immediately delete the corresponding information from our backup system, but will delete it when possible. Deleting your Personal Information will not affect the lawfulness of the handling before you deleted your Personal Information.

- **Right to Withdraw Consent.** You may withdraw any consent you previously provided to us regarding the handling of your Personal Information at any time and free of charge. This will not affect the lawfulness of the handling before you withdrew your consent.
- **Right to Explanation.** You have the right to request Northwestern to explain our Personal Information handling rules.

You may exercise these rights by contacting us using the contact details at the end of this Statement. We will not charge you for your reasonable requests in principle. However, a fee to reflect the cost will be imposed as appropriate on repeated requests beyond reasonable scope. We may reject repeated requests, those that are groundless, and/or those that need excessive technological means (e.g., developing a new system or fundamentally changing the current practices) to fulfill, bring about risks to others' legitimate rights and interests, or are downright impractical (e.g., involving information stored on a backup disk).

Note that applicable laws contain certain exceptions and limitations to each of these rights. We will not be able to respond to your request when it: affects our compliance with obligations under applicable laws and regulations; directly relates to national security or defense security; directly relates to public security, public health, or major public interests; directly relates to criminal investigations, prosecutions, trials, and enforcement of court decisions, etc.; or involves trade secrets. We also will not respond to requests when we have sufficient proof that you have subjective malice or are abusing your rights; for the purpose of safeguarding your life, property, or your other important legal rights and interests or those of other individuals from whom it is difficult to obtain consent; or when responding to your request would cause serious harm to your legitimate rights and interests, or those of other individuals or organizations.

If we do not grant your rights request, we will explain the reason for doing so, and you may file a lawsuit with a People's Court of the People's Republic of China according to applicable laws. For security, we may require you to submit your request in writing, and we will also need to verify your identity before you exercise these rights to ensure that your Personal Information is not inappropriately disclosed.

8. International Data Transfers

We provide our Services based on our resources and servers worldwide, so, with your consent or as permitted by law, your Personal Information might be transmitted to or accessed from the United States or other jurisdictions outside of the People's Republic of China when necessary for business or other valid purposes.

Such jurisdictions might have different data protection laws, or even no relevant laws. Under such circumstances, your Personal Information will enjoy the same level of protection as it does in the People's Republic of China.

9. Data Security, Minimization, and Retention

We use physical, managerial, and technical safeguards that are designed according to industry standards to protect your Personal Information and prevent unauthorized access to, disclosure, use, modification, damage or loss of information. We will take appropriate practical measures to protect your Personal Information. For example, the University's [Data Access Policy](#) classifies data according to its sensitivity to unauthorized exposure and provides appropriate access limitations; the University's [Electronic Communications Standard](#) outlines the necessary actions each person or organization with access to University electronic communications is responsible for taking to ensure the integrity of the systems and data for which the University is responsible; etc.

We will take all reasonable and practical measures to ensure that unnecessary Personal Information is not collected, and we delete or anonymize your Personal Information when it is no longer necessary for the purposes for which we handle it, unless we are required or allowed by policy or law to keep it for a longer period. When determining the retention

period, we select the shortest retention period necessary to achieve the purpose of the handling and take into account various criteria, such as the type of products or services provided to you, the nature and length of our relationship with you, mandatory retention periods, and applicable statutes of limitations.

More information regarding data protection is available under the University's [IT Policies, Guidelines, and Practices](#).

10. Third-Party Services

Our Services may contain features or links to websites and services provided by third parties. Any information you provide via these websites or services is provided directly to these third-party operators and is subject to their privacy policies, even if accessed through our Services. We encourage you to learn about these third parties' policies before providing them with your Personal Information.

11. Changes and Updates to this Statement

We may update this Statement from time to time to reflect changes in our privacy practices. We will follow applicable laws and regulations regarding notification of such changes.

12. How to Exercise Your Rights

Northwestern is the entity responsible for the handling of your Personal Information. If you have any questions, doubts, comments, or suggestions about this Statement, our privacy practices, or if you would like to exercise your rights with respect to your Personal Information, please contact us through our request portal, by email at **privacy@northwestern.edu** or in writing to:

Northwestern University
Attn: AVP Risk & Compliance
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Evanston, Illinois 60208

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