



Getting Started with Transported Patient Data Sharing

What is Data Sharing?

Data Sharing is a new feature on the CPQCC NICU Data site that allows two or more NICUs that care for the same patient to share data about that patient with each other. This simplifies data entry and increases data consistency and quality, helping members to:

- Complete data items for transported infants
- Obtain follow-up status for infants transported out to another CPQCC NICU
- Make patient data consistent across NICUs.

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.

➔ **Activate Data Sharing by signing the authorization letter, found on NICU Data Resources, and emailing it to CPQCC.**

➔ **Check to see if your NICU has activated Data Sharing on the NICU Data site at “NICU Settings”:**

Settings for NICU 0000 (NICU Member)

NICU ID:	0000
NICU Name:	Demo Center 'A'
NICU Name (shortened, used in labels):	Demo Ctr A
NICU Name (used in menus):	Demo Ctr A
First year of Participation:	2000
CCS Level(s) for 2006 or later:	2006: Regional · 2007: Regional · 2008: Regional · 2009: Regional · 2010: Regional · 2011: Regional · 2012: Regional · 2013: Regional · 2014: Regional · 2015: Regional · 2016: Regional · 2017: Regional · 2018: Regional · 2019: Regional · 2020: Regional
Perinatal Region:	00.0 - Demo Region
IDs used for this NICU:	CPeTS Transport ID (OSHPD ID): 000000 VON Hospital ID: 99999 HRIF Program ID: 9999 CDPH Maternity Hospital ID: None
Satellite NICU:	Main NICU with 1 satellite NICU CPQCC participant: Demo Center C (Satellite of A at non-CPQCC member D)
May submit EDS files?	EDS submissions enabled for 2019 and 2020. EDS password: Test2.14
Users for cpqccdata.org: Suspended (if any) / Primary users	Demo, A (demo0000); Pickle, Joe (jpickle); User, Demo (DEMOUser).
NICU Users for cpqccreport.org: Suspended (if any) / Primary users	Gupta, Munish (mugupta); Kaplan, Heather (hkaplani); Nisbet, Courtney (cnsibet); Pickle, Joe (jpickle); User, Demo (DEMOUser).
HRIF Users for cpqccreport.org: Suspended (if any) users	No HRIF users have access to HRIF reports for this center on cpqccreport.org.
Access on cpqccreport.org to this NICU's perinatal region	Arora, Vasudha; Bain, Lisa; Braun, David; Davis, Alexis; Gupta, Munish; Jegatheesan, Priya; Joe, Priscilla; Kaplan, Heather; Morton, Christine; Nisbet, Courtney; Payton, Kurlen; Paz, Pedro; Pickle, Joe; Rogers, Elizabeth; Sey, Rachelle; Slagle, Terri; User, Demo; VanWoerkom, Richard.
Data Sharing guide user's NICU group	Data sharing turned ON .
QI Projects:	Breast Milk Nutrition (2009-2011): No Health-care Associated Infections (2008-2009): No Delivery Room Management (2011-2012): No Length Of Stay (2013-2015): No Antibiotic Stewardship (2016-2017): No Grow, Babies, Grow! (2018-current): No
Miscellaneous:	Children's Hospital: No Optional DCC (2016/7): Yes VON expanded DS: No MATEX DB: Yes MBSEI DB: Yes Delivery Room Oxygen: Yes
Comment:	
Responsible NICU Data Center Agent:	Fulani Davis (fdavis@stanford.edu)

Logon to www.cpqccdata.org and go to NICU Settings to confirm whether Data Sharing is on or off.

To turn data sharing on or off, please submit a help ticket to www.cpqcchelp.org.



How Does It Work?

The first NICU to enter data 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 “recipient NICUs”.
- As the “source NICU,” patient data will be made available to other CPQCC NICUs if the infant has 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 new “Add via Shared Record” menu item on NICU Data to find records for shared patients. You can then use their data to start your own record.

HOW DO I ACCESS NICU DATA SHARING?

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).

