



North Dakota Long-term Follow-up Program

Lessons Learned





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ND Fun Facts:

- ND holds the Guinness World Record for the most snow angels made simultaneously in one place
- ND is the #1 producer of honey in the nation
- Lake Sakakawea has more shoreline than the California Pacific Coast
- 4 of 12 birthing facilities deliver over 60% of the babies born in ND
- Approximately 12,000 babies per year

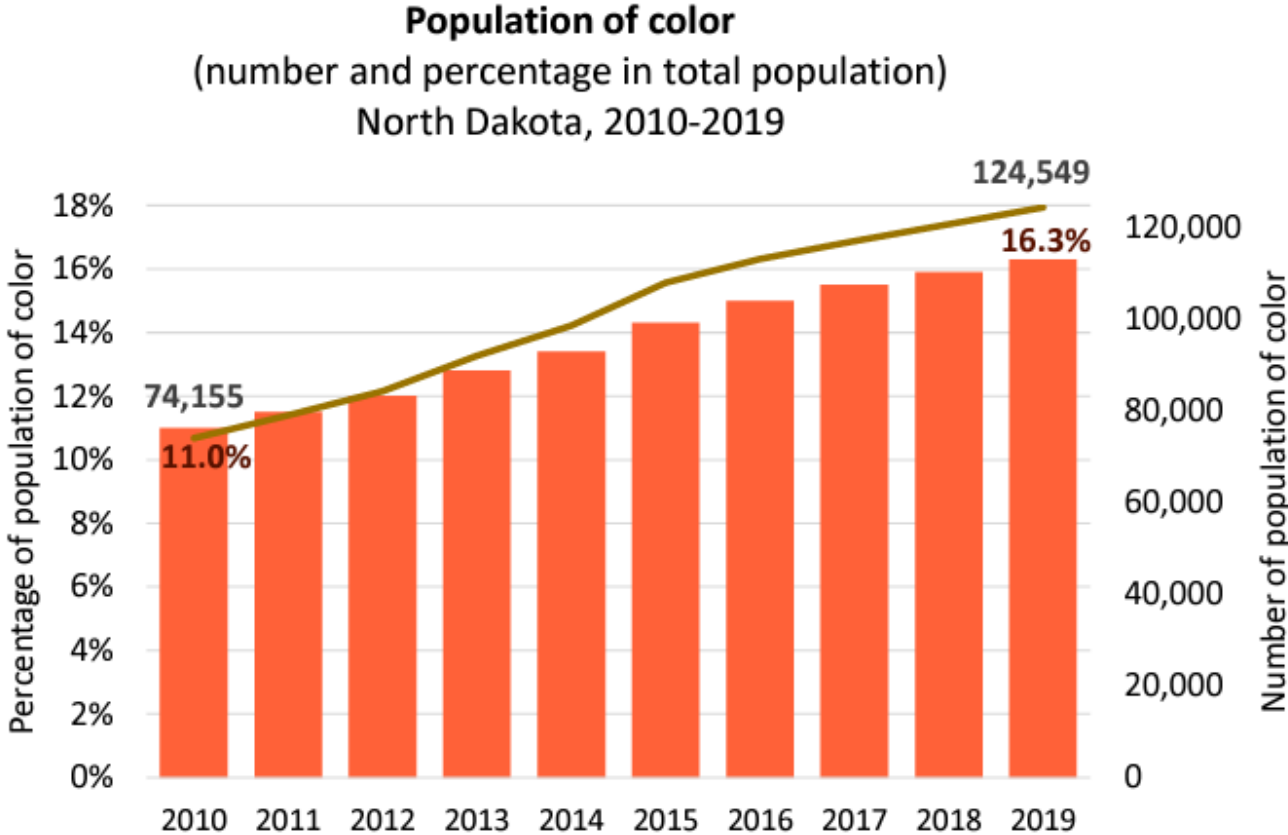




North Dakota Births 2011 to 2021

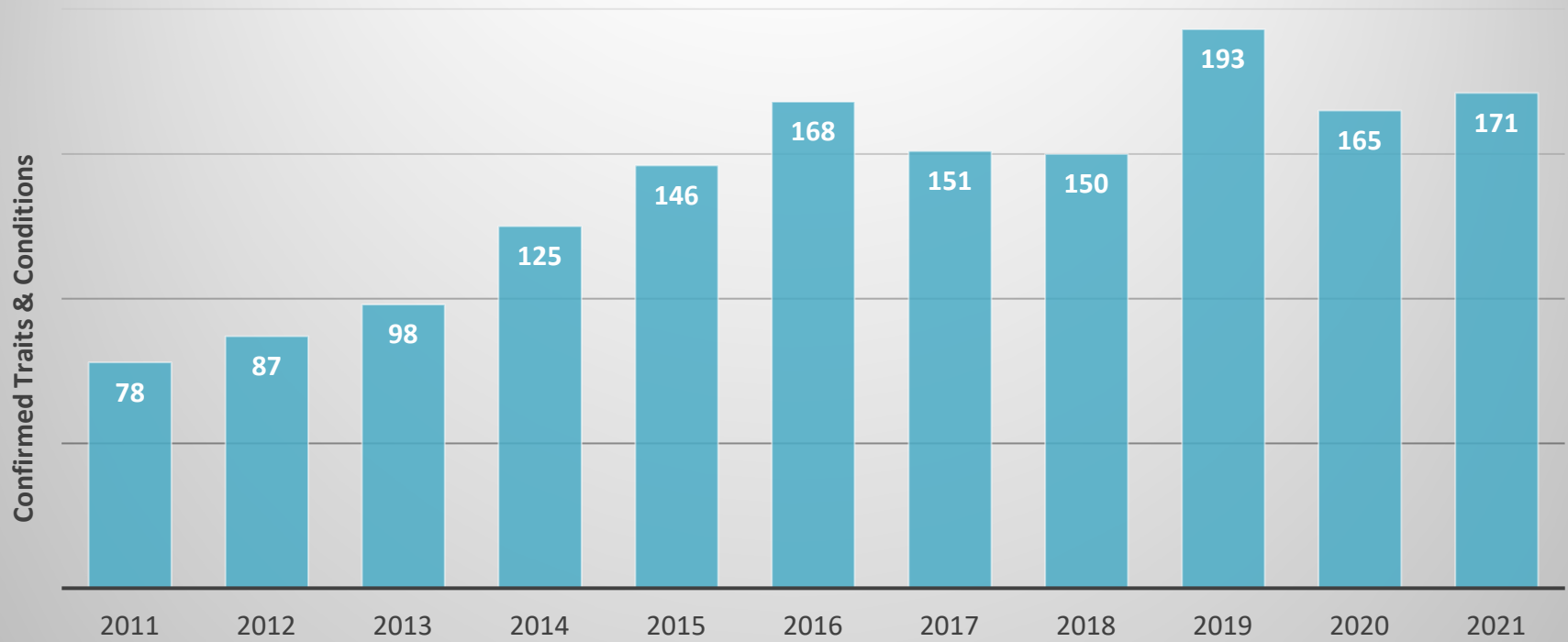


North Dakota Compass, March 2021





North Dakota Newborn Screening Traits & Conditions



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The 5 Whys

Define the Problem



Why is it happening?



Why is that?



Why is that?



Why is that?

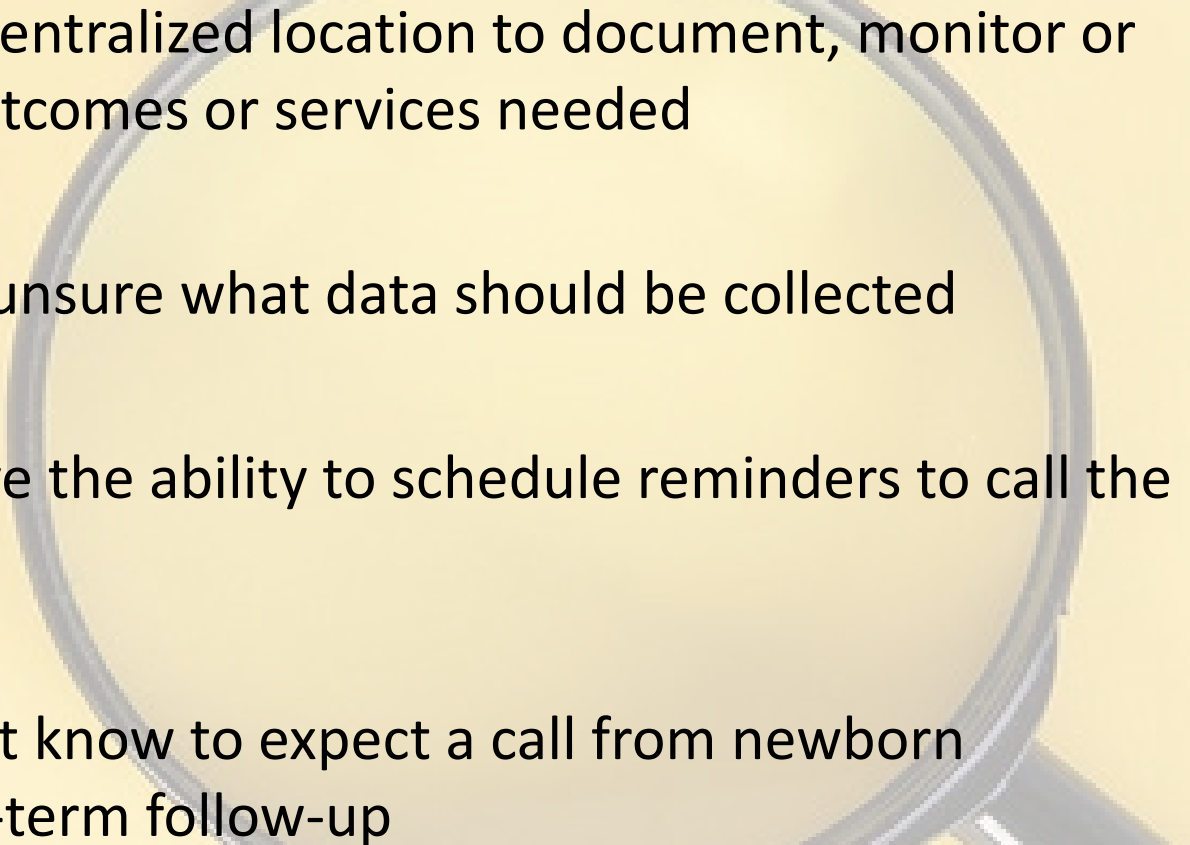


Why is that?

