Informatics Needs Assessment Based on the Newborn Screening Health Information Technology Resource Guide and Toolkit

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Data exchange within the newborn screening system is complex.
Timely and accurate data exchange can decrease the time elapsed between birth and notification.
JMC partnered with Virginia and NewSTEPs 360 to identify solutions to improve timeliness through better data exchange.
February 2017 JMC along with the Virginia NBS program convened a face to face meeting to determine the content needed for a Guidebook focused on implementing electronic data exchange between laboratories and hospitals.
The Building Blocks Guide

**SECTIONS**

I. GETTING READY
II. WORKING WITH HOSPITALS
III. IMPLEMENTATION AND DATA EXCHANGE
IV. OPERATIONS AND MAINTENANCE

**CHAPTERS**

Each section is broken down into chapters that address key aspects of the data exchange process to ensure project success. Each chapter also includes a summary, timeline, and list of resources.

**TASKS**

Each chapter includes step-by-step tasks to lead your program through the details involved in setting up an electronic data exchange from start to finish.
The Building Blocks Guide

APPENDIX

TOOLS

FROM PROJECT MANAGEMENT TEMPLATES TO COMMUNICATION PLANS, THE GUIDE PROVIDES RESOURCES BOTH FROM PUBLIC AND PRIVATE DOMAINS. THESE TOOLS WILL SAVE YOU VALUABLE TIME AND ENABLE SUCCESS.

SME MATRIX

WHAT KIND OF PROFESSIONS ARE NEEDED TO HELP WITH THIS PROJECT? THIS MATRIX IDENTIFIES KEY SKILLS AND EXPERTISE NEEDED TO IMPLEMENT NBS DATA EXCHANGE THROUGH THE LIFECYCLE OF THE PROJECT.

CASE STUDIES

VARIOUS PROGRAMS HAVE GRACIOUSLY SHARED STORIES TO PROVIDE LESSONS LEARNED TO THE NBS COMMUNITY. YