NICU Data Sharing Manual

For Transported Infants

CPQCC

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INTRODUCTION

NICU Data Sharing is the process site that allows two or more NICUs that care for the same patient to share data about that patient with each other. This process ensures that all data that is submitted into CPQCC's NICU Database for transported infants is accessible only to the NICUs involved in the infant's care. This new functionality reduces the burden of accessing data for these infants and simplifies the data entry process. In addition, it increases data consistency and data quality, helping members to:

- Complete data items for transported infants
- Obtain follow-up status for infants transported out to another CPQCC NICU

Each NICU must decide whether to use the new functionality, and if they wish to use it, must activate it for their center. Data will not be shared from NICUs that do not activate Data Sharing, even if they share patients with other member centers. For the sake of brevity, so that we do not have to specify "for all NICUs that have activated Data Sharing" repeatedly, please assume that all NICUs mentioned in the rest of the document have activated Data Sharing.

NOTE: NICU data cannot be shared for CPQCC NICUs not participating in NICU data sharing, or Non-CPQCC NICUs.

Getting Started with NICU Data Sharing

- o **Sign the Data Sharing Agreement**

    - Download the Data Sharing Agreement from our website
    - Sign and submit it to Jessica Washington, our Program Assistant at jwash11@stanford.edu.

- o **Data Sharing must be turned on for your NICU**

    - Jessica will open a help ticket to request the NICU Data Center to turn on data sharing for your center
    - Log into the NICU Database to check your NICU Settings page to confirm that NICU Data Sharing has been turned on for your hospital (see below)

How To Access Shared Records

The first NICU to enter a new Admission/Discharge (A/D) form or CPeTS (Transport) form about a patient is called the **"source NICU"**. (Note: this does not have to be the birth hospital, or the first NICU to care for the patient). All other NICUs are then considered **"recipient NICUs"**.

- **As the "source NICU"**, patient data will be made available to other CPQCC NICUs that cared for the same infant, if the record includes the other NICU(s) listed as any of the following:
  - birth location
  - transport location
  - referring location
  - previous transport referring location
- **As the "recipient NICU"**, use the "Add via Shared Record [xx]" link in the left side menu bar of the NICU Data site to find records for shared infants.

When you are ready to enter data on a shared patient, you may not know yet whether another NICU has already entered a record for that patient (making you a "recipient NICU"), or if you will be the first to enter data (making you the "source NICU"). You can confirm whether or not a record was already entered for an infant by clicking the "Add via Shared Record" link and searching throught the list.

NICU Data Sharing is implemented on 2 levels:

1. **Group Users (Users with access to 2 or more NICUs)**

   Group Users can start a new A/D form or CPeTS record based on records already present for this infant at another NICU within their group. This level of sharing is restricted to the NICUs a user has access to, it does not go beyond this set of NICUs.

2. **NICU Data Sharing Users (Network – outside user's group)**

   NICU Data Sharing must have been formally agreed to by all NICUs who cared for the same infant to access each other's records. A **"recipient NICU"** can start a new A/D or

CPeTS record based on data already present for an infant at the **"source NICU"**. Sharing is restricted to those NICUs who were cared for the same infant, and evidence of the other NICU's involvement has to be present in the A/D or CPeTS of the **"source NICU's"** record.

NOTE: NICU data cannot be shared for CPQCC NICUs not participating in NICU data sharing, or Non-CPQCC NICUs

What NICU data items are shared?

- **Infant Demographics Items** 1-8, C.3-C.5, C.11, C.19, C.30-C.32
- **Maternal History Items** 9-18, C.7-C.8
- **Delivery Room Items** 19-23, C.9
- **Congenital Anomalies Item** 52, C.6
- **Disposition and Length of Stay Items** 57, 60, 62, 63, 65-67

How To Use Data Sharing

Add New Data – Source NICU

The source NICU adds a new record or updates an existing record and specifies another CPQCC NICU as birth location or transport location on the A/D form, or as birth location, referring hospital or previous transport referring hospital on the CPeTS form.
During data entry, the source NICU is made aware that – once saved – the record will be available as a source for infant level items through the addition of a note on the form.

