FINGER LAKES REGION DATA REQUEST FORM

[Research]

PLEASE RETURN TO SARAH MCKINNEY (sarah\_mckinney@urmc.rochester.edu) IN PUBLIC HEALTH SCIENCES

Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Date: \_\_\_\_\_\_\_\_\_\_\_\_\_

**Details: Details/Comments:**

Requester phone number email

1

address

2

Department

Reason for Request

3

4

Date Desired

Format: Please, state your desired receipt format.

5

Research PI or who also will have

6

access to this data

*(internal use only)*

RSRB Approval (when needed) (please

7

attach copy to this form)

Data Agreement Signed

8

*(internal use only*)

Report Request Details: List of variables needed in the report or data, years needed and what specific

Region (hospital data, Monroe County or the entire region).

**Variable definitions are available through the Finger Lakes Region Perinatal Program web page,** [https://www.urmc.rochester.edu/finger-lakes-regional-perinatal-program.aspx](https://www.urmc.rochester.edu/finger-lakes-regional-perinatal-program.aspx%20)

|  |
| --- |
| **Years Requested:**  **Specific geographic area, region, hospital, etc:**  **Specific Data Requested:**  **Variables (see data dictionary):**  \*\*\*if you have any questions regarding this form, please contact Sarah McKinney\*\*\* |

FINGER LAKES REGION DATA USE AGREEMENT

[Research]

To receive Finger Lakes Regional Statewide Perinatal Data System data you must:

* Review the following conditions for data release.
* Sign this form and fax it, *along with a completed data request form*, to the Finger Lakes Region Perinatal Data System (585-461-4532) prior to receiving the requested database.

1. You have requested data from the Finger Lakes Region Statewide Perinatal Data System (SPDS). The SPDS data are collected from all birthing hospitals in the Finger Lakes New York Region. The NICU data are collected from all level II - IV hospitals in the region. It is critical that this information be released carefully and with all assurances of complete confidentiality.
2. This information may not be re-released by you under any circumstances without the prior approval of the Finger Lakes Region Statewide Perinatal Data System. This includes distribution of the data file or a subset of the data file, publication or public presentation that includes this data by any person other than the person signing this agreement.
3. This information has been released solely for the purpose of conducting research.

**You are not authorized to use this information for any use other than the approved study.**

1. If you are unfamiliar with the Perinatal Data System (PDS/NICU), it is strongly recommended that you involve a PDS/NICU expert to assist you with the interpretation of the data.
2. You may apply for permission to receive PDS/NICU data prior to receiving IRB approval but you must submit a signed IRB approval for your work prior to the actual release of data.
3. These data are for your exclusive use only. *You must maintain these files in a password protected file, accessible to you only*. Failure to comply with this agreement will precluded your access to additional PDS/NICU data and will be reported to authorities at your institution.

If you have any questions about any of the above requirements, or have any questions about the summary of data provided, please contact Sarah McKinney, sarah\_mckinney@urmc.rochester.edu

I understand and agree to comply with all URMC/Strong Health HIPAA policies regarding the use and disclosure of PHI.

Additional information on HIPAA requirements can be found on the URMC/Strong Health intranet site at http://intranet.urmc.rochester.edu/policy/HIPAA

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Researcher Date Ann Dozier, Ph.D. Date

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

Print Name

# University of Rochester

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Updated December 2019 by Sarah McKinney