

Newborn Screening Funding Model Workgroup Meeting

Wednesday August 16, 2023, 12:00 PM – 2:00 PM

Meeting Location:

Virtual (Zoom Webinar)

Registration: https://www.zoomgov.com/webinar/register/WN_4HPFhLDORDqPmmVNNmrSma

Note: Workgroup Members have been pre-registered.

Meeting Minutes

Workgroup Member Attendance	Representative Organization	Voting Record Y=Yes, N=No, A=Abstain
Bold = Present * = Proxy (Name) <i>Italicized</i> = Absent		Approve 7/24/23 Minutes
Voting Members		
Denise Toney, PhD	Division of Consolidated Laboratory Services/Department of General Services (DCLS/DGS)	Y
Vanessa Walker Harris, MD	Virginia Department of Health (VDH)	Y
Abraham Segres (Proxy: Rachel Becker)	Virginia Hospital and Healthcare Association (VHHA)	Y
Jana Monaco	Virginia Rare Disease Council (RDC)	Y
Chrissy Owen, CPM	Virginia Midwife Alliance (VMA)	Y
Lisa Stevens, MD* (Proxy: John Morgan, MD)	Department of Medical Assistance Services (DMAS)	Y
Julie Murphy	Parent Advocate	Y
William Wilson, MD	Newborn Bloodspot Screening Advisory Committee (NBS AC)	Y
<i>Dr. Nayef Chahin, MD</i>	Virginia Chapter of the American Academy of Pediatrics (VA AAP)	
Support Staff		
Christen Crews	Virginia Department of Health (VDH)	
Mary Lowe	Virginia Department of Health (VDH)	
Parker Parks	Virginia Department of Health (VDH)	
<i>Jennifer Macdonald</i>	Virginia Department of Health (VDH)	
Emily Hopkins	Division of Consolidated Laboratory Services/ Department of General Services (DCLS/DGS)	
Keith Kellam	Division of Consolidated Laboratory Services/ Department of General Services (DCLS/DGS)	
<i>Jessica Hendrickson</i>	Division of Consolidated Laboratory Services/ Department of General Services (DCLS/DGS)	
Angela Fritzinger	Division of Consolidated Laboratory Services/ Department of General Services (DCLS/DGS)	
Consultant		
<i>Sikha Singh</i>	Association of Public Health Laboratories (APHL)	

Council Business

- The Co-Chairs called the meeting to order at 12:03 pm, conducted roll call, and confirmed a quorum of members assembled virtually.
- The Co-Chairs reviewed the draft meeting agenda and draft minutes from 7/24/2023.
- The Workgroup then voted to approve the draft minutes from 7/24/2023 as presented. Abraham Segres motioned to adopt, and Chrissy Owen/Dr. William Wilson seconded. All members in attendance voted in favor.

Public Comment

A public comment period was opened and there was one member of the public that requested to speak to the Workgroup. The member of the public inquired about general newborn screening practices, specifically if the screenings are required for all newborns, even in the respect for “tribal rights, religious rights, and other serious beliefs.” Dr. Walker-Harris and Christen Crews confirmed that the only exception permitted by the Code of Virginia is for religious exemption, and that education to a family on the importance of a newborn screen can potentially alleviate any questions or concerns.

Workgroup Overview

Christen Crews, MSN, RN, Newborn Screening and Birth Defects Surveillance Programs Manager, VDH, presented to the Workgroup on updates from action items from the 7/24/2023 meeting. The first action item was to provide additional clarification regarding the presentation of Kansas’ newborn screening program. There is a medical fee “Fund” in Code for 4 priorities, one of them being the Newborn Screening Program. Health insurances pay into the fund with an amount based on a calculation from the number of subscribers they had from the previous year. Any unspent funds revert back to medical fee fund at end of the fiscal year (FY) for other priority programs, and the fee covers all costs for the blood spot screen. Facilities do incur cost for shipping, there is a pilot project for pre-paid overnight shipping labels through FY25.