Root Cause



North Dakota's "WHY"

- There was no centralized location to document, monitor or track health outcomes or services needed
 - Our team was unsure what data should be collected
 - We did not have the ability to schedule reminders to call the families
 - Families did not know to expect a call from newborn screening long-term follow-up
- 

The background of the slide features a top-down view of several hands of different skin tones reaching towards the center, holding together a circular arrangement of light blue puzzle pieces. The overall tone is bright and collaborative.

Long Term Goals

- To provide quality care coordination for families
- To gather necessary data to inform programmatic development and improvement
- To provide meaningful feedback to specialty providers to drive improved patient care



Activities

1. Build an IT care coordination/case management system for long-term follow-up.
2. Build a system to reduce lost to follow-up for patients with a positive newborn screen to improve long-term follow-up.
3. Revise education materials to include all components of NBS, highlighting the importance of long-term follow-up.



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Where We Started...

- Approach to Long-term Follow-up was still in development
- Initially: Started with Maven, but had to abandon this
- End product – ND Health Information Network Care Coordination Pathway/Module



State Health Information Network

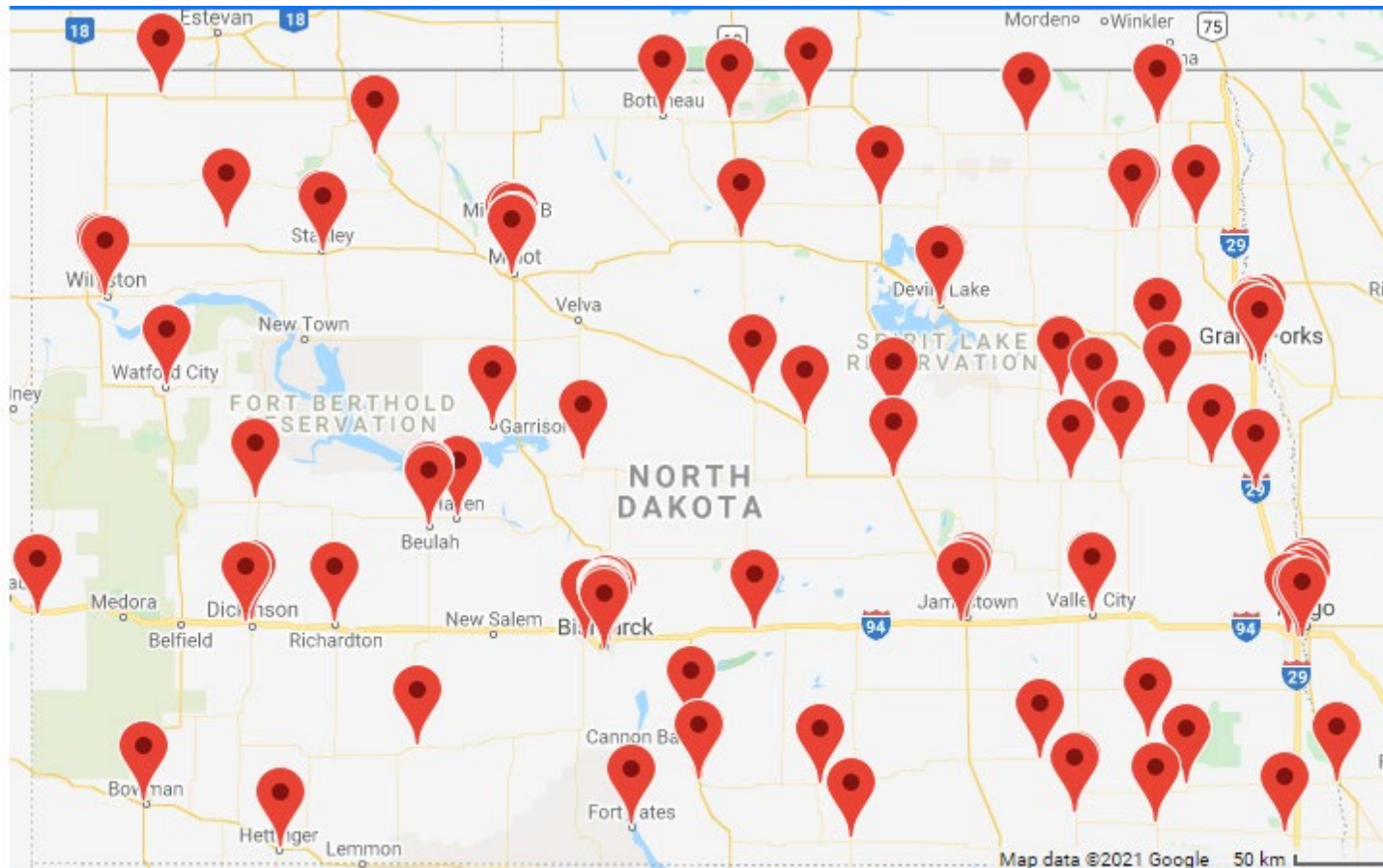
- The North Dakota Health Information Network (NDHIN) is a public / private partnership of health care stakeholders charged with expanding the secure exchange of health information in the State of North Dakota.
 - Clinical Portal
 - Search/query patient information
 - Communicate
 - Direct Secure Messaging email
- Enables authorized clinical users to view a patient's unified longitudinal health record across organizations
- Only statewide HIN in North Dakota