To find out whether this infant has already been entered, select “Add via Shared Record” from the NICU Data menu. This will display a list of records for infants whose care your NICU participated in. Use birth date, weight and location to identify the correct record, and

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 or CPeTS form based on forms 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**

NICU Data Sharing Users can start a new A/D or CPeTS form based on forms already present for an infant at another NICU that has agreed to NICU Data Sharing. NICU Data Sharing must have been formally agreed to by both NICUs. Sharing is restricted to infants who were cared for by both NICUs, and evidence of the other NICU's involvement has to be present in the A/D or CPeTS form.

HOW IS DATA SHARING FACILITATED?

There are three options available to obtain infant level items for a specific record from a source NICU:

1. 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.

NICU ID: 0001 Record ID: 00701 Birth Year: 2020 DOB: 02-01-2020 BW: 2499 GA: 32/1 NICU Data Eligible Infant

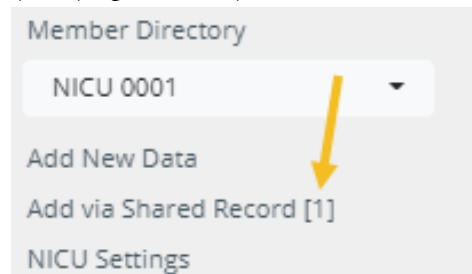
Demographics Items 1-8	Maternal HX Items 9-18	DR Items 19-23	Respiratory Items 24-39	Infections Items 40-42	Other DX/PX Items 43-47	Neurological Items 48-51	Anom. / Bill Items 52-55	Disposition Items 56-60	Transport-Out Items 61-67	Network Info
Post-Transport Status										
<i>Complete items 61-63 if this infant was transported to another hospital.</i>										
61. Reason for Transport <input type="text" value="Medical/Diagnostic Services"/>										
62. Hospital the infant was transported to: <input type="text" value="Demo Center A (000000)"/>										
<i>Note: Your NICU and the NICU at the transport location both have agreed to data sharing. Saving the record will give the NICU at the transport location access to items 1-23, item 52 and disposition information.</i>										
63. Post-Transport Disposition <input type="text" value="..."/>										

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.

2. The Network Info tab on the A/D form allows syncing of infant-level items across NICUs that participated in the care of the same infant.
3. The source NICU communicates with the recipient NICU and provides the record ID and infant birth weight at the source NICU.

Adding a New Record to link to an existing record at another NICU

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.



← Add New Record Via Shared Record - Opportunities

Show 10 entries CSV Search: OUTSTANDING

#	Source NICU Name (OSHDP 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	<input type="radio"/> Only A/D Form <input type="radio"/> CPeTS + A/D	<input type="checkbox"/> PDH	<input type="button" value="Add 2020 Record"/> <input type="button" value="Click to select"/>

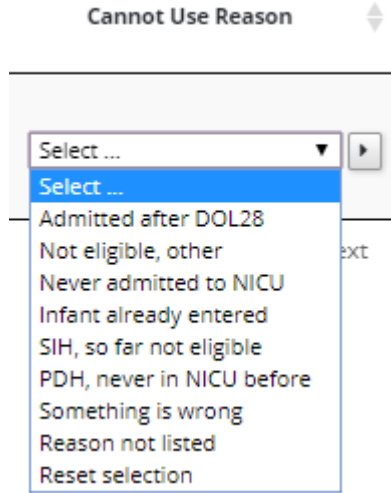
Showing 1 to 1 of 1 entries (filtered from 9 total entries) Previous 1 Next

The list loads with the search filter set to OUTSTANDING, in other words, only new opportunities are listed. The other search filter options are COMPLETED (sharing opportunity used), UNUSED (cannot use reason selected) or REVIEWED (either COMPLETED or UNUSED).

