



Developing NBSChat: A Digital Education Tool for Sickle Cell Trait Follow-Up

December 10, 2025

1:00 - 2:00 pm ET

Moderator

- **Courtney Sumby, MS**, Association of Public Health Laboratories
Senior Specialist

Today's Webinar

This webinar will highlight the development and evaluation of NBSChat, a scripted chatbot designed to provide accessible education and emotional reassurance for parents receiving SCT results. Learn how participatory design and mixed-methods research informed this innovative digital health intervention aimed at improving NBS follow-up care. The session will include a live demo of NBSChat, showcasing its features and usability.

Objectives

1. Summarize the participatory design process used to develop a digital health intervention resource for newborn screening follow-up.
2. Describe how NBSChat addresses parental information needs and emotional reassurance following sickle cell trait results.
3. Discuss preliminary usability findings and implications for integrating digital tools into NBS follow-up care

Speakers

- **Karen Eilbeck, PhD**, Professor, Biomedical Informatics, University of Utah
- **Courtney Gauchel, RN-BSN, MS**, APHL Newborn Screening Fellow, University of Utah

Participatory Design of a Chatbot for Sickle Cell Trait Newborn Screening Results

University of Utah

Courtney Gauchel, MS; Guilherme Del Fiol,
MD, PhD; Kim Kaphingst, ScD; Anne Madeo,
MS, Karen Eilbeck, PhD



The initial spark for the project

Utah Department of Health and Human Services

Scoping the work for max impact:

- In Utah in 2022
 - Number screened: 46,754
 - Confirmed diagnosis: 676
 - 544 Hemoglobinopathies
 - 3 disease
 - 541 traits = 80%
- Test fee is \$200 = minimal budget

Psychosocial distress & Uncertainty

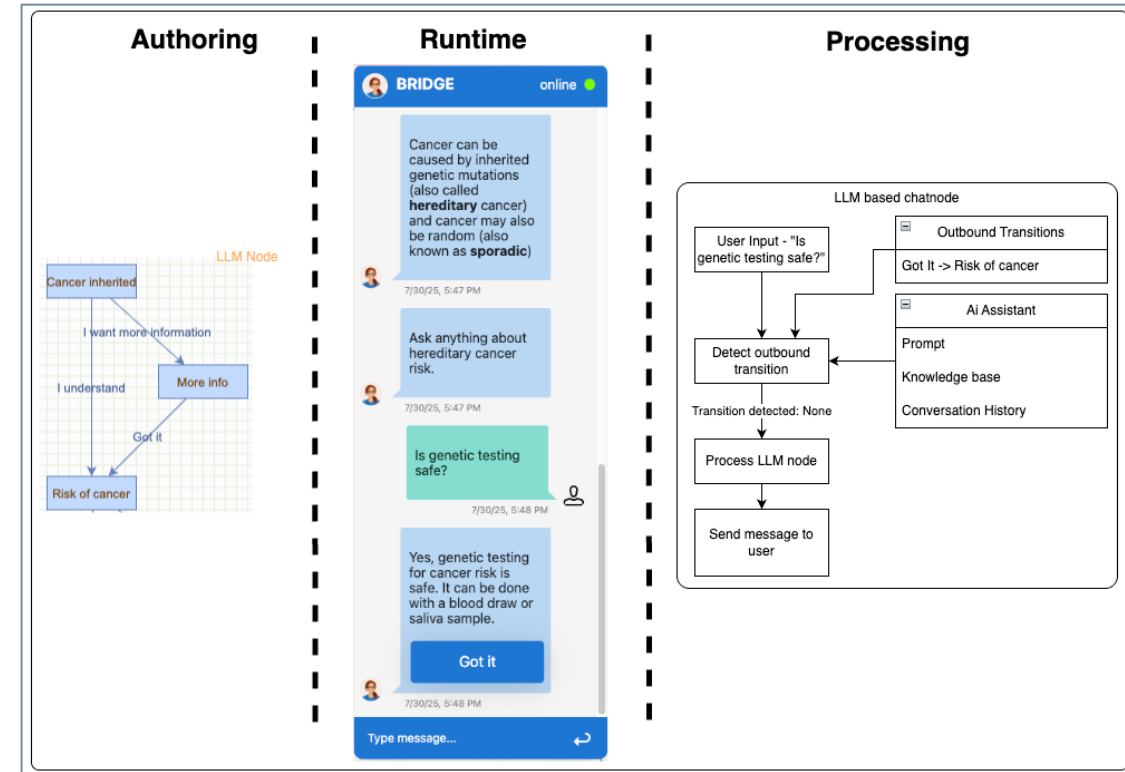
Text messaging

Chatbot?



