ED3N: Enhancing Data-driven Disease Detection in Newborns

Better Data. Better Decisions. Healthier Newborns.






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Creating a Vision to Enhance Data Analysis

Laying the Foundation for ED3N

Anticipating Domestic NBS Program Needs

What do current challenges tell us about what we should expect of the future?

- More diseases on RUSP, increased complexity, nuanced risk assessment
- New or more sensitive testing platforms and emerging technologies
  - multiplexing, metabolomics, NGS
- Increased data generated

The Best Way to Predict the Future is to CREATE IT.

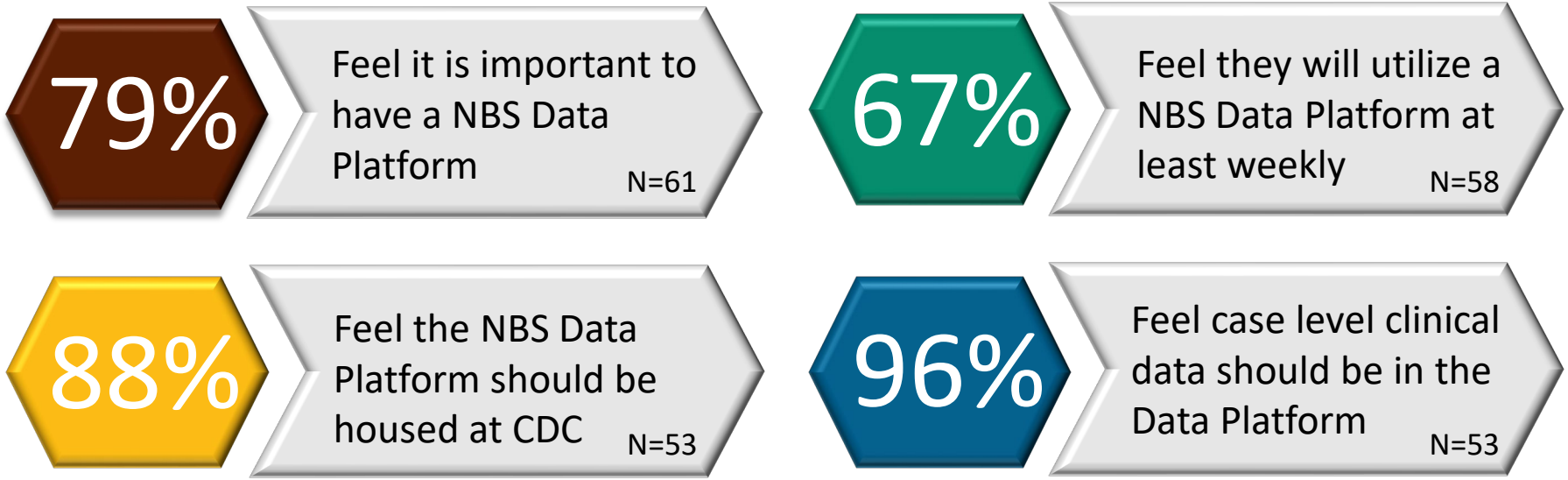
The Long Road to ED3N

Identified Gaps in Newborn Screening Programs

- Lack of harmonization between state programs in testing practices and data output and capacity
- Inadequate number of data analysts and interoperability specialists within NBS programs
- Disparate ability and resources to review and analyze screening data to improve performance
- Data silos and one-off connections within and between NBS programs and other relevant health programs

2019 National Data Analytics Meeting

Programs were Supportive of ED3N Development as a possible solution



Data obtained via APHL at 2019 National Data Analytics Mee

ED3N: *Enhancing Data-driven Disease Detection in Newborns*

A nationally representative NBS Platform to support Decision-Making

Aims to:

- **Improve detection of at-risk newborns**, allowing for more timely diagnosis and intervention for an increasing number of diseases
- **Decrease disparities** across state NBS programs and family experiences