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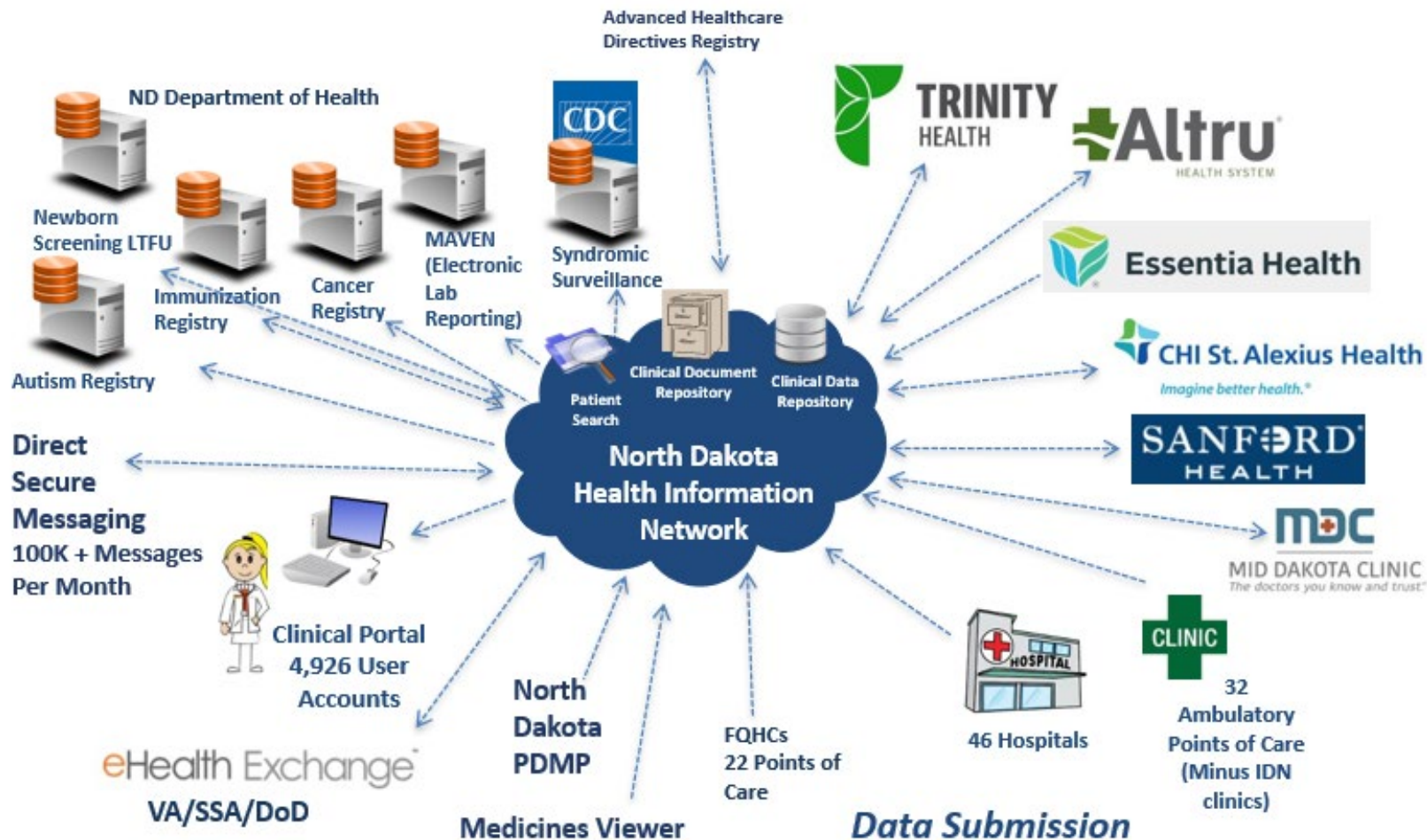
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2022 NDHIN Snapshot



- All ND Acute Care Hospitals, FQHCs & RHCs
- Adding ancillary providers- chiro, public health, EMS etc.
- 1.4M Unique Patient IDs
- Data feeds increased from 361 feeds in 2018 to 676 feeds in 2022

NDHIN

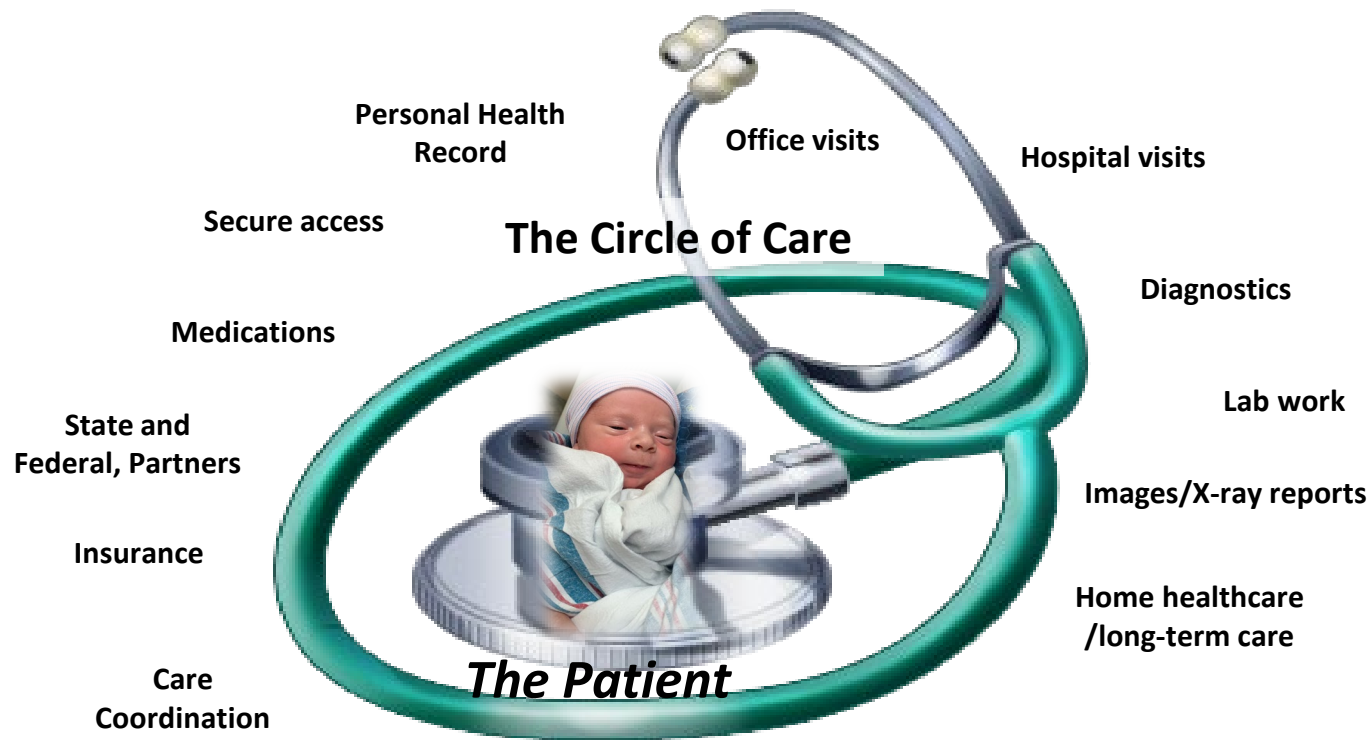


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It's All About the Patient



Module Layout

Collaborative Worklists

- Recent Patients
- Patient Search
- All Collaborative Worklists
- Subscribed Notification Patients

WORKLISTS

- Shared
- Awaiting Call Back
- Jeanette's Test List**
- Unconfirmed NBS Case >30 days

NOTIFICATIONS

- System
- Newborn Screening

TASK LIST

MESSAGING

Jeanette's Test List ☆

Shared with 5 users

Filter List

	Patient ID	Name ^	DOB (Age)	Newborn Screening	Notes
<input type="checkbox"/>	ABD-43277-4	NBSPATIENT5, 5years2mos	01-Oct-2016 (5y 9m)	Jul-11-2022	!
<input type="checkbox"/>	ABE-66090-8	NBSSMOKETEST14, 5years2months	01-Oct-2016 (5y 9m)	Jun-16-2022	
<input type="checkbox"/>	ABD-43284-7	NBSSMOKETEST2, 2years2months	04-Oct-2019 (2y 9m)	May-17-2022	

POWERED BY ORION HEALTH

+ Create List

Home Page for Cases

NBSPATIENTS, 5years2mos SEX Male DOB Oct-01-2016 (5y 9m)

Amy BURKE

- Coordinate
- Patient Summary
- Medicines Viewer
- Timeline
- External Record
- Pathway
- Images
- Circle of Care
- Laboratory Results Flow Sheet

- Coordinate Summary
- Care Plan
- Medications
- Notes and Dates
- Problem List
- Quick Comments

Pathway Enrollment

Pathways

Newborn Screening

Enrolled by Jeanette POLASCHEK on Jul-11-2022 (3 days ago)
[Deactivate](#)

ACTIVE

Showing 1 of 8 [Show Inactive](#)

Contact Note

Contact Note

Contact note type	Contact reason	Comment	Created by	Date and time	Status
Important event			Jeanette POLASCHEK	Mar-31-2022 12:10	DRAFT
Patient call	Initial call	No voice mail. Will try again	Amy BURKE	Mar-30-2022 12:59	COMPLETE
Patient call	initial call	some test	Jeanette POLASCHEK	Dec-18-2021 16:19	COMPLETE

[Download CSV results](#)

Incomplete Tasks

Task Name	Create Date	Status	Assigned To	Due
NBS Follow Up Actions	Jul-11-2022	New		Jul-18-2022
NBS Patient Follow Up	Jul-11-2022	New		Jul-28-2022

[Download CSV results](#)

Communication Preferences

Communication Preferences	Value
Primary Language	Spanish
Interpreter Needed?	No
Language Comments	
Preferred Phone Number	(702) 555-5555
Preferred Mailing Address	5 nbspatient5 avenue, BOWBELLS, ND, 58721, null
Preferred Email	iheartnbs@gmail.com
Preferred Contact Method	Phone call
Preferred Contact Times	Anytime
Permission to Text?	Yes
Permission for Social Media?	Yes

Medications

- Summary
- Schedule
- Full Review
- List History

Medications Summary

Last updated by Jeanette POLASCHEK on Dec-18-2021 16:19

Out of date medication data, last updated Dec-18-2021 16:19.

Insurance

Insurance	Value
Primary Insurance	Private

Durable Medical Equipment

Durable Medical Equipment	Value
Assistive Devices	

Unique Considerations

Transportation

Furthest distance traveled (one way) to reach specialty providers less than 1 hour 1-2 hours 2-3 hours 3-4 hours > 4 hours

Distance traveled (one way) to reach primary care provider less than 1 hour 1-2 hours 2-3 hours 3-4 hours > 4 hours

Is time off work required? Yes No

Transportation Comments

Add transportation barriers to Problem List Alerts.

[Top](#) | [Bottom](#)

Services

Current Services Care coordination services DD Services Early Intervention Food assistance Genetic testing for child Genetic testing for parent or carrier Insurance In-state services Medically Fragile Out-of-state medical services Out-of-state referral Reproductive Health/Fetal Medicine Respite care Right Track Social Services Telehealth services Transportation assistance Waivered Services WIC Other

Perceived level of support from current services Fully supported Somewhat supported Not supported

Current Services Comments

Needed Services Care coordination services DD Services Early Intervention Food assistance Genetic testing for child Genetic testing for parent or carrier Insurance In-state services Medically Fragile Out-of-state medical services Out-of-state referral Reproductive Health/Fetal Medicine Respite care Right Track Social Services Telehealth services Transportation assistance Waivered Services WIC Other

Needed Services Comments

Financial Coverage Program SHS Diagnostic Services SHS Treatment Services Other

Has family received special circumstances info? Unique immunization Physical observation Unique child care Other

Patient Follow Up

Patient Disposition * Continue follow up Lost to follow up Family does not want to participate Child expired Other

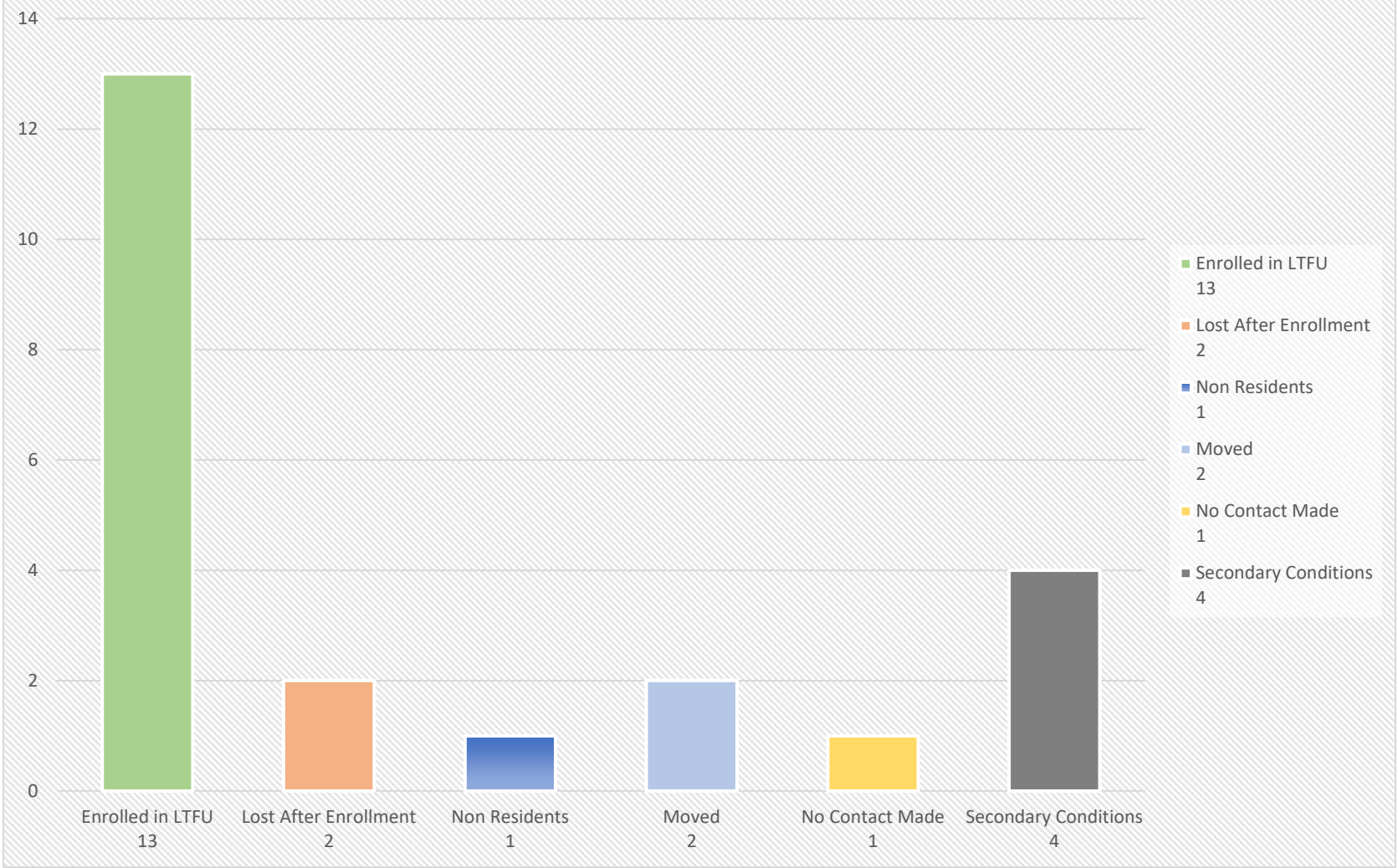
Patient Follow Up Date



Specialist are located in far eastern ND (with a few outreach clinics in central ND). Distance and extreme weather can cause difficulty for many families needing specialty care.