The second action item to review was the stakeholder survey to gather information on newborn screening reimbursement. Christen Crews explained that draft survey questions for 3 audiences (hospital, out of hospital birth providers, and pediatricians) were sent through a survey to the workgroup members for their feedback and approval to include the question in the final survey. Approval was received from 8 of the 9 workgroup members, and the survey would be finalized for dissemination by the end of the week. Jana Monaco inquired as to how the survey would be distributed and in what format. Christen Crews explained that it will be an anonymous survey in REDCap that will have logic built in to tailor questions based on the provider type. The goal of the survey is to have a better understanding of how NBS collection fees are being billed and/or reimbursed and if negotiations are with insurance company contracts include the newborn screening fee. There are a lot of unknown practices that this data will help clarify. The Workgroup members were advised that they will be requested to disseminate the survey to their respective stakeholder groups and the data will be reviewed at the next Workgroup meeting.

Arizona Newborn Screening Program Funding Model

Ward Jacox, Arizona Newborn Screening Program, reviewed the program’s funding model and recent changes. Arizona is a 2 screen state, and previously the program billed the submitter for the 1st screen (\$36) and then the insurance directly for the 2nd screen (\$65). Initially, billing was done through the newborn screening laboratory; however, this was challenging as they did not have sufficient resources or staff to ensure reimbursement. They partnered with a third party billing organization to process claims and collect funds from insurance/families. The program changed their funding model last year to a fee-for-service (FFS) model and the submitters are invoiced monthly a one-time fee (\$171) that covers both screens. They are facing challenges with midwives not paying invoices or stating that they will submit to alternative testing laboratories such as Perkin Elmer (follow-up not able to track). Arizona’s annual birth rate is around 85,000 and they try to avoid 2nd tier testing due to added costs for send out testing. Ward shared that when implementing new disorders, it is always a challenge to acquire funds to support acquisition of new equipment and fund staff.

Newborn Screening Reimbursement Data

Parker Parks, MPH, Epidemiologist, VDH, presented to the Workgroup on the potential utilization of data from the statewide All Payers Claim Database (APCD). She provided a demonstration of using it with the known CPT code for direct billing of Newborn Screening Fee (S3620). This database will be used in parallel

with the survey results of identifying alternative CPT codes to review deidentified reimbursement data. It was discussed that the newborn screening fee may be included in the global billing charge for daily newborn care while in the hospital. While modifiers do exist for certain procedures (i.e., circumcision), we have not been able to find one for the newborn screen. Additionally, different CPT codes may be used with the various contracted insurance providers.

Workgroup Discussion: NBS Fee Concerns and Issues

- Hospitals (VHHA): Rachel Becker (proxy for Abraham Segres)
 - Rachel Becker shared feedback from the VHHA regarding the NBS fee and impact on the hospitals. She informed that hospitals perform most of the NBS, paying over 11 million dollars annually, and reimbursement rates are not considered including Medicaid deliveries. She proposed the following:
 - Greater transparency: Public report to include annual costs to hospitals for specimen collection kits, effectiveness of newborn screening, the number of tests performed, the number of positive tests, number of diagnosed cases, and including guidelines as far as how fees are determined.
 - Evaluating other sources of funding: consider looking at other potential sources for state funding.
- Out of Hospital Birth Providers (VMA): Chrissy Owens
 - Chrissy Owens, President Virginia Midwife Alliance, shared feedback on the newborn screening fee and out of hospital birth providers. She stated it is a fiscal burden on providers as midwives. The provider attempts to recoup the cost of the newborn screening fee by either raising their service fees or covering the cost themselves so clients can have the testing. She advised that there is a small subset of clients that will opt out of the newborn screen “to stay off grid”, for religious reasons, or cost. In her own personal practice, 99.9% of clients have agreed to collect the screen regardless of if they foot bill or if insurance covers, as midwives are out of network providers. Medicaid only covers \$103 of the current \$138 fee. She said they do educate families prenatally on the importance of the newborn screen and provide a good standard of care. Midwives with smaller practices and low fees, may feel more of a burden than her practice might. Dr. John Morgan, DMAS, said that regulations affect how Medicaid reimburses and how billing codes are priced is complex. He said that he would reach out to DMAS team members for additional information.
- Provider: Dr. William Wilson
 - Dr. William Wilson shared that in the infancy of the NBS program, there was not a fee for service (FFS) model and the program was supported by general funds (GF). Funds were also received from the federal government for a time. The program moved to the FFS model when those funds were no longer available. He expressed concerns that newborn screening is being done on the “backs of parents and backs of hospitals, but it benefits of state”. The state can save money because of decreased impact on medical infrastructure from diagnosis and early intervention of positive cases, yet the costs of this is being born by consumers, hospitals, etc. Dr. Wilson stated that there should be a partnership. If it is a legislative decision to expand the newborn screening panel, there should be funding support from the state. A discussion occurred regarding estimating cost savings for children diagnosed through newborn screening. Denise Toney said she would send Jana Monaco a few disorders (high incidence, middle, and low) to see if any information on fiscal impact from the Rare Disease community.
- Parents: Jana Monaco and Julie Murphy
 - Jana Monaco shared her experience with having one child identified through newborn screening with a disorder and one child who was not identified early due to the state not screening for the disorder. With her 2 children, there is such a significant difference in the medical interventions that have been needed over the years. A rough estimate for her child who was not identified through newborn screening is likely close to 2 million and turns 26 this year. If he had been diagnosed and received early intervention as a result from newborn screening, then it could have saved the state a lot of money.