GARDE-chatbot platform

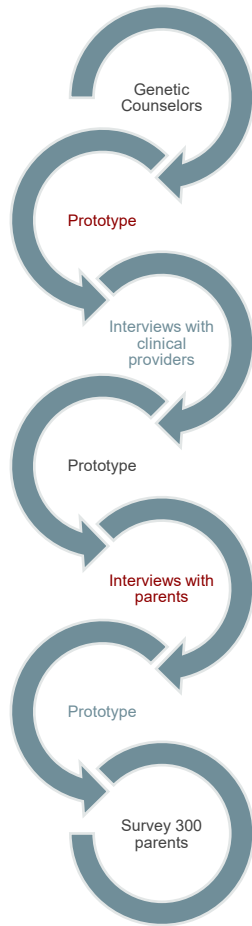
Study/project description	Domain	Implementation approach	Study type	Status	Setting and sample size
Pre- and post-test education and test facilitation of genetic testing for hereditary cancer (GARDE-Chat used to create an open-source version of the BRIDGE trial chatbot)[24]	Cancer genetics	GARDE algorithms integrated with population registry in Epic® EHR and MyChart patient portal. Chatbot interactions and patient decisions about genetic testing stored in the EHR.	Pragmatic clinical trial	C	University of Utah Health and New York University Langone Health (N=3,073 patients)
Education and access to free, mailed, at-home COVID-19 test kits (SCALE-UP II trial)[25]	Infectious diseases	Eligible patient cohorts obtained from multiple EHR systems via data reports. Chatbot interactions and patient decisions about test kits tracked in study dashboard.	Pragmatic clinical trial	C	Utah Community Health Centers (N=33,556 patients)
Bundled intervention providing education and access to state tobacco <u>quitline</u> , and services addressing social needs (REI-UT trial)	Disease prevention	Eligible patient cohorts obtained from multiple EHR systems via data reports. Chatbot interactions and patient decisions tracked in study dashboard. Chatbot delivered via SMS.	Pragmatic clinical trial	E	Utah Community Health Centers (N=1,560 patients from persistent poverty census tracts)*
Education and access to telehealth-based shared-decision making for lung cancer screening (<u>LungSMART</u> trial)	Cancer screening	Eligible patient cohorts obtained from multiple EHR systems via data reports. Chatbot interactions and patient decisions about test kits tracked in study dashboard.	Pragmatic clinical trial	D	Utah Community Health Centers (N=18,994 patients)*
Education and access to online evidence-based weight management program (<u>SMARTLife</u> trial)	Disease prevention	Eligible patient cohorts obtained from multiple EHR systems via data reports. Chatbot interactions and patient decisions tracked in study dashboard. Chatbot delivered via SMS.	Pragmatic clinical trial	D	Utah Community Health Centers (N=5,354 patients)*
Pre- and post-test education and test facilitation of genetic	Cancer genetics	GARDE algorithms integrated with population registry in	Pilot observational study	E	Primary care patients at Medical



- Scripted
- AI
- Hybrid option

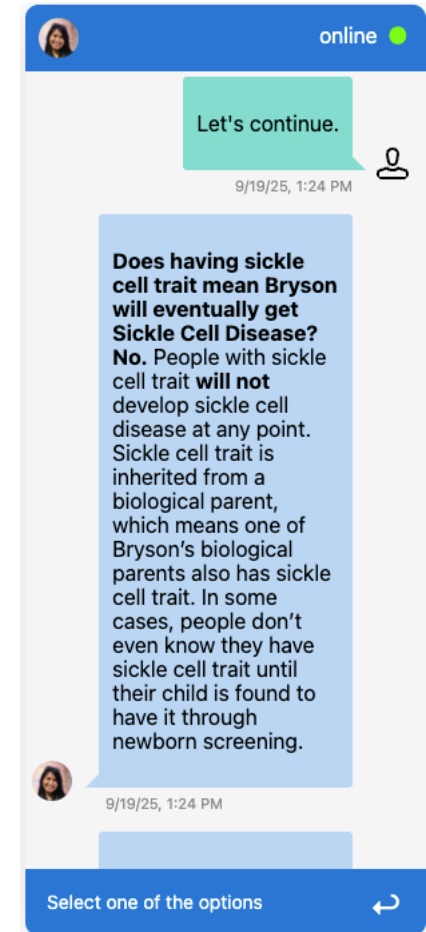
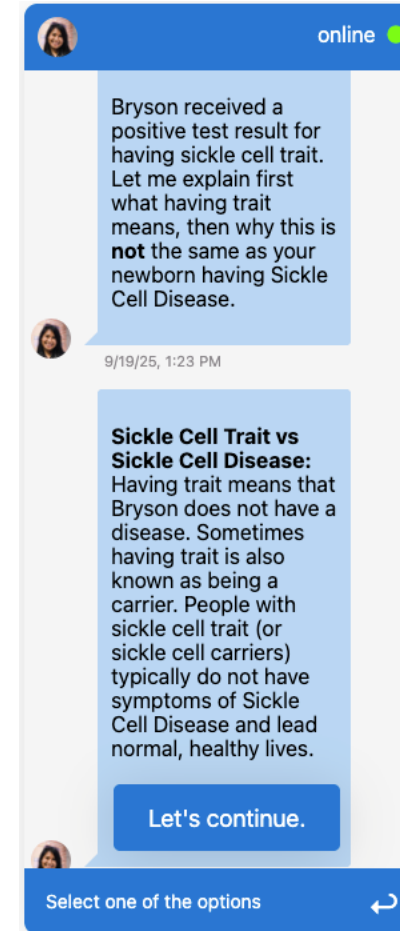
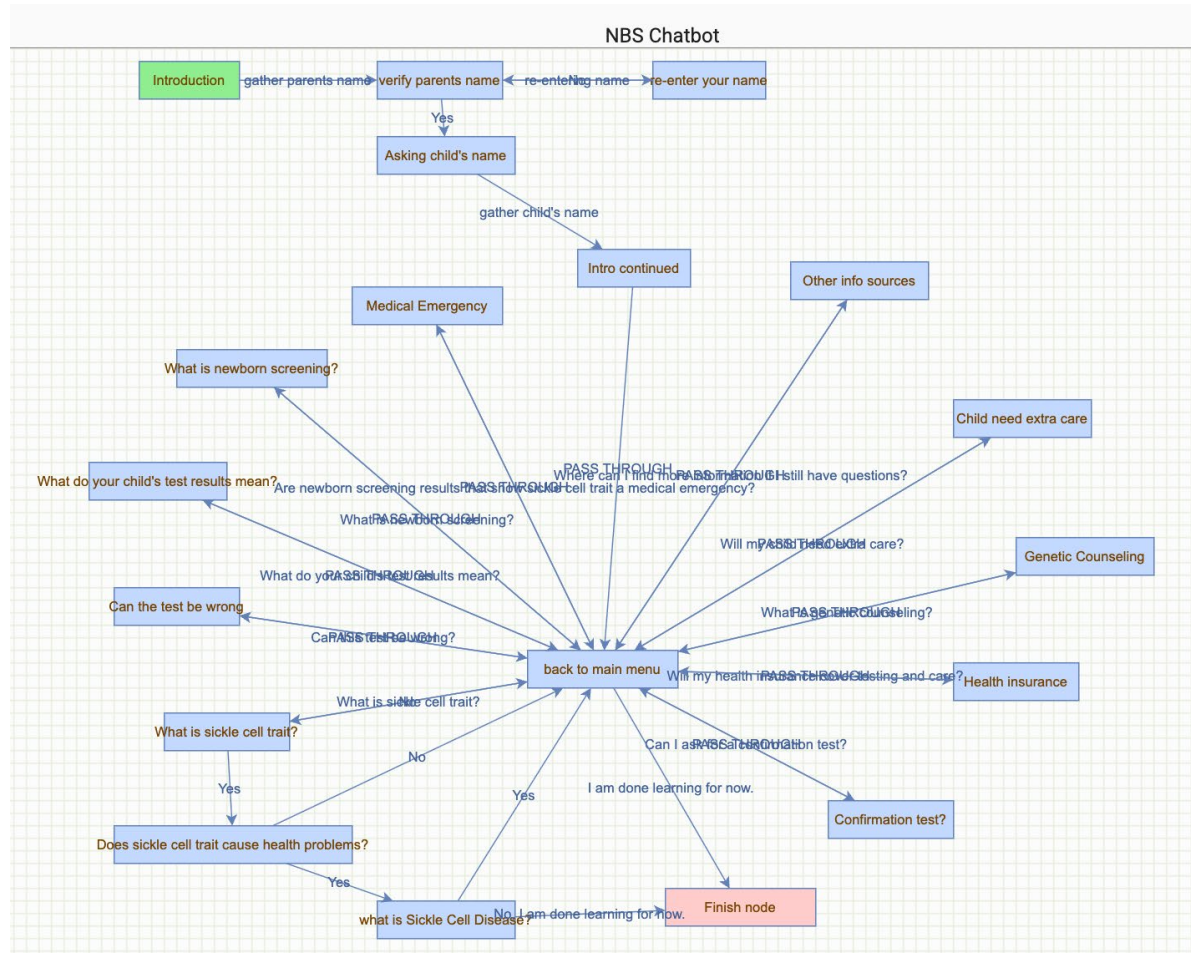
GARDE is an open-source software platform that supports the design and implementation of various interventions designed to promote patient engagement, education, and access to services, including PHM interventions

