

Genetic Integrated Screening Information System (SIS)



Why did the State of California choose to replace its Newborn and Prenatal Screening System?

1. March of Dimes' published recommendation that all states screen newborns for a set of 29 disorders
2. Success of California's expansion pilot, which received significant media attention with articles in both the Wall Street Journal and New York Times
3. Legislation was passed mandating expansion of California's newborn screening program
4. Advancements in technology
 - New technologies, such as tandem mass spectrometry, are driving the movement to increase genetic disease screening for newborns. (Science Magazine, 2002)
 - California's existing system was unable to accommodate the increased testing, and was meeting its limit in terms of database growth

What is the Screening Information System (SIS)?

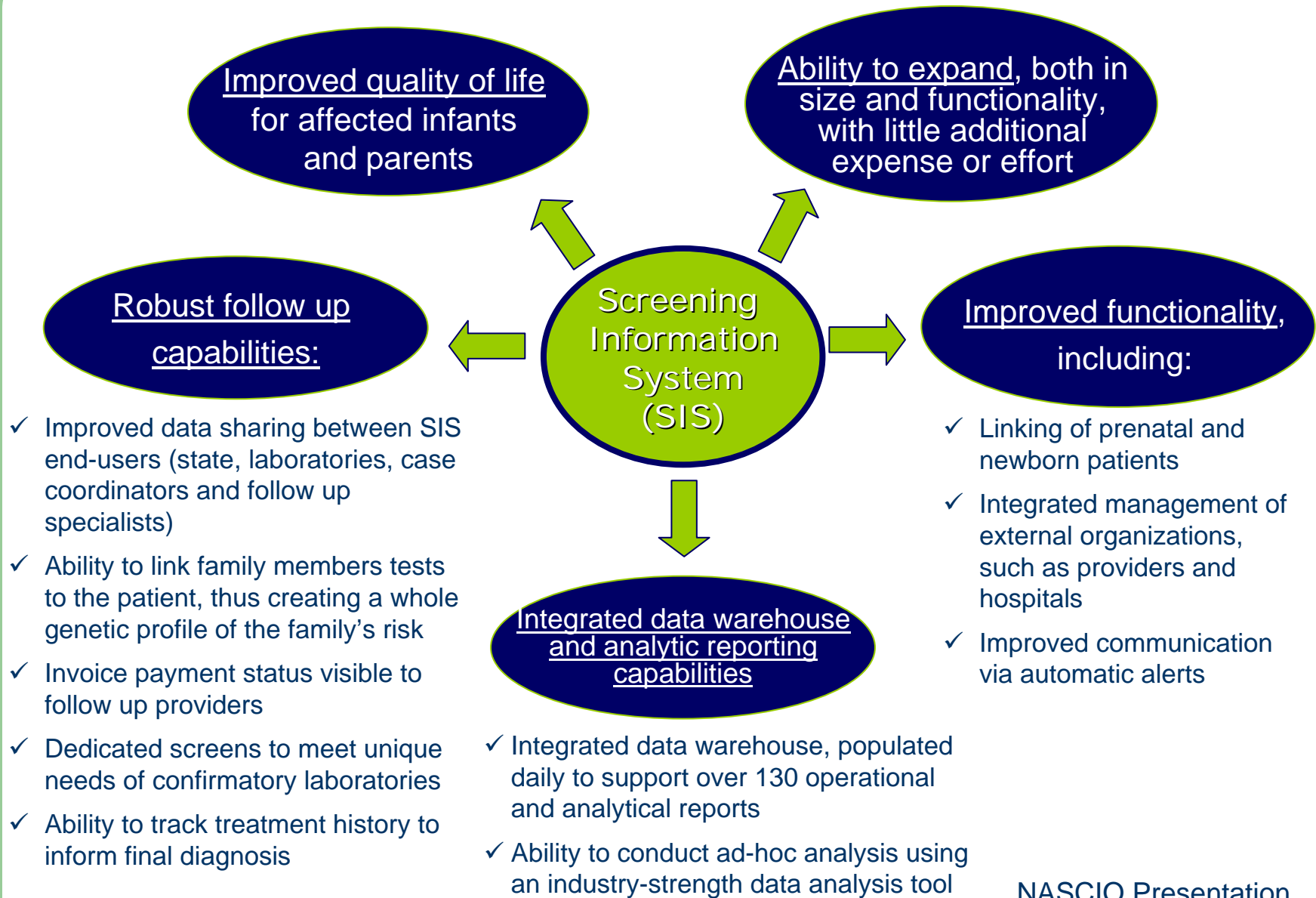
SIS is a web-based application that integrates prenatal and newborn genetic disease screening and follow up, including:

- ✓ Identification of cases with a positive risk assessment for a genetic disease
- ✓ Notification to physicians and patients for negative and positive risk assessments
- ✓ Tracking of cases, from identification through follow up with primary care physicians and specialists
- ✓ Ongoing case tracking and monitoring

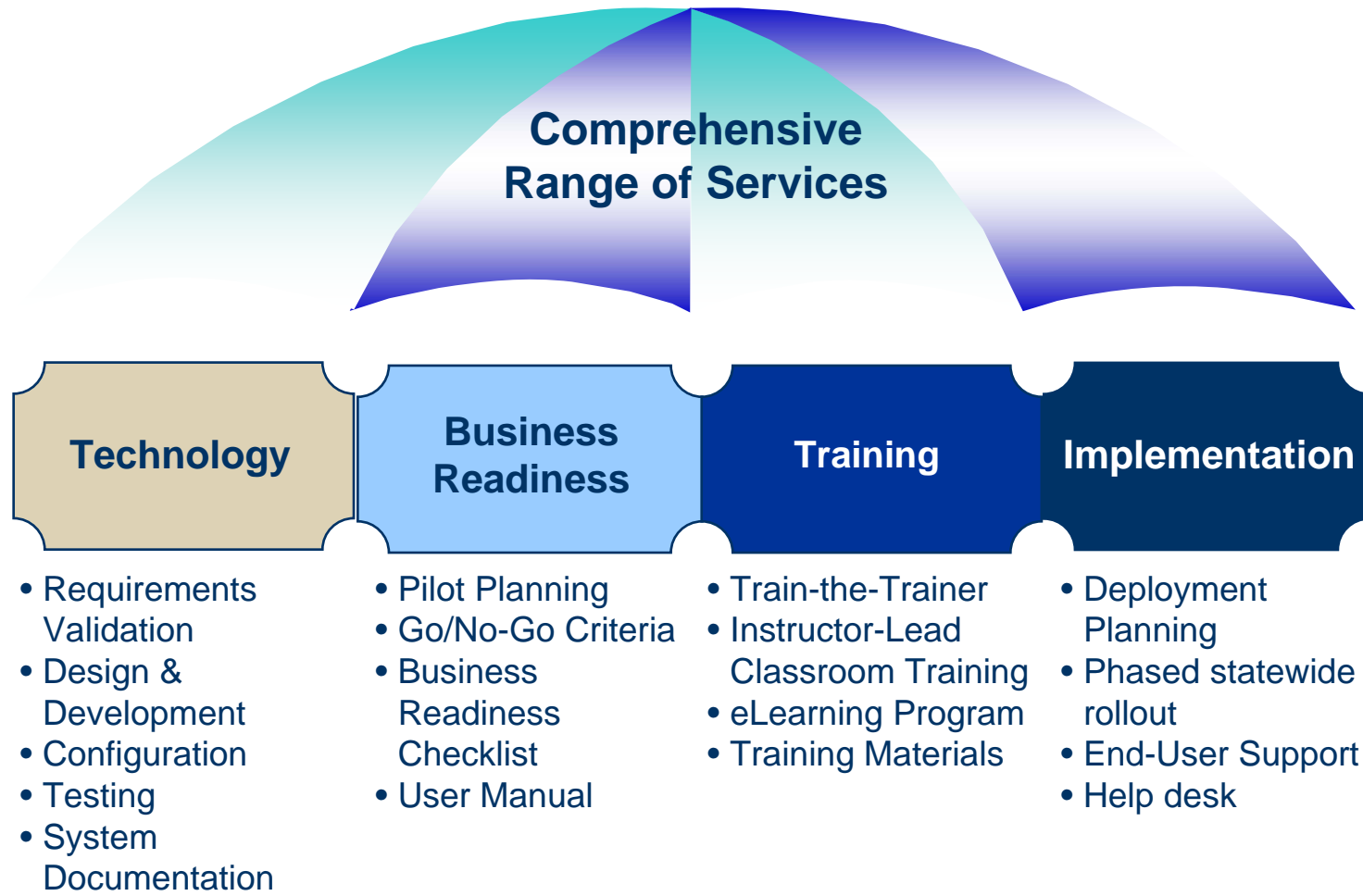
Solution Overview:

- Approximately 3000 blood specimens are processed through SIS each day
- Capability to screen for 31 distinct NBS disorder patterns and properly interpret results using demographic information and collection time factors, as necessary
- Over 150 Screens
- 26 Interfaces and Batch programs
- Over 25 different Mailer types with hundreds of permutations/combinations within each type
- Over 70 Reports
- Over 700 users supported

What benefits can be realized with SIS?



What was the solution for the California Genetic Disease Branch?



Collaboration with other State entities and end users

How does SIS work?

<p>End- Users</p>	<ul style="list-style-type: none"> Laboratories 	<ul style="list-style-type: none"> Case Coordination Centers Follow-up Centers GDB Program Administrators GDB Program Monitors 	<ul style="list-style-type: none"> GDB Research GDB Program Monitors Quality Assurance
<p>Data flow</p>	<p>The diagram illustrates the data flow process. On the left, two photographs show a person's arm with a bandage and a person writing on a document. Lines from these photos point to a server icon with a yellow flame effect. From the server, lines connect to two computer monitors. These monitors are connected to a central 'Transaction Database' represented by a blue cylinder. A line from the Transaction Database connects to another 'Reporting Databases' cylinder. Finally, a line from the Reporting Databases connects to a stack of envelopes labeled 'Mailing Vendor'.</p>		
<p>Technology</p>	<ul style="list-style-type: none"> Optical Character Recognition (Kofax) Imaging Management (Acorde) Web Interface (.NET) 	<ul style="list-style-type: none"> N-tier Application (MS ASP.NET) XML Web Services (MS .NET) Transactional DB (MS SQL Server) Application Security (MS AD) Fax 	<ul style="list-style-type: none"> Bus. Intelligence (Business Objects) Analytical Reporting (SAS) Reporting DB (MS SQL Server)

Why was the State of California SIS implementation successful?

Success Factor #1: Stakeholder buy-in

- ✓ Department of Health Services Executives
 - Involved GDB staff and vendor teams in key business decisions
 - Conducted regular Steering Committee meetings
 - Helped remove roadblocks
- ✓ GDB Staff
 - GDB staff were involved in all aspects of SIS preparation, including design, testing, training, business readiness, pilot, and implementation
 - Communicated regularly with SIS end-users
- ✓ Interest Groups
 - Key interest groups, including the March of Dimes, were critical in helping to gain momentum for the SIS implementation

Success Factor #2: Worked As One Team

- ✓ Made partnership between the State, Deloitte and other vendor teams a top priority
- ✓ Worked together to identify and mitigate issues and risks
- ✓ How?
 - Held regular Project Management meetings
 - Conducted Cut-Over meetings
 - Facilitated cross-functional meetings with attendance from all project areas
 - Made continuous communication a top priority

SIS Success Factors (cont'd)

Success Factor #3: Legislative Mandate

- ✓ SB142 mandated inclusion of Tandem Mass Spectrometry, which would provide for screening of an additional 30 treatable genetic diseases.
- ✓ The March of Dimes and other interest groups were critical in securing the passage of SB142

Success Factor #4: Comprehensive Implementation Plan

- ✓ GDB and Deloitte staff partnered to provide a comprehensive and effective hands on training program, including both instructor lead training and eLearning components
- ✓ A SIS Pilot was conducted, which helped the team to identify and resolve issues prior to the Statewide Implementation
- ✓ On-site end-user support provided by GDB and vendor staff during the Pilot and statewide go-live was critical to end-users' initial success
- ✓ The GDB and Deloitte teams partnered to provide knowledgeable Help Desk staff for several months during and after go-live

Where is SIS now?

Outcomes:

- ✓ Successfully implemented SIS statewide in July 2005 (ahead of schedule)

Recent Enhancements:

- ✓ New screening tests, both prenatal and newborn, can be seamlessly integrated into the SIS application with little additional cost or effort, as they become available in the future
- ✓ The California DHS continues to work with Deloitte to improve the State's SIS application
- ✓ The latest expansion of SIS includes the addition of biotinidase deficiency and cystic fibrosis to the list of disorders
- ✓ These additions now place California as a global leader in genetic screening
- ✓ California's pre-natal screening program now includes Inhibin, known as the fourth marker

Collaborators and Partners

- California Staff
 - GDB Richmond staff
 - Information Technology Staff
- Partners
 - Deloitte Consulting – System Integrators
 - Lance Jackson – Project Manager
 - Leslie Janoe – IPOC
 - Rochelle Furtah – IPOC
 - Chris Gartner – IV&V
 - Brent Hammond – IV&V