- Julie Murphy shared that her children have another metabolic disorder that does not have as much cost for treatment/intervention. They were also caught early. She questioned compliance for newborn screening and that it is a tremendous burden to midwives.

Newborn Screening Funding Models Review and Discussion

- Christen Crews presented visualizations of the different funding models previously discussed. An additional proposed hybrid funding model, including both state general funds (GF) and fee for service (FFS), was reviewed with the Workgroup. This model would request GF annually based on an estimate from the births the previous year for certain situations (out of hospital births, self-pay, uninsured). The outcome of this funding model would be to remove the financial burden to families and out of hospital birth providers in order to ensure compliance with testing. Unspent GF would revert back to the treasury at the end of the fiscal year. Dr. Wilson stated he supported having the fiscal burden removed from parents. The Workgroup members were requested to view the visualizations in detail and be prepared to discuss at the next meeting.
- Dr. Denise Toney shared information on how the newborn screen fee is determined. A cost analysis is performed when a disorder is being reviewed by a Newborn Screening Advisory Committee Workgroup or legislatively mandated for consideration to be added to Virginia's core disorder newborn screening panel. The cost analysis includes laboratory equipment, supplies, personnel (DCLS laboratory and VDH follow-up), technical modifications to the laboratory information management system, reporting, training/education, etc. The annual cost, birth rate, and start-up costs are reviewed and shared with stakeholders and the Governor's office to be approved by the Department of Planning and Budget. The addition of new disorders, 2nd tier testing, legislatively mandated 7 days/365 testing, etc. has impacted the newborn screening fee. The program does look for grant opportunities to fund costs associated for implementation of new disorders. Stakeholders (providers, families, VHHA, etc) are able to provide input regarding the fee increase when the program is evaluating the addition of new disorders. The program has requested GF in the past for new disorders or legislative mandates that have been denied due to an alternative funding model in place for the program.
- Rachel Becker, VHHA, questioned limiting the fee increase of the newborn screen. She advised that the hospitals struggle with increases and questioned if there could be a maximum increase. Dr. Toney advised that while there is no limit to what the fee can be increased or decreased, the program is held accountable to the review of planning and budget. The fee is only adjusted if it is not covering the expenses of the newborn screening program. It was questioned how Virginia compares to other states with their newborn screening fees, and Christen Crews shared the slides and data presented on the previous meeting on 7/24/2023. The costs can vary by funding models and the number of disorders screened- the fees range to \$235 for 35 disorders (Virginia is at \$138). Not all states have 2nd tier testing; however, this increases the emotional and financial harm to families due to false positives on the newborn screen. Rachel Becker proposed considering imposing a cap on the maximum percentage increase of the NBS fee in a year. This would result in potential delay of implementation of disorders while the fee is being increased to allow implementation of testing. Dr. Denise Toney discussed a regular annual percentage increase, and Dr. Vanessa Walker Harris agreed that this model should be considered as well.

Adjourn

- The Workgroup summarized the following Action Items/Next Steps:
 - Review visualizations of funding models before next workgroup meeting
 - Workgroup members disseminate reimbursement survey to their stakeholders
 - Next meeting date TBD after poll of Workgroup members.
- The Co-Chairs adjourned the meeting at 2:00pm.