2021: 23 Confirmed Cases



Newborn Screening Brochure

BLOOD SPOT SCREENING

- A** Every baby born in North Dakota is required by state law to complete the newborn blood spot screening, which is a blood test that identifies nearly 50 disorders.
- B** Babies with these disorders may look and act like a healthy newborn, but may have a medical condition that could cause serious illness, disability, or death.
- C** Treatments are available for all the disorders screened for and most babies who are identified early can grow up to be healthy. Ongoing family support is available at no cost.

WHAT IS NEWBORN HEARING & PULSE OXIMETRY SCREENING?

HEARING SCREENING

Identifies possible hearing loss in your baby. The screening can be done while your baby is awake or sleeping. Hearing professionals use these important 1-3-6 Benchmarks below:

- 1** Before **1 month** of age: Hearing Screening
- 3** Before **3 months** of age: Hearing Evaluation
- 6** Before **6 months** of age: Early Intervention

PULSE OXIMETRY SCREENING

Measures the amount of oxygen in your baby's blood and can help detect a variety of serious heart problems. This may also be known as Critical Congenital Heart Disease (CCHD) screening. The goals of pulse oximetry screening include:

- 1** Early identification of a concern with your baby's heart, before symptoms occur
- 2** Early diagnosis of a heart condition
- 3** Early intervention with medications or possible surgery

Both screenings are completed before discharge and the results are available immediately.



NEWBORN SCREENING, STEP-BY-STEP



CONGRATULATIONS, BABY IS BORN!



The blood spot, hearing and pulse oximetry screenings are done to check your baby's health.



After a few drops of blood are taken from your baby's heel and placed on a blood spot card, the card is sent to a lab for processing. At the lab, special equipment tests the blood spots. Your baby's blood is tested for nearly 50 disorders.



The results of the hearing and pulse oximetry screenings are available immediately and will be shared with you before you take your baby home. Blood spot results will be sent to your baby's primary care provider.



Your health care provider will give you the blood spot results when they are available.

NORMAL RESULTS

If everything looks ok, the results are sent to your baby's health care provider. Ask for your baby's results at the first newborn visit!

ABNORMAL RESULTS

If there is a concern, the lab will call your baby's health care provider. Screening can only tell if your baby **MIGHT** have a health concern; we won't know for sure until your baby has more testing. Your baby's health care provider will talk to you about what needs to happen next.

CONGRATULATIONS ON THE BIRTH OF YOUR BABY!

May your journey
be filled with support,
love, and warm cuddles.



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Congratulations on your new baby!

Through a blood test (called newborn screening) that was done at birth, your baby was found to have a condition that needs special treatment. We understand that you may not be aware of the many community supports that are available to help you and your baby. These supports can include (but are not limited to): Family Voices of ND, Right Track/ Early Intervention, WIC, and/or Medicaid.

We are here to help connect you with resources that can help your child and your family. In the next few weeks, a nurse will call from a Department of Health phone number and talk with you about this information and answer any questions you have.

If you have any questions before the nurse calls you or if you need interpreter services, please contact us at **1-800-755-2714** or **701-328-2436** or visit <https://nbs.health.nd.gov>.

We look forward to working with you to help your child grow up to be healthy.

Sincerely,

North Dakota Newborn Screening Staff



NBS Welcome Card

ENGLISH: In order to best serve you, interpreter services are available upon request.

SPANISH (LA): A fin de servirle mejor, los servicios de interpretación están disponibles a solicitud.

FRENCH: Afin de mieux vous servir, des services d'interprétation sont disponibles sur demande.

RUSSIAN: По запросу доступны услуги переводчика в целях обеспечения наилучшего обслуживания.

NEPALI: तपाईंलाई सर्वोत्तम सेवा दिनको लागि, अग्रह अनुरूप दोभासे सेवाहरू पनि उपलब्ध छन्।

SOMALI: Si sida ugu fiican laguugu adeego, adeegyada turjubaanka ayaa la heli karaa markii la codsado.

SWAHILI: Ili kuwahudumia bora zaidi, huduma za ukalimani zinapatikana kwa ombi.

ARABIC: بلطالما دنع تيو فشرنا تمجرتنا تامدخ حانت، ولتتم توي رطب لغت مدخل.

BOSNIAN: Kako bismo vam pružili najbolje usluge, usluge prevodjenja će vam biti dostupne na zahtjev.

KURDISH: اواد رهگه ئی، ناپزئگرمو یی رازوگت سبزخ، نینکب تنه مزخ موئیش نیرتشاراب هب نیناوتب یهوه ئی و ب هتسرحدهب هل، هتئیرکب.

FULANI: Ngam huuwa neeki ma no woodata, kuude nantinoobe do waagi to dabbitida.

HAITIAN CREOLE: Pou sèvi-ou pi byen, sèvis entèprèt yo disponib sou demann.

CHINESE: 为了给您最好的服务，口译服务可按需提供。

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Car Seat Sticker



**CHILD
EMERGENCY
CONTACT
MEDICAL ID
CARD
ENCLOSED**

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Please use this **EMERGENCY INFORMATION** card/adhesive pouch on your child's car seat. Be careful to not cover up any car seat safety instructions. Place the pouch either on the side or back of the car seat in an area free from car seat safety information. In emergencies, young children are most often transported to a medical facility in a car seat so this information is important. *Be sure to read the instructions on the back of the pouch.