For each opportunity, the following columns are shown:

- The name of the source NICU that entered a NICU Data record that initiated the sharing opportunity.
- The record ID at the source NICU.
- The infant's date of birth, birth weight and multiple status.
- How the sharing opportunity was identified based on the source NICU's A/D and/or CPeTS record.
- The implied DOL on which the infant was admitted at the recipient NICU. For CPQCC big babies and if the recipient NICU is identified as the birth location, a range is provided for the DOL as the infant might have been admitted any time between his/her birth date and the date of admission at the source NICU.
- Form to enter a record ID for the infant at the recipient NICU. The form requires the specification of a record ID, checking a radio box indicating whether only an A/D form is needed or an A/D and CPeTS form, and possibly checking a Previously Discharged Home (PDH) box indicating whether the infant was discharged home prior to admission at the recipient NICU. Clicking on the Add YYYY Button initializes 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.

- The last column can be used by the recipient NICU to identify a reason why the opportunity listed cannot be used. Using this column will update the count of sharing opportunities in the sidebar.



If any reason is selected, the form button for adding the record at the recipient NICU is disabled.

The options **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.

The option **Infant already entered** should be used if a record linking to the source NICU's infant has already been 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.

The option **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.

The option **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.

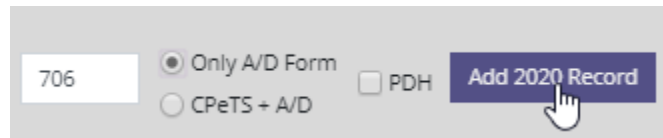
The option **Something is wrong** should be used if the recipient NICU is unable to identify the infant based on the information provided.

The option **Reason not listed** should be used if the opportunity cannot be used for another reason that is not listed.

The last option **Reset selection** should be used to reset the selection. As an example, if an infant is SIH and not eligible when the sharing opportunity first comes up, the SIH, so far not eligible option is selected. During the infant's stay at the recipient NICU, the infant qualifies. At this point, resetting the selection is necessary to be able to use information from the source record.

Adding a new infant record at the recipient NICU always opens an A/D form. The form comes pre-loaded with infant level items 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.

NICU ID: 0001 Record ID: 706 Birth Year: 2020 DOB: 01-04-2020 BW: 3500 GA: 39/1 Infant Not NICU Data Eligible

- Demographics
Items 1-8
- Maternal HX
Items 9-18
- DR
Items 19-23
- Respiratory
Items 24-39
- Infections
Items 40-42
- Other DX/PX
Items 43-47
- Neurological
Items 48-51
- Anom. / Bill
Items 52-55
- Disposition
Items 56-60
- Transport-Out
Items 61-67

Demographics

1. Birth Weight grams
2. Head Circumference at Birth cm Not Done Unknown
3. Best estimate of gestational age a) Weeks Unknown b) Days: Unknown
4. Date of Birth Time of Birth Unknown
5. Infant Sex
6. Died in Delivery Room
7. a) Location of Birth

Note: For infants who were previously home, always check Outborn, even if the infant was born at your hospital or - for satellite NICUs - was born at the co-located hospital.
- b) Age in Days at Admission to your NICU
- c) Select hospital of birth for outborn infants

Once the record is saved, the sidebar link Add via Shared Record [xx] is updated. Opening the Add via Shared Record list reflects the updated list of sharing opportunities.

Add New Record Via Shared Record - Opportunities									
Show <input type="text" value="10"/> entries	<input type="button" value="CSV"/>		Search: <input type="text" value="OUTSTANDING"/>						
#	Source NICU Name (OSHDP ID)	Source NICU Record ID	Infant DOB	Infant BW	Multiple Status	How related?	DOL (?) Admitted at Your Hospital	Status	Cannot Use Reason
No matching records found									
Showing 0 to 0 of 0 entries (filtered from 9 total entries) Previous Next									

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 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 <input type="radio"/> Only A/D Form <input type="checkbox"/> PDH <input type="checkbox"/> Add 2020 Record <input type="button" value="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) Previous 1 Next

Network Info Tab

- For NICUs with access to either group sharing or NICU Data sharing, the A/D form Network Info tab lets users import infant-level information and inspect disposition information (e.g. discharge dates, LOS etc.) in instances where the same infant visited multiple CPQCC NICUs.