Iterative Development of Scripted Chatbot



1. Developed a prototype with Amy Gaviglio as our content expert.
2. Use the prototype to frame the conversations in interviews, using the critical incident technique and think aloud with parents and providers
3. Modified the chatbot accordingly
4. Embedded in a Qualtrics survey and used validated instruments to measure uncertainty, negative and positive emotions and self efficacy

Qualitative: Interviews with parents and GCs



Qualitative: Parents' Reactions

- “It seemed very compassionate .”
- “The additional information is helpful because parents will have unanswered questions. As a worried parent, we would rather have immediate answers rather than waiting for a follow-up with a medical professional.”
- “It was useful to have different options to choose from on what you wanted to know. I liked that it gave detailed information on the topic and also other topics that may be of interest.”



Quantitative: 300 parents across the US

INSTRUCTIONS: The following questions ask about how you **would feel** after reading this letter about your child's newborn screening results. Please indicate how much you would expect to have each specific feeling after reading the letter by choosing one answer for each question.

None at all A little Somewhat A good deal A great deal

How **upset** would you feel about the newborn screening result?

☐ ☐ ☐ ☐ ☐

How **happy** would you feel about the newborn screening result?

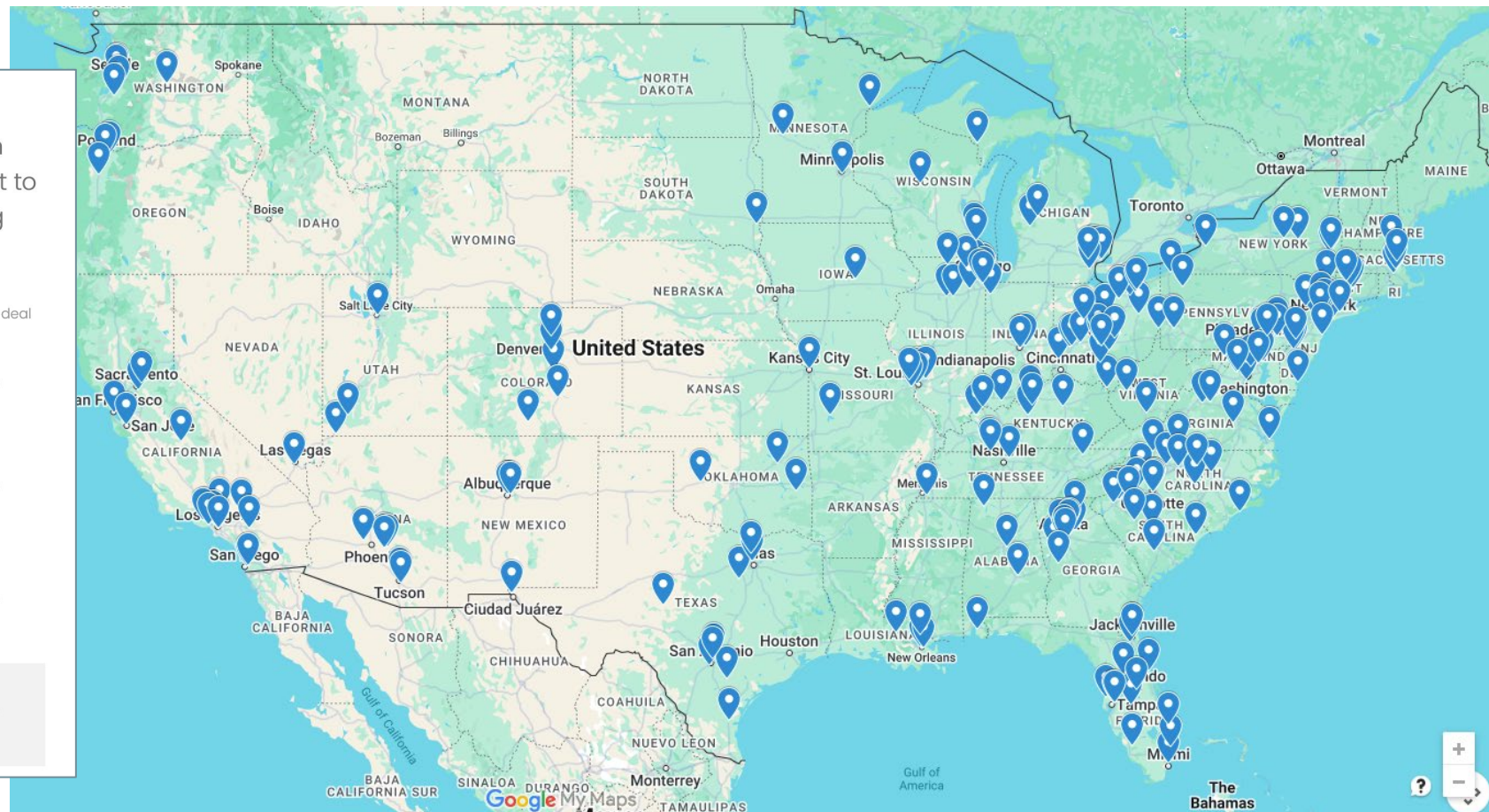
☐ ☐ ☐ ☐ ☐

How **anxious or nervous** would you feel about the newborn screening result?

☐ ☐ ☐ ☐ ☐

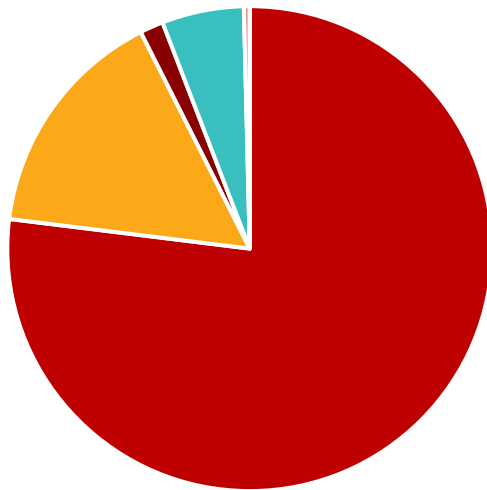
How **relieved** would you feel about the newborn screening result?

☐ ☐ ☐ ☐ ☐



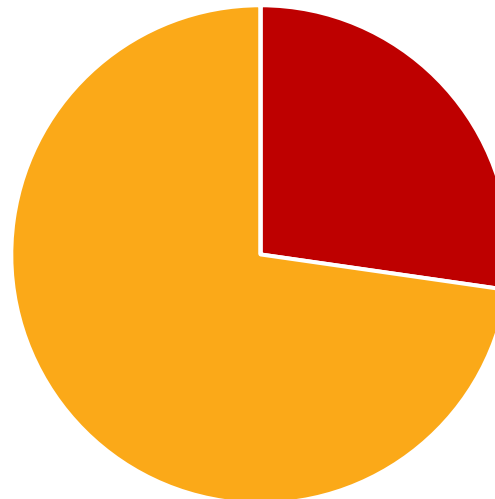
Demographics of participants

Ethnicity



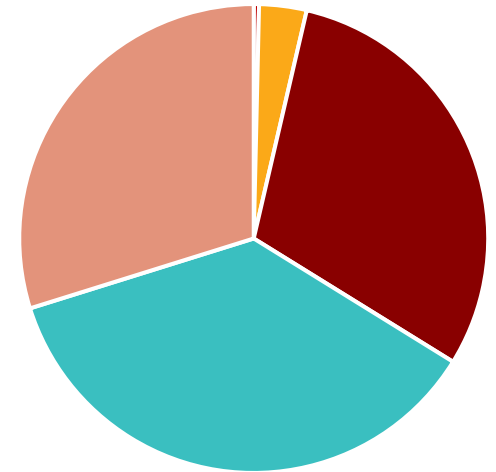
- White
- Black or African American
- American Indian or Alaska Native
- Asian or Asian American
- Native Hawaiian or Pacific Islander
- Some other ancestry or origin

Sex



- Man
- Woman
- Some other way

Education Level



- Elementary School
- Junior high or some high school
- High school diploma or Graduate Equivalency Diploma (GED)
- Some college or Associate Degree
- College degree or higher

Significant differences in positive & negative emotions, and uncertainty

FACToR validated Survey	Before chatbot	After chatbot	T statistic	p-value	Cohen's D
Negative subscale (0-12)			6.1	p<.0001	0.3881
Means (SD)	7 (3.2)	5.8 (3.2)			
Range	0-12	0-12			
Positive subscale (0-16)			3.6	p<.0001	0.2301
Mean (SD)	8.6 (4.2)	7.8 (4)			
Range	0-12	0-12			
Uncertain subscale (0-12)			4.9	p<.0001	0.3091
Mean (SD)	6.5 (3)	5.5 (3.4)			
Range	0-12	0-16			

- Negative emotion = significant decrease
- Uncertainty = significant decrease
- Positive emotion = significant increase
- Was the information helpful = significant increase
- Usability Score 73.5 (above 68 is good, above 80 excellent)
- Self-efficacy did not change.

Themes derived from the parent narrative about using NBSchat.

Theme	Quotes
Learned something new	• Learning that just because someone has a trait doesn't mean they have the disease.
	• I thought that it was useful how the bot gave an in-depth explanation of the results and what they mean and explaining the difference between sickle cell trait and disease
Gained reassurance	• The reassurance that the trait doesn't mean Sickle Cell Anemia.
	• The fast clear responses. The response wasn't in medical terms, so I could understand it easily. I also liked that the chat answered my questions and honestly would have made me feel better if this [w]as a real situation
Convenience	• Quickly find out that everything is okay without waiting until the morning, when the doctors' working day begins.
	• As a worried parent, we would rather have immediate answers rather than waiting for a follow-up with a medical professional.
Predefined questions	• I like the pre-developed questions to ask further information.
	• I found it useful that it gave me pre-question to ask further, because it could be hard at this moment to even know what to Google and seek out more information.

Combining quantitative and qualitative results

- Consistent message across both investigations
- Parents like having a menu to guide learning
- They like the idea of having immediate answers to health concerns
- Filling the knowledge gap reduced negative feelings and was described as reassuring
- The usability was good.

Time to Pivot!

In May 2025, Utah passed House Bill 363—Maternal and Infant Amendments.

This means the law now requires:

- The Department of Health must **publish a privacy consent form** for parents.
- This form must include:
 - **Why** biological samples (like residual blood dried blood spots) and genetic data are retained.
 - **How long** the state keeps those samples/data (retention policy).
 - A clear **option for parents to consent or decline** retention.