NOTE: Double check data entry for birth location, transport location, referring location and previous transport referring location to ensure data is shared with the correct NICU.

Add via Shared Record [xx] link

Each time a source NICU submits an A/D or CPeTS form and it includes another hospital with a CPQCC NICU as birth location, transport location, referring location or prior transport referring location, and the Day of Life (DOL) at admission at the "recipient NICU" is 1 to 28 days, a sharing opportunity is registered. Note that these opportunities are updated each time the source NICU

makes changes (record deletion, birth location update, transport location update, length of stay (LOS) update, etc.).

Sharing opportunities for each NICU can be accessed through the Add via Shared Record [xx] sidebar link. Depending on the currently selected NICU, xx is replaced by the number of opportunities currently available based on the current user's NICU access and the NICU's global network sharing setting. If xx is 0, no opportunities are available. The number of sharing opportunities is updated constantly throughout a user's on-line session.

Clicking on the sidebar link Add via Shared Record [xx] opens a list of opportunities for the currently selected NICU.
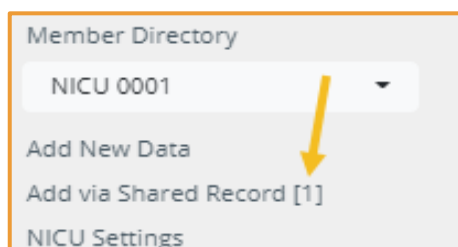
The list defaults to OUTSTANDING in the search filter, as part of the options below:

- OUTSTANDING – new and unsused records
- COMPLETED – records already used
- UNUSED – record has a 'cannot use reason' selected
- REVIEWED – record was either COMPLETED or UNUSED

Add New Record Via Shared Record - Opportunities

#	Source NICU Name (OSHPD ID)	Source NICU Record ID	Infant DOB	Infant BW	Multiple Status	How related?	DOL (?) Admitted at Your Hospital	Status	Cannot Use Reason
5	Demo NICU 0000 (000000)	01504	01-04-2020	3,500	Pending	Source indicates that your NICU's hospital is the birth location and that your NICU's hospital is a location that referred a transport.	1	New ID ○ Only A/D Form ○ CPeTS + A/D ☐ PDH Add 2020 Record	Click to select!

Showing 1 to 1 of 1 entries (filtered from 9 total entries)

For each opportunity, the following columns are shown:

- **Source NICU Name:** The name and OSHPD ID of the source NICU that entered a NICU Data record to initiate a sharing opportunity.
- **Source NICU Record ID:** The record ID at the source NICU.
- The infant's **date of birth, birth weight** and **multiple status**.
- **How Related?:** Explains how the sharing opportunity was identified based on the source NICU's A/D and/or CPeTS record.
- **DOL Admitted at Your Hospital:** The day of life on which the infant was admitted at the recipient NICU. For CPQCC big babies, a range is provided for the day of life as the infant might have been admitted any time between his/her birth date and the date of admission at the recipient NICU (if the recipient NICU is identified as the birth location).
- **Status:** The status column is where the recipient NICU can choose to accept the source NICU's record.

- **New ID:** Enter a record ID for the infant
- **Only A/D Form/CPeTS+A/D:** Check a radio box to indicate whether only an A/D form is needed or an A/D and CPeTS form
- **PDH:** If applicable, check the Previously Discharged Home (PDH) box indicating that the infant was discharged home prior to admission at the recipient NICU.
- **Add YYYY Button:** Creates a new form at the recipient NICU that has items on the Demographics, Maternal HX and DR tabs as well as any birth defects pre-loaded based on the source NICU's record.

- o If you choose not to accept the record, the last column can be used to identify a reason why the opportunity listed cannot be used. Using this column will update the count of sharing opportunities in the sidebar (Add Via Record [xx]).
  - ▪ If any reason is selected, the **Add YYYY Button** for adding the record at the recipient NICU is disabled.
- o Below are a list of options that can be used along with examples for using them.