Demographics Items 1-8	Maternal HX Items 9-18	DR Items 19-23	Respiratory Items 24-39	Infections Items 40-42	Other DX/PX Items 43-47	Neurological Items 48-51	Anom. / Bill Items 52-55	Disposition Items 56-60	Transport-Out Items 61-67	Network Info	
			ID 1	ID 2	ID 3						
			Demo Ctr C (Satellite NICU)	Demo Ctr B	Demo Ctr A						
			Record ID at NICU (Last Update)	00701 (2020-03-23 12:57)	00702 (2020-05-20 12:58)	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)					

Network connections last updated May 16, 2020

Mark this record as deleted Allow Errors to be written to CPQCC DBs

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

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

The screenshot above explains how infant level items in the current NICU's record (cyan sync symbol) can be updated based on either one of the source NICU records. Note that the current



NICU can only modify values on their own form but cannot modify values on the other NICUs' forms. Only items with non-missing information are synced.

The Network Info tab can also be used to obtain follow-up information on where the baby was discharged and length of stay in the NICU. 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.

Add New Data by Providing Source Record Information Directly

The third option for starting a NICU Data Sharing record is by importing it from a source NICU's existing NICU record ID. To do this, you need to specify the source NICU, source NICU record ID and infant birth weight by following the prompts when adding a new record.

Add New DRD, A/D or CPeTS Record Eligibility Help

CPeTS Acute Inter-facility Transport: Was the infant transported to your NICU within 28 days of life, who requires medical, diagnostic, or surgical therapy that is not provided, or for 2018 that cannot be efficiently provided due to temporary staffing /census issues, or due to insurance restrictions at the referring hospital? Yes No

Note that starting from 2019, an infant transported solely for insurance reasons or staffing/census issues is not considered an acute transport!

[Acute Transport-in: The infant is eligible for data submission.](#)

To start the process of submitting data on-line, check birth year of infant, enter record ID, and retrieve the correct form. Note that you will only be able to continue if you check the birth year and enter a valid record ID!

Birth Year: 2019 2020 NICU ID: 0000 Record ID: Last 3 Record IDs Entered: 1510 1509 1508

Has this infant stayed at another NICU, and if so do you know the record ID number and birth weight for this infant for this NICU? Yes No

NICU: Record ID at this NICU: Birth Weight: PDH

When starting the A/D form or CPeTS form, infant-level items are imported from the source record into the newly started forms. This option allows starting with either the CPeTS or the A/D form. This option is also available if the relationship between the source and recipient NICU is more complicated. For instance, the recipient NICU might see this infant at readmission after being previously being discharged home from the source NICU.



DATA SHARING QUESTIONS & ANSWERS

Q: Are all my records automatically shared?

A: Records for infants that were cared for at your NICU and other NICUs are shared automatically if you identify any other CPQCC member NICU as the birth location, transport location, referring location or previous transport referring location on an A/D or CPeTS form with an implied admission age of 1 to 28 days. The A/D and CPeTS forms both show a note reminding you of data being shared underneath the location item(s) that may "trigger" sharing.

Q: How can I see which of my records are shared?

A: You can identify all records shared by reviewing your Edit List. Used sharing opportunities are marked with a teal dot; records available for sharing are marked with a light teal dot.

Q: How do I find sharing opportunities for my NICU?

A: You can identify records shared with you by clicking on the Add via Shared Record [xx] link in the sidebar of the NICU Data website. The [xx] information in the sidebar provides a quick check whether any sharing opportunities are available to you. This information is constantly updated while you are logged on.

Q: What data is being shared?

A:

- 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

Q: Will my data be updated by other NICUs' data automatically?

A: No. The link to other NICUs' data allows you to sync items from another NICU's record to your NICU's record, but you retain control over how each item is coded. Nothing is updated automatically.

Q: Can I turn data sharing off?

A: Yes. Data sharing is optional and can be turned off at any time. Please let the Data Center know you would like this turned off by submitting a help ticket to www.cpqcchelp.org