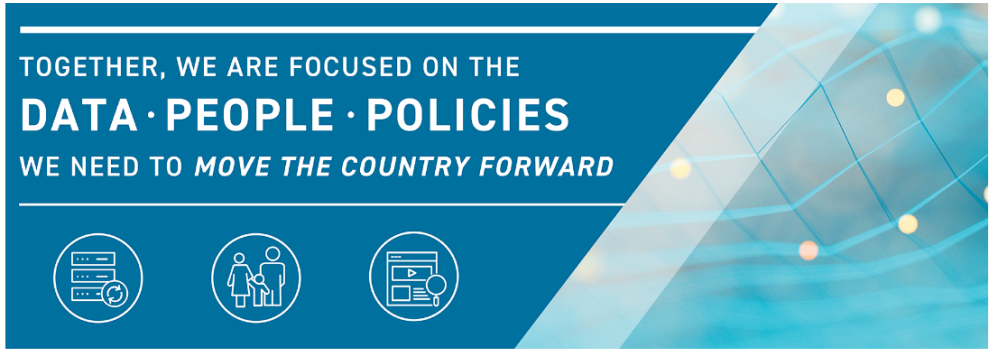
Achieved By:

- **Increasing capacity and infrastructure** to collect, aggregate, and analyze newborn screening data across federal, state, and healthcare systems
- **Providing a national data solution** to remove burden on NBS programs and ensure equal access to high-level data analytics

CDC's Data Modernization Initiative

ED3N selected for Accelerated Modernization

Data saves lives. Better data saves more lives.



"At CDC and throughout public health, we are in a pivotal moment for data and surveillance — one marked by opportunities, challenges, and the need for change."
Dr. Rochelle P. Walensky, CDC Director

The ultimate goal of CDC's Data Modernization Initiative (DMI) is to get better, faster, actionable insights for decision-making at all levels of public health.

Our vision is to create one public health community that can engage robustly with healthcare, communicate meaningfully with the public, improve health equity, and have the means to protect and promote health.

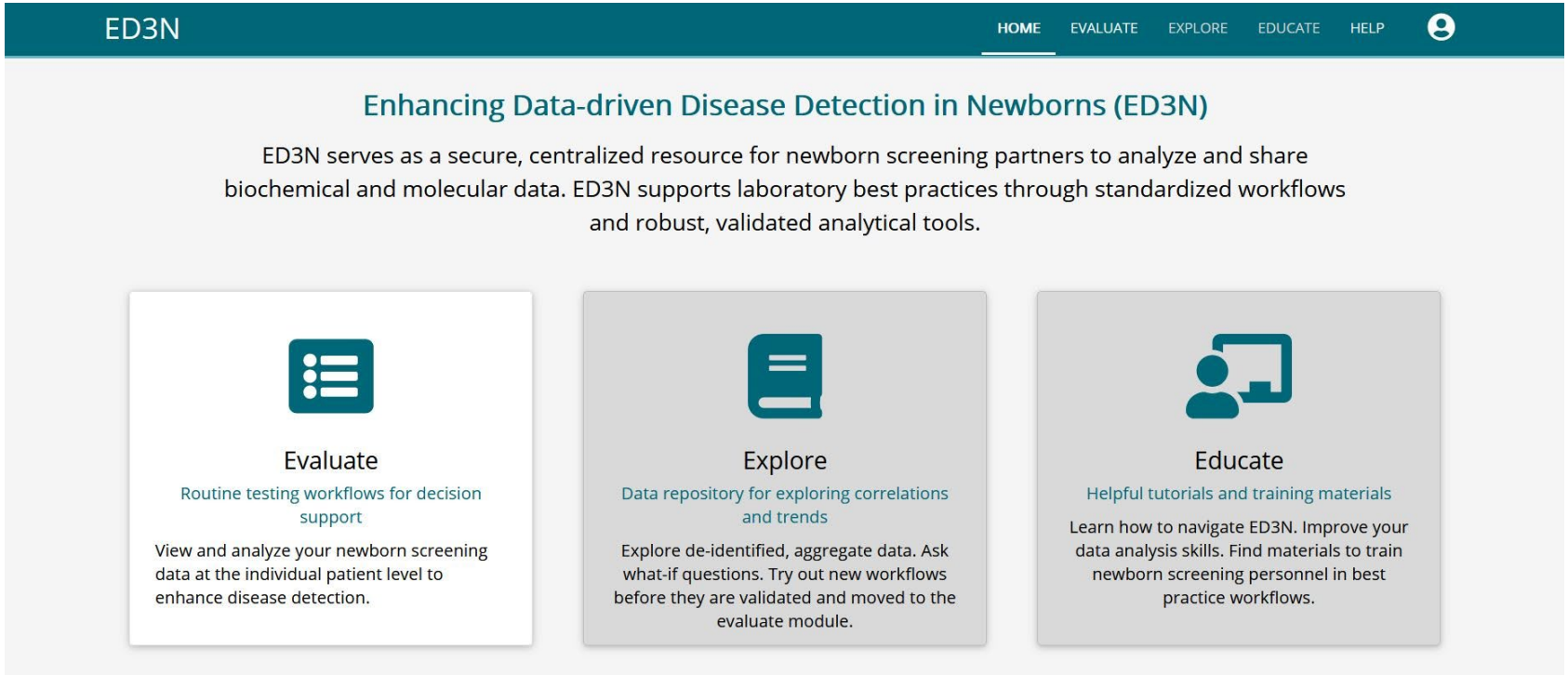
Accelerated Modernization of Select Systems

