

Data Practices Policy:

Requests for Data About You and Your Rights as a Data Subject

Minnesota Statutes, sections 13.025 and 13.03 require this policy.

If your entity adopts this model policy, it must notify the Commissioner of Administration per Minnesota Statutes, section 13.073, subd. 6. Please use the notification information at the end of this model policy.

What is a “Data Subject”?

When government has information recorded in any form (paper, hard drive, voicemail, video, email, etc.), that information is called “government data” under the Government Data Practices Act (Minnesota Statutes, Chapter 13). When we can identify you in government data, you are the “data subject” of that data. The Data Practices Act gives you, as a data subject, certain rights. This policy explains your rights as a data subject, and tells you how to request data about you, your minor child, or someone for whom you are the legal guardian.

When The Minnesota Rare Disease Advisory Council Has Data About You

The Minnesota Rare Disease Advisory Council has data on many people, such as employees, job applicants, vendors, and public data (i.e., names and emails). We can collect and keep data about you only when we have a legal purpose to have the data. Admin must also keep all government data in a way that makes it easy for you to access data about you.

Government data about an individual have one of three “classifications.” These classifications determine who is legally allowed to see the data. Data about you are classified by state law as public, private, or confidential. Here are some examples:

Public Data

The Data Practices Act presumes that all government data are public unless a state or federal law says that the data are not public. We must give public data to anyone who asks. It does not matter who is asking for the data or why the person wants the data. The following are examples of public data about you that we might have:

Your email and mailing address; this could be used for reimbursement forms, tickets for agency events, appointment letters etc.

Private data

We cannot give private data to the general public. We can share your private data with you, with someone who has your permission, with our government entity staff whose job requires or permits them to see the data, and with others as permitted by law or court order. The following are examples of private data about you that we might have:

Your home and work mailing address.

Confidential Data

Confidential data have the most protection. Neither the public nor you can access confidential data even when the confidential data are about you. We can share confidential data about you with our government entity staff

who have a work assignment to see the data, and to others as permitted by law or court order. The following is an example of confidential data about you:

Personal addresses and contact information.

Your Rights Under the Government Data Practices Act

As a data subject, you have the following rights.

Access to Your Data

You have the right to look at (inspect), free of charge, public and private data that we keep about you. You also have the right to get copies of public and private data about you. The Data Practices Act allows us to charge for copies. You have the right to look at data, free of charge, before deciding to request copies.

Also, if you ask, we will tell you whether we keep data about you and whether the data are public, private, or confidential.

Access to Data on Minor Children

As a parent, you have the right to look at and get copies of public and private data about your minor children (under the age of 18). As a legally appointed guardian, you have the right to look at and get copies of public and private data about an individual for whom you are appointed guardian.

Minors have the right to ask us not to give data about them to their parent or guardian. If you are a minor, we will tell you that you have this right. We will ask you to put your request in writing and to include the reasons that we should deny your parents access to the data. We will make the final decision about your request based on your best interests.

When We Collect Data from You

When we ask you to provide data about yourself that are not public, we must give you a notice called a Tennessen warning. The notice controls what we do with the data that we collect from you. Usually, we can use and release the data only in the ways described in the notice.

We will ask for your written permission if we need to use or release private data about you in a different way, or if you ask us to release the data to another person. This permission is called informed consent.

If you want us to release data to another person, you must use the consent form we provide.

Protecting Your Data

The Data Practices Act requires us to protect your data. We have established appropriate safeguards to ensure that your data are safe.

In the unfortunate event that we determine a security breach has occurred and an unauthorized person has gained access to your data, we will notify you as required by law.

When Your Data are Inaccurate or Incomplete

You have the right to challenge the accuracy and/or completeness of public and private data about you. You also have the right to appeal our decision. If you are a minor, your parent or guardian has the right to challenge data about you.

How to Make a Request for Your Data

You can ask to look at (inspect) data at our offices, or ask for copies of data that we have about you, your minor child, or an individual for whom you have been appointed legal guardian.

Make a written request; you may make your request by emails. Also include whether requests should go to the Responsible Authority, a Designee, or someone else listed on page 6], using the data request form on page 8.

We recommend using the sample **Data Request Form – Data Subjects** on page 8. If you do not choose to use the data request form, your request should:

- Say that you are making a request as a data subject, for data about you (or your child, or person for whom you are the legal guardian), under the Government Data Practices Act (Minnesota Statutes, Chapter 13).
- Include whether you would like to inspect the data, have copies of the data, or both.
- Provide a clear description of the data you would like to inspect or have copied.
- Provide proof that you are the data subject or data subject's parent/legal guardian.

We require proof of your identity before we can respond to your request for data. If you are requesting data about your minor child, you must show proof that you are the minor's parent. If you are a legal guardian, you must show legal documentation of your guardianship. Please see the Standards for Verifying Identity on page 9. If you do not provide proof that you are the data subject, we cannot respond to your request.

How We Respond to a Data Request

Upon receiving your request, we will review it.

- We may ask you to clarify what data you are requesting.
- We will ask you to confirm your identity as the data subject.

If we do not have the data, we will notify you in writing within 10 business days.

- If we have the data, but the data are confidential or not public data about someone else, we will notify you within 10 business days and identify the law that prevents us from providing the data.
- If we have the data, and the data are public or private data about you, we will respond to your request by doing one of the following:
 - Arrange a date, time, and place to inspect data in our office, ensuring you have a meaningful opportunity to inspect data within 10 business days of your request at no charge
 - Tell you how much the copies cost, and then provide you with copies of the data within 10 business days and upon payment of charges for the copies. You may choose to pick up your copies or have us mail or email them to you. We will provide electronic copies (such as email or CD-ROM) upon request, if we keep the data in electronic format and we can reasonably make a copy.

We will provide notice to you about our requirement to prepay for copies. Following our response, if you do not make arrangements within 5 business days to inspect the data or pay for the copies, we will conclude that you no longer want the data and will consider your request closed.

- After we have provided you with your requested data, we do not have to show you the same data again for 6 months unless there is a dispute about the data, or we collect or create new data about you.

If you do not understand some of the data (technical terminology, abbreviations, or acronyms), please tell the person who provided the data to you. We will give you an explanation if you ask.

The Data Practices Act does not require us to create or collect new data in response to a data request, or to provide data in a specific form or arrangement if we do not keep the data in that form or arrangement. For example, if the data you request are on paper only, we are not required to create electronic documents to respond to your request. If we agree to create data in response to your request, we will work with you on the details of your request, including cost and response time.

In addition, we are not required to respond to questions that are not about your data requests, or that are not requests for government data.

Data Practices Contacts

Responsible Authority

Name: *Erica Barnes, Executive Director*

Address: *1600 University Avenue #8, St. Paul MN 55104*

Phone number/fax number/email address:

651-706-1960 / NA / erica.barnes@state.mn.us

As Responsible Authority, Erica Barnes, orders the following individuals as data practices compliance official and designees.

Data Practices Compliance Official

Name: Olivia Chiarelli, Operations Manager

Address: *1600 University Avenue #8, St. Paul MN 55104*

Phone number/fax number/email address

651-802-1516 / NA / olivia.chiarelli@state.mn.us

Data Practices Designee(s)

Name

Address

Phone number/fax number/email address

Copy Costs – Data Subjects

Minnesota Statutes, section 13.04, subdivision 3 allows us to charge for copies.

You must pay for the copies before we will give them to you. We charge \$0.10 per page for a black and white copy. Or \$0.20 per page for a colored copy.

Multiple requests made within the same 10 business-day period will be treated as a single request for the purposes of calculating total copy costs.

If possible, and upon request, we will provide you with an estimation of the total cost of supplying copies.

Actual Cost of Making the Copies

We will charge the actual cost of making copies for data about you. In determining the actual cost, we include the employee-time to create and send the copies, the cost of the materials onto which we are copying the data (paper, CD, DVD, etc.), and mailing costs such as postage (if any).

If your request is for copies of data that we cannot copy ourselves, such as photographs, we will charge you the actual cost we must pay an outside vendor for the copies.

Data Request Form – Data Subject

Request date: Contact information:

Data Subject Name:

Parent/Guardian Name (if applicable):

phone number/email address:

To request data as a data subject, you must show a valid state ID, such as a driver’s license, military ID, or passport as proof of identity.

The data I am requesting:

Describe the data you are requesting as specifically as possible:

I am requesting access to data in the following way:

- Inspection
- Copies
- Both inspection and copies

Note: Inspection is free, but The MN Rare Disease Advisory Council has the right to charge for the time and resources spent obtaining the requested data.

We will respond to your request within 10 business days

To Be Completed by Staff Member Responding to Data Request:

Identity Confirmed:

Date:

Staff Name: Erica Barnes, Executive Director

Standards For Verifying Identity

The following constitute proof of identity:

- An adult individual must provide a valid photo ID, such as
 - a driver's license
 - a state-issued ID
 - a tribal ID
 - a military ID
 - a passport
 - the foreign equivalent of any of the above
- A minor individual must provide a valid photo ID, such as
 - a driver's license
 - a state-issued ID (including a school/student ID)
 - a tribal ID
 - a military ID
 - a passport
 - the foreign equivalent of any of the above
- The parent or guardian of a minor must provide a valid photo ID and either
 - a certified copy of the minor's birth certificate or
 - a certified copy of documents that establish the parent or guardian's relationship to the child, such as
 - a court order relating to divorce, separation, custody, foster care
 - a foster care contract
 - an affidavit of parentage
- The legal guardian for an individual must provide a valid photo ID and a certified copy of appropriate documentation of formal or informal appointment as guardian, such as
 - court order(s)
 - valid power of attorney

Note: Individuals who do not inspect data or pick up copies of data in person may be required to provide either notarized or certified copies of the documents that are required or an affidavit of ID.

Notice of Adoption of Model Policies

[Minnesota Statutes, section 13.025, subdivisions 2 and 3](#), require government entities to prepare written policies that relate to public access to government data, and rights of subjects of data and [Minnesota Statutes, section 13.03, subdivision 2](#), requires entities to establish procedures so that data requests are complied with appropriately and promptly.

[Minnesota Statutes, section 13.073, subd. 6](#), requires the Commissioner of Administration to prepare [model policies and procedures](#) to help government entities comply with those requirements. Entities that choose to adopt the Commissioner’s model policies must notify the Commissioner. Please use the following statement to notify the Commissioner if you choose to adopt the model policies and procedures. *

Notice to Commissioner of Administration: Adoption of Model Policies

The Minnesota Rare Disease Advisory Council has adopted the Commissioner’s Model Policy for the Public and Model Policy for Data Subjects. This notice to the Commissioner satisfies The Minnesota Rare Disease Advisory Council s obligation under Minnesota Statutes, section 13.073, subdivision 6.

Erica Barnes, Executive Director

August 28, 2023

**Government entities may submit this notification by mail or email:*

Commissioner of Administration
c/o Data Practices Office
200 Administration Building
50 Sherburne Avenue
St. Paul, MN 55155
info.dpo@state.mn.us