NAME	
NICKNAME	BIRTH DATE
PARENT/GUARDIAN	PHONE
EMERGENCY CONTACT	PHONE
MEDICAL PROVIDER	PHONE
ALLERGIES	
MEDICAL INFORMATION	

Newborn Screening Follow-Up Program

Resources and Referrals

EARLY INTERVENTION/ INFANT DEVELOPMENT (EI)

This free program provides services for children between birth and age three who meet certain criteria; (e.g., physical therapy, speech). Your primary care provider or newborn screening follow-up nurse can make a referral, or you can contact the Human Service Center nearest you for more information.

Web: [Click here](#)

FAMILY VOICES OF NORTH DAKOTA (FVND)

FVND is a family-led organization that works directly with families who have children with special health care needs. They also offer one-to-one matches with other families who have similar needs and experiences. Your newborn screening follow-up nurse can make a referral, or you can contact FVND directly.

Web: [Click here](#)

Email: fvnd@drtel.net

Phone: 1-888-522-9654

NORTH DAKOTA MEDICAID (NDMA)

Once enrolled in EI, your child automatically qualifies for ND Medicaid (not income dependent) through age three. This is available even if you have other insurance coverage for your child. It can help cover additional out of pocket expenses not covered by primary insurance. If your child is eligible for EI and Medicaid, they may also qualify for the Women's Infant's & Children (WIC) nutrition program. Contact your EI worker for assistance to complete the necessary paperwork.

Web: [Click here](#)

SPECIAL HEALTH SERVICES FINANCIAL COVERAGE PROGRAM

This program can provide coverage for testing and services that promote early diagnosis and treatment to children with special health conditions, who meet eligibility criteria. There are separate diagnostic and treatment criteria. Your newborn screening follow-up nurse can make a referral, or you can contact them directly.

Web: [Click here](#)

Phone: 701-328-2436

NORTH DAKOTA ASSOCIATION FOR THE DISABLED (NDAD)

This non-profit organization can help with various medical supplies (for purchase or loan) and provide transportation, gas, food, and/or lodging assistance, if needed. *If you have ND Medicaid, you will need to contact them first and then NDAD can help with what is not covered by ND Medicaid.

Web: [Click Here](#)

FIRST LINK

This is free/confidential service available 24/7 for listening, support and referrals for various resources and programs across the state (food, housing, utility, transportation, etc.). A Directory of Community Resources is available on the website.

Web: [Click here](#)

Phone: 2-1-1 or 701-235-7335

PATHFINDER

This is a parent support and resource group. Pathfinders provides educational trainings and information for parents/guardians as they navigate life with a child who has special needs (ages birth to 26).

Web: [Click Here](#)

Email: info@pathfinder-nd.org

Phone: 701-837-7500

COORDINATED TREATMENT CLINICS

There are multidisciplinary clinics (e.g., Metabolic, Cleft Lip/Palate, Cardiac) that are intended to provide access to pediatric specialty care and enable families to see many different medical providers and other health care professionals in one place at one time.

Web: [Click Here](#)



School-Based Services (*Transition from Part C to Part B*): Information For Families

After turning three years old, a child with special needs may need to transition from the Department of Human Services (NDDHS) to the Department of Public Instruction (NDDPI), as they may be eligible for certain supports and/or services from the school. This transition process is a team effort that involves the child, their family, their current service providers (Early Intervention/Part C), and those who will provide services in the future (Department of Public Instruction/Part B). More information can be found in [Understanding Early Childhood Transition: A Guide for Families and Professionals](#).

What is a 504 Plan?

- A 504 plan ensures that a child who attends school and has a disability or medical condition will receive any needed accommodations to ensure their academic success. An example of this would be if your child has cystic fibrosis and needs medical treatments during the school day.
- More information on a 504 Plan is available here: [Section 504 Federal Law](#).

What is an Individualized Educational Program (IEP)?

- An IEP is a program or plan that ensures a child who has a disability and is attending an elementary or secondary school receives specialized instruction and related services. An example of this would be if your child has a speech delay and needs ongoing speech-language services.

What is an Individualized Health Plan (IHP)?

- An IHP is a plan that is developed by the school (or local public health) nurse and parents and is designed for children who require more complex school nursing services. The IHP gives the school necessary medical information about the child, identifies their specific needs, creates solutions for potential problems that could happen in the school environment, and plans for emergency medical situations. This plan is reviewed at least annually and can be changed to meet the student's individual health care needs.
- More information on an IEP and IHP can be found here: [ND Parent Guide to Special Education](#).

What if My Child is on a Medical Diet?

- If a child is on a medical diet or needs dietary accommodations, they will need a medical statement to request school meal modification. The form to make this request can be found on the NDDPI website here: [School Meal Modification](#).



Highlights

- Great Teamwork
- Established new relationships and enhanced communication
- Collaborated with various partners
- Established Data Set
- Decreased lost to follow-up rate from 46% (2019) to 13% (2021)
- We are PDSA Pros who know how to make run charts!



Lessons Learned

1. The RIGHT Project (Long Term Follow Up Was Needed)
2. The RIGHT People (Our Team is AMAZING)
3. The RIGHT Product (It Meets Our Needs)
4. The RIGHT Funding (APHL grant opportunity)
5. The RIGHT Timing (funded FTE to support follow up)



Here's Where We Are Headed...

- Module Enhancements
- Build Reports
- Continue to improve patient outcomes
- Program Improvements



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Special Thanks



Special Health Services



**ND Medicaid
ND Part C**