Admitted after DOL 28 and **Not eligible, other** should be used to identify situations in which the infant was not eligible at the recipient NICU.

Never Admitted to the NICU should be used if the baby was never admitted to the recipient NICU.

Infant already entered should be used if a record linking to the source NICU's infant has already been manually entered. This situation might occur if the daily linkage update has not yet run after either of the infant's record were entered, or if that update missed identifying the match.

SIH, so far not eligible should be used for infants on the watch list for CPQCC eligibility. Typically, these are still-in-house big babies that have not yet qualified for the NICU Database collection.

PDH, never in NICU before should be used for situations in which the recipient NICU's hospital is identified as the birth location of an infant that was admitted to the source NICU after a previous discharge home, but was never admitted to the recipient NICU.

Never in this hospital should be used if the infant was never in the recipient NICU's hospital. **Reason not listed** should be used if the opportunity cannot be used for another reason that is not listed.

Reset selection should be used to reset the selection. For example, if an infant is SIH and not eligible when the sharing opportunity first comes up, the **SIH, so far not eligible** option might be selected. If during the infant's stay at the recipient NICU, the infant later qualifies, resetting the selection is necessary to be able to use information from the source record.

Accepting a Shared Record:

- o Accepting a shared infant record at the recipient NICU always opens an A/D form. The form comes pre-loaded with infant level data imported from the source NICU's record. Note that if CPeTS + A/D is selected, the CPeTS form will be pre-loaded as well.

- The recipient NICU is free to change any of the values imported. The record must be saved for the opportunity to be marked as completed and for this record to be added to your NICU's Edit Data list.

- o Once the record is saved, the sidebar link Add via Shared Record [xx] and the list of sharing opportunities are updated (e.g. if Add via Shared Record [10], it would now be Add via Shared Record [09])
- o It is possible to review the status of previously used opportunities by typing REVIEWED in the search bar.

Add New Record Via Shared Record - Opportunities

Show 10 ▼ entries   CSV

Search: REVIEWED 2020

# ▲	Source NICU Name (OSHPD ID)	Source NICU Record ID	Infant DOB	Infant BW	Multiple Status	How related?	DOL (?) Admitted at Your Hospital	Status	Cannot Use Reason
5	Demo NICU 0000 (000000)	01510	04-29-2020	3,209	Singleton	Source indicates that your NICU's hospital is the birth location.	1 to 24	New ID ○ Only A/D Form ○ CPeTS + A/D ☐ PDH Add 2020 Record	PDH, never in NICU before
6	Demo NICU 0000 (000000)	01502	01-02-2020	870	Singleton	Source indicates that your NICU's hospital is the birth location and that your NICU's hospital is a location that referred a transport.	1	Record ID 705 added through sharing on 05-20-2020 16:03.	
7	Demo NICU 0000 (000000)	01504	01-04-2020	3,500	Pending	Source indicates that your NICU's hospital is the birth location and that your NICU's hospital is a location that referred a transport.	1	Record ID 706 added through sharing on 05-21-2020 09:02.	
8	Demo NICU 0000 (000000)	01507	02-01-2020	2,499	Pending	Source indicates that your NICU's hospital is the birth location.	1	Record ID 701 linked on 05-20-2020 12:57.	
9	Demo NICU 0000 (000000)	01508	01-02-2020	1,489	2A	Source indicates that your NICU's hospital is a location that referred a transport.	1 to 3	Record ID 702 linked on 05-20-2020 12:57.	
10	Demo NICU 0002 (000002)	00701	01-02-2020	1,489	2A	Source indicates that this infant was transported from the source NICU to your NICU's hospital.	1	Record ID 702 linked on 05-20-2020 12:57.	

Showing 1 to 6 of 6 entries (filtered from 10 total entries)

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Network Info Tab

This shows up as the last tab in the Admission/Discharge form and includes sync buttons that can be used to update your NICU's record. This tab is available to NICUs with access to either group sharing or NICU Data sharing.

The screenshot below explains how infant level items in your NICU's record (cyan sync symbol) can be updated based on either one of the source NICU records. Note that you can only modify values on your own form but cannot modify values on the other NICUs' forms. Only items with non-missing information are synced.

- Click the **purple sync icon** to update my NICU's record (Demo Ctr A) with non-missing values for items 1-5, 7c, 9-23 and 52 from the previous NICU stay (Demo Ctr B)
- Click the **cyan sync icon** to reset my NICU's record (Demo Ctr A) for items 1-5, 7c, 9-23 and 52 back to the original values that I entered.
- Obtain follow-up information on where the baby was discharged and length of stay in the NICU by clicking on the boxes below to copy and pasted discharge dates into your record. In the example above, Demo Ctr A has coded information on disposition and LOS, allowing Demo Ctr C and Demo Ctr B to update their A/D forms' Transport-Out section.

	ID 1	ID 2	ID 3
NICU	Demo Ctr C (Satellite NICU)	Demo Ctr B	Demo Ctr A
Record ID at NICU (Last Update)	00701 (2020-03-23 12:5...)	00702 (2020-05-20 12:59...)	01508 (2020-03-25 13:19...)
Birth date / time	01-02-2020 / 13:56	01-02-2020 / 13:56	01-02-2020 / 13:56
Date of / Age @ Admission	01-02-2020 / 1 day	01-02-2020 / 1 day	01-04-2020 / 3 days
Birth Weight	1,489 grams	1,489 grams	1,489 grams
Gestational Age	32 weeks 0 days	32 weeks 0 days	32 weeks 0 days
Sex	Male	Male	Male
Birth Location	DEMO CENTER D (000003)	DEMO CENTER D (000003)	DEMO CENTER D (000003)
PDH / Re-Admit	Not Applicable	Never Discharged Home from a Hospital after Birth	Never Discharged Home from a Hospital after Birth
Multiple	2A	2A	2A
Mother's Birth Date / Age	04-14-1981 / 38 years	04-14-1981 / 38 years	04-14-1981 / 38 years
Delivery Mode	Cesarean	Cesarean	Cesarean
Initial Disposition	Transported	Transported	Home
Discharge Date / Initial LOS	01-02-2020 / 1 day	01-04-2020 / 3 days	03-15-2020 / 72 days
Transport Location	Demo Ctr B (000001)	Demo Ctr A (000000)	
Disposition after Transport	Pending	Pending	
Disposition after Re-Admission			
Final Disposition			
Final Discharge Date/ Total LOS	Pending	Pending	
Previous Transport Referring Location	No CPeTS form	NOT APPLICABLE (777777)	Demo Ctr C (Satellite NICU) (000002)
Referring Location	No CPeTS form	Demo Ctr C (Satellite NICU) (000002)	Demo Ctr B (000001)

Purple sync = update my record based on non-missing infant level items in that NICU's record

Cyan sync = reset my record to all non-missing infant level items at load

Network connections last updated May 16, 2020

Add New Data – Recipient NICU

Another option is to add a new shared record by providing the "Source NICU" record information directly. To do this, you need to specify the following by following the prompts when adding a new record:

- Select Yes if the infant stayed at another NICU
- Select the NICU where the infant stayed (only NICUs participating in Data Sharing can be selected)
- Enter the infant's Record ID at that NICU
- Enter the birth weight in grams

Note: If you select your own NICU, you'll need to check the Previously Discharged Home (PDH) box

How To Identify Linked Records

You can identify linked records in the second column of the Edit Data section, which is the link column.

- The <u>solid</u> teal dot indicates that a record is currently shared and visible in the Network Info tab, which we just reviewed.

- The <u>pale</u> teal dot indicates that a record is currently shared, but that the other NICU(s) have not entered their record for that infant yet. So in this case, your NICU is the source NICU and this record will be listed in the other NICU's list of sharing opportunities.

Please contact the CPQCC Help Desk if you have any questions.