Why This Matters

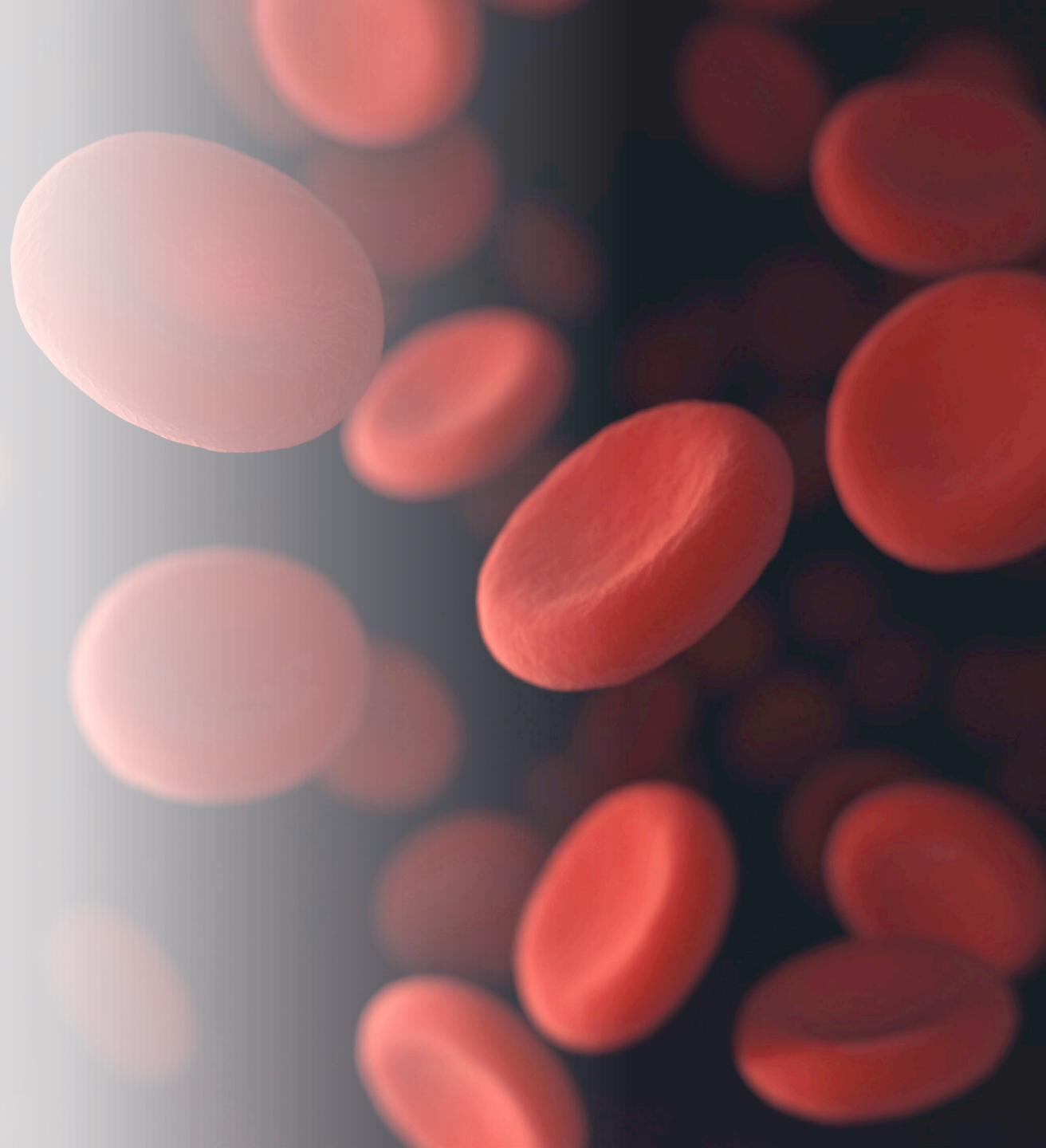
Previously, many parents **were not aware** that their child's blood spots could be stored and used beyond the initial newborn screening test.

This change **formalizes transparency**: parents must now be told the purpose and retention policy, and must actively consent.

The law creates a **shift in responsibility**:

Parents need understandable information.

Healthcare providers are expected to explain it at a sensitive time (right after birth), but often **lack detailed knowledge** about storage, secondary use, and research impacts.





Gap in Practice

Most clinicians know how newborn screening works for detecting disorders BUT

Few are trained to explain what happens to leftover blood spots:

- Storage duration.
- Future research use.
- Privacy protections.
- Impact on children's health, public health, and medical discoveries.

Without clear explanations, parents cannot give **true informed consent**

Our Solution:

Pivot and Use NBSChat (SCT Chatbot) for Newborn Screening Education

Currently writing R01 proposal to the NIH to utilize NBSChat to educate parents during the 3rd trimester.

Created to **bridge the knowledge gap** between policy and practice.

Parents can access clear, plain-language answers about:

Residual dried blood spot storage.

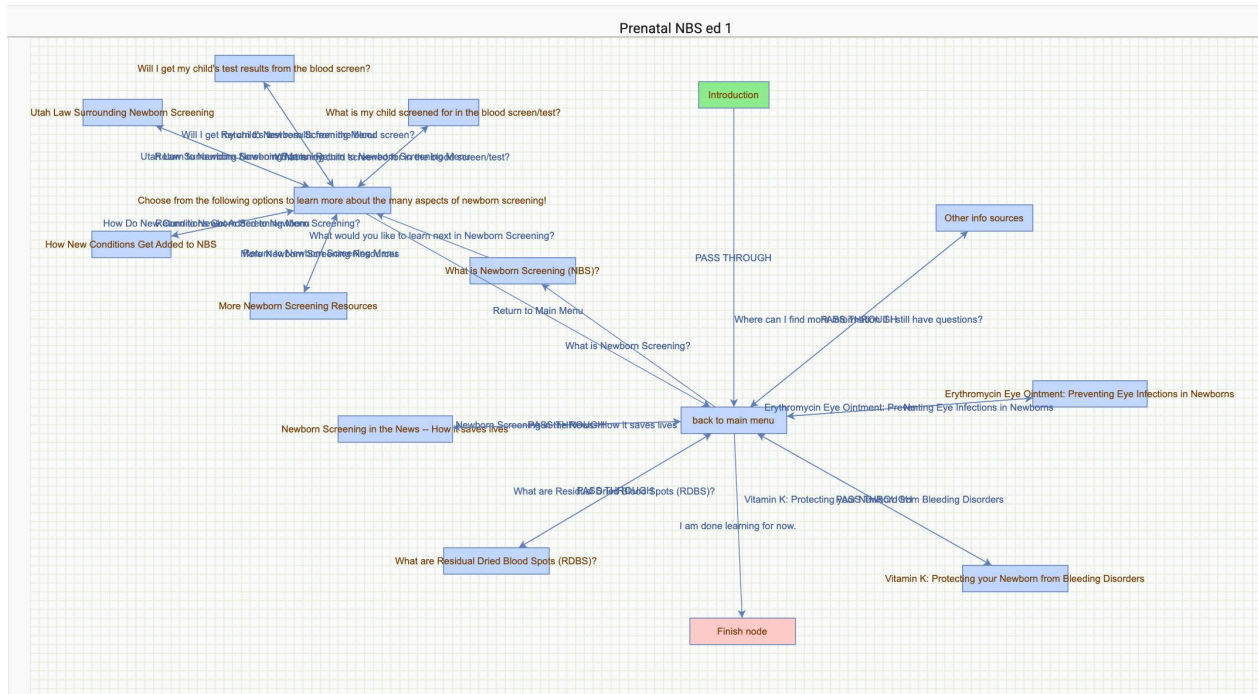
Why retention matters for **quality assurance** and **future research**

Their rights to consent or decline.

Ensures consent is **informed, not just signed**.

Supports healthcare providers by giving families a reliable, 24/7 educational tool.

NBSChat Expanded



online

NBSChat: Hi, my name is Olivia. I am a virtual assistant here to walk you through Utah's Newborn Screening process.

9/18/25, 10:54 AM

Today we will cover: What newborn screening (NBS) is, Why is Newborn Screening done? And what are Utah's laws about newborn screening?

9/18/25, 10:54 AM

What is Vitamin K and why it is given to newborns? And What is Erythromycin and why it is put in newborn's eyes upon delivery

I'm ready to learn more.

9/18/25, 10:55 AM

Select one of the options

online

You can take your time navigating through the information. I will keep things as plain and simple as I can. I'm here to help you learn so that you can make the most informed decision for your child.

9/18/25, 10:56 AM

Please choose what you would like to learn about next from the following:

- What is Newborn Screening?
- Newborn Screening in the News--How it saves lives
- What are Residual Dried Blood Spots (RDBS)?
- Vitamin K: Protecting your Newborn from Bleeding Disorders
- Erythromycin Eye Ointment: Preventing Eye Infections in Newborns
- Where can I find more information if I still have questions?
- I am done learning for now.

9/18/25, 10:56 AM

Select one of the options

Where do we go from here?

We have NOT forgotten the important work we began with our **Sickle Cell Trait Chatbot**.

- Our team has met with other states and continue working towards implementation

Our new **Newborn Screening and Residual Blood Spot Education Chatbot** builds the same foundation:

- Using informatics and technology to empower families with knowledge, support providers, and strengthen the future of newborn screening.





This is JUST the BEGINNING!

Whether it's sickle cell trait, residual blood spots, or future conditions, we are committed to ensuring parents have the tools they need to make informed choices and that public health continues to advance through innovation.

We want to collaborate on NBS issues



Q&A Session

Share your feedback

Please let us know what other topics you would like us to consider for future webinars!



Thank you!!!