Two systems from each Non-Infectious Disease Center have been designated for accelerated modernization.

Enhancing Data-driven Disease Detection (ED3N)
Is one of eight Systems selected.

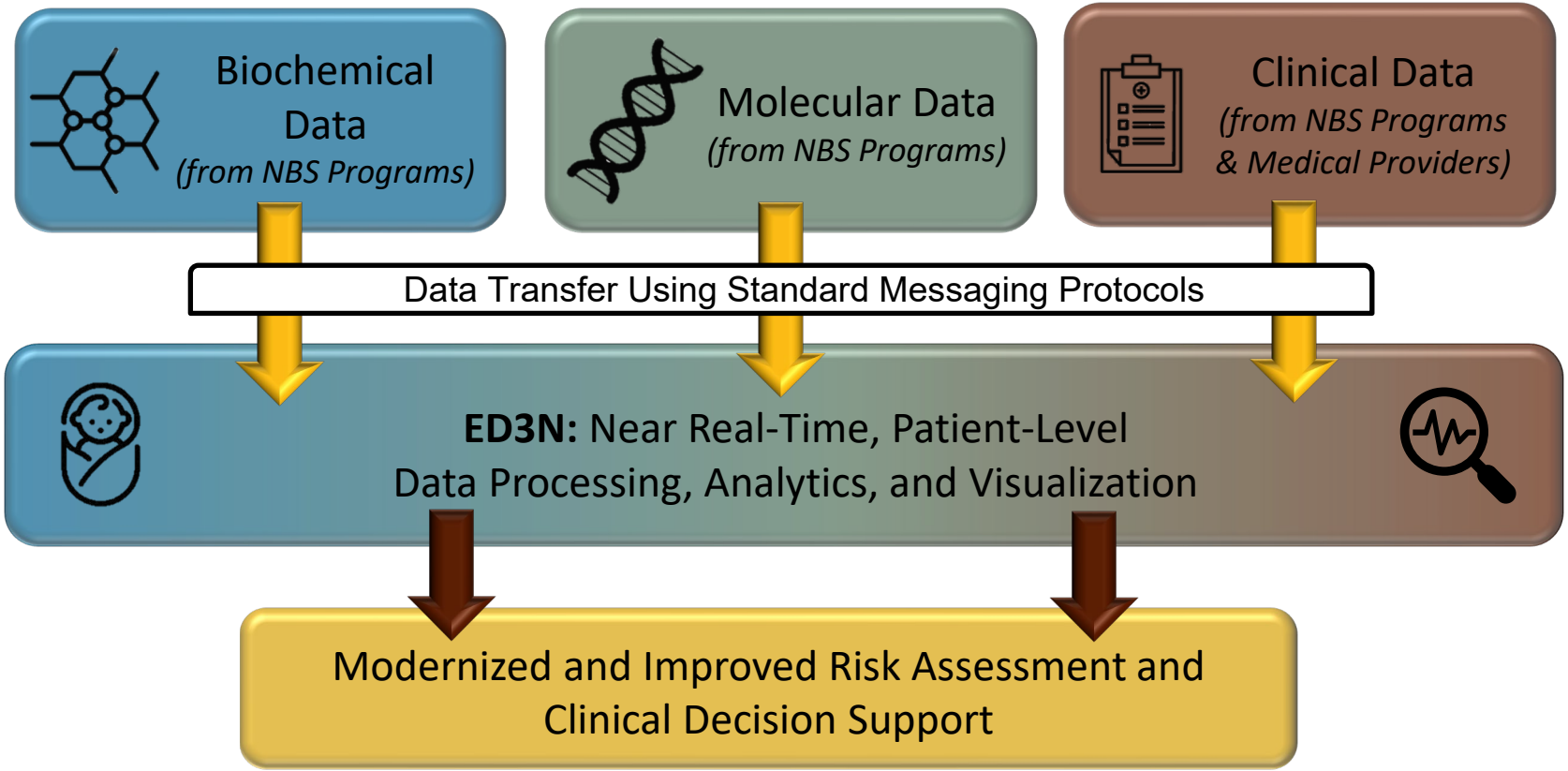
Public Health Surveillance and Data | CDC

ED3N Structure

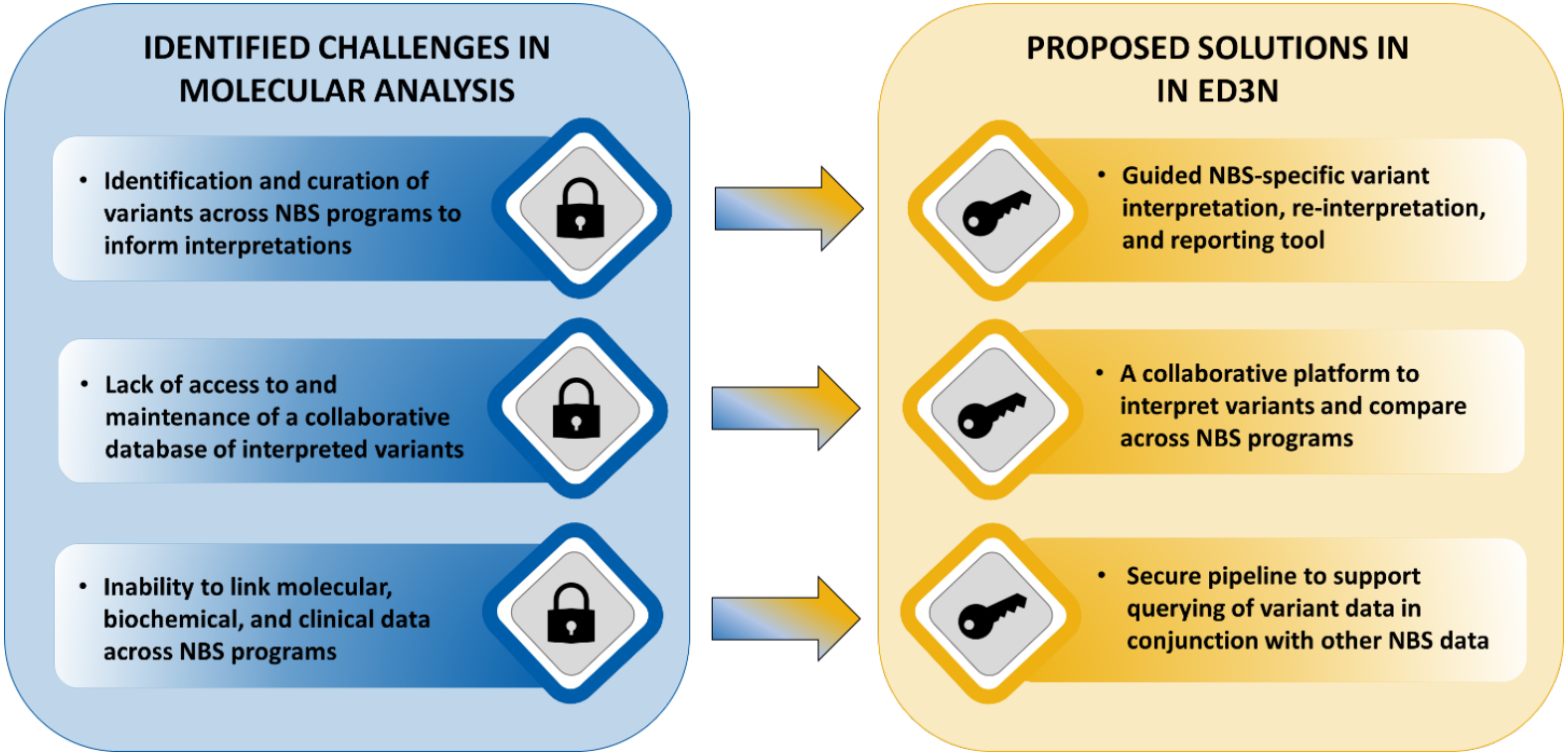


ED3N Can Lead to Improved Public Health Decision Support

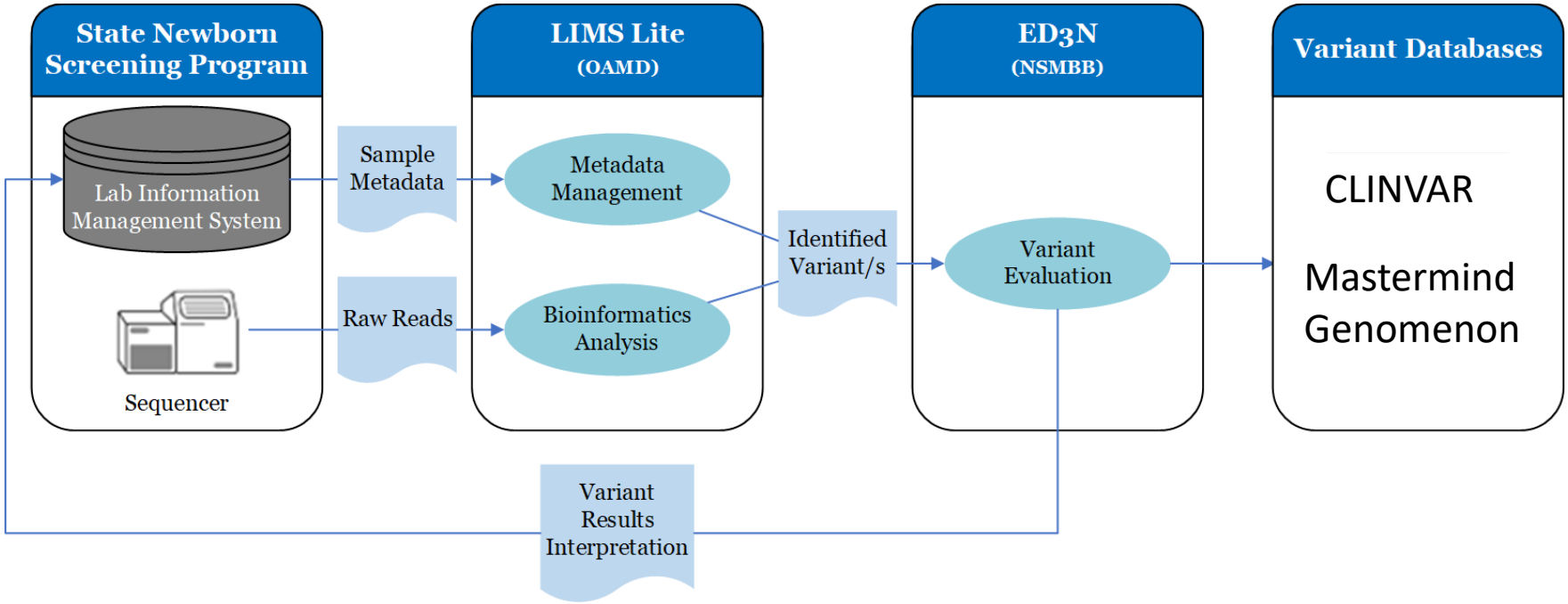
Proposed high-level structure and workflow



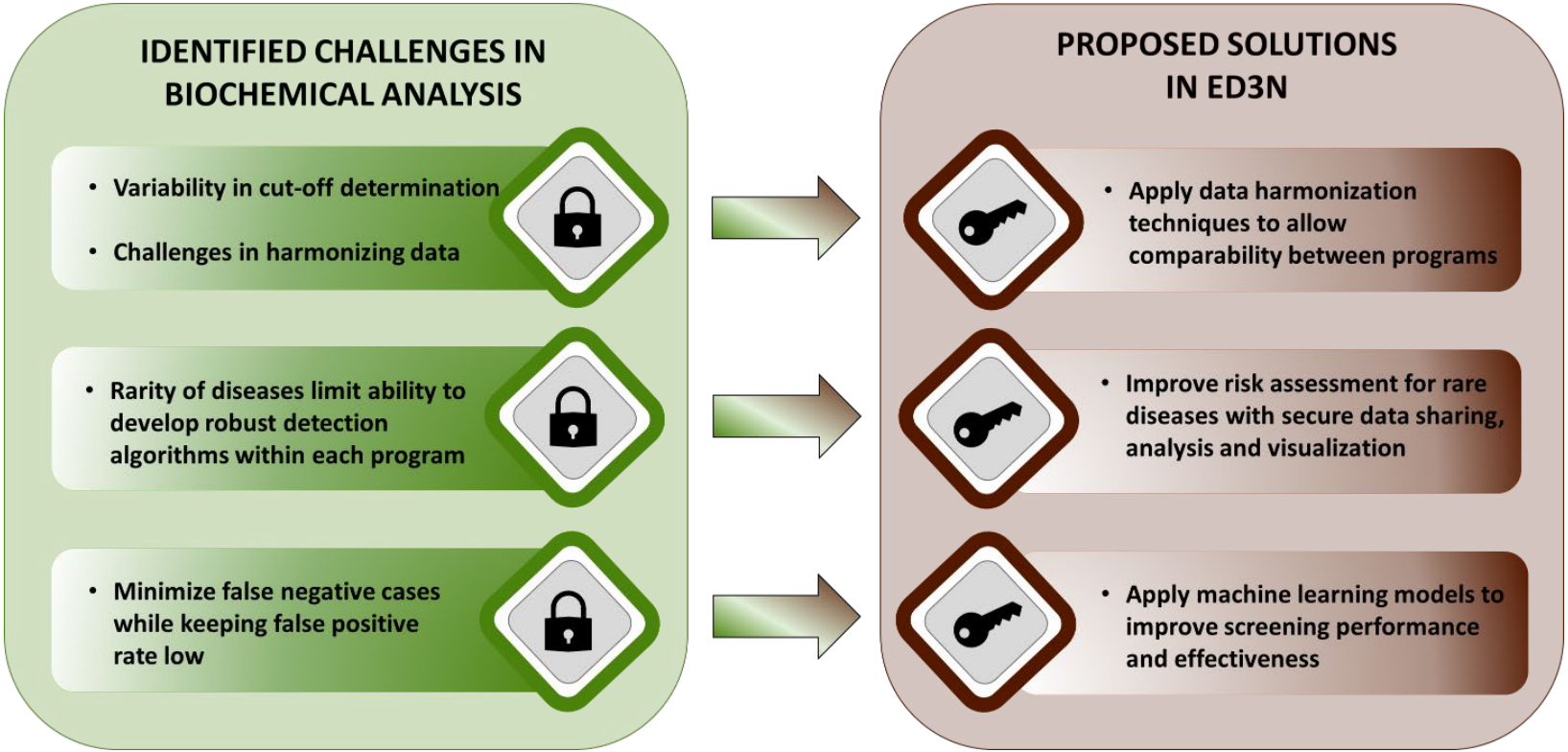
Proposed Molecular Module



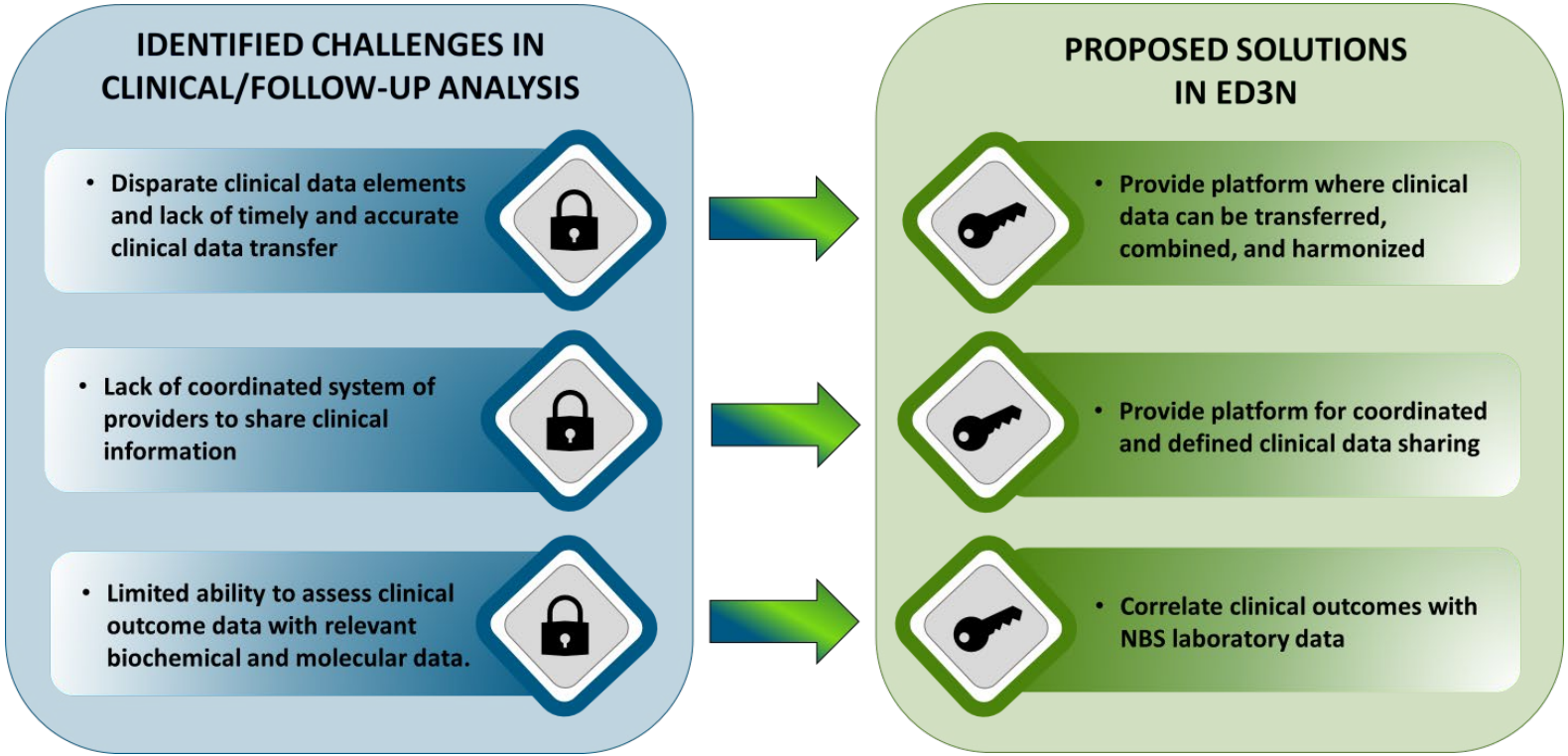
Molecular End-to-End Solution in ED3N



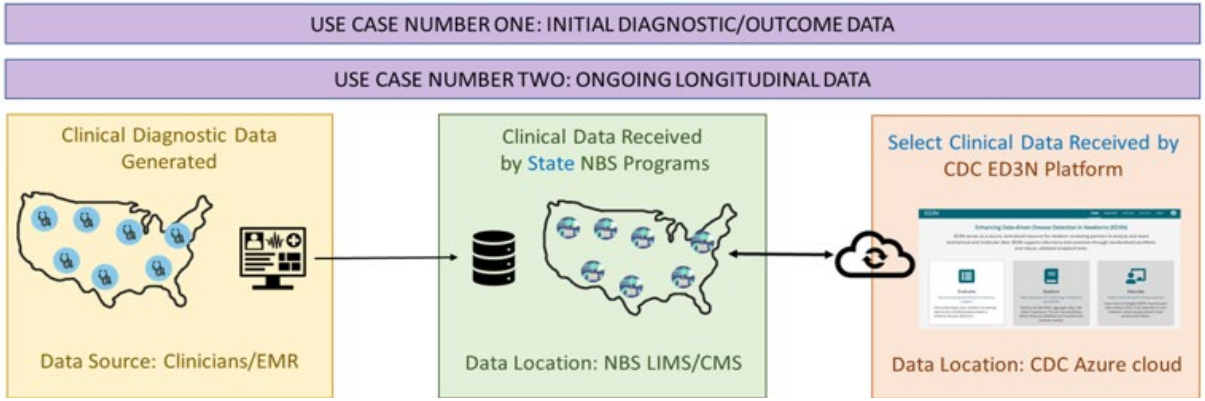
Proposed Biochemical Module



Proposed Clinical Module



Developing a sustainable follow-up data collection model



Oversight Org	Project Name	Description
HRSA	Long Term FU and Propel Grants	State-based grants to support development of LTFU (post -diagnostic) methods
HRSA	NewSTEPs	Collects case-level data on confirmed cases detected through NBS Programs
NIH	NBSTRN	Hosts the Longitudinal Pediatric Data Resource (LPDR) and provides support for standardized data collection using Common Data Elements
NIH	Pilot Screening Projects	Pilots new conditions in state programs to test screening protocols and implementation in real-world settings
CDC	eCR	Automated, real -time exchange of case report information between electronic health records (EHRs) and public health agencies
CDC	ED3N	National NBS data platform incorporating biochemical, molecular, and clinical data for enhanced risk assessment for NBS programs

Federal and National Partner Initiatives

Data Use and Privacy

- **Data Use Agreements**
  - Approved by CDC's Office of General Council
  - In ratification process with identified NBS pilot programs
    - < 9 for each of biochemical and molecular pilots
- **Paperwork Reduction Act**
    - Approved as of April 2023
- **Privacy-Preserving Record Linkage**

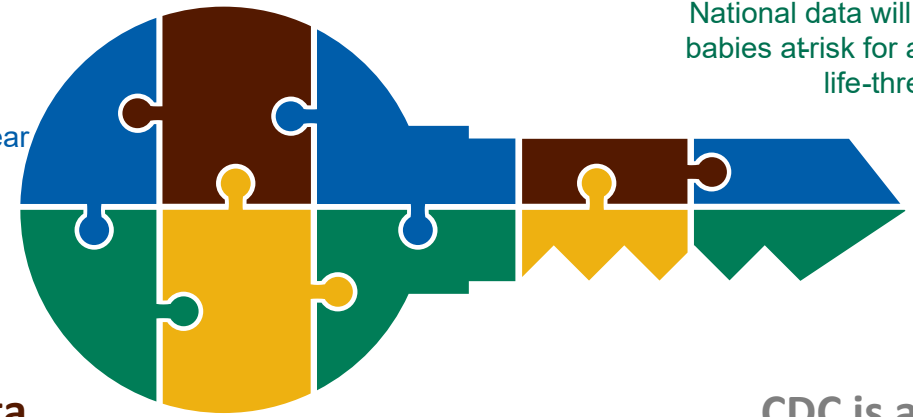
ED3N: The Key to NBS Data Modernization

3,800,000 babies/year

More than 1 in 550 babies affected with NBS diseases each year.
Over 60 diseases currently need enhanced screening and surveillance
Nearing 500 million data points across disparate data sources each year

Aggregated Data Analytics = Enhanced Disease Detection

Novel predictive analytics using aggregated National data will allow for better detection of babies at-risk for an increasing number of rare, life-threatening diseases



A National NBS Data Infrastructure is Needed

Individual programs are unable to build and sustain robust data transfer and analysis mechanisms on their own – leading to risks for more false positive and false negative results

CDC is a Trusted Host for NBS Data Modernization

NBS Programs are looking to CDC to take the lead on an interoperable data solution to address increased complexities in NBS

Thank You!

Questions?

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For more information, contact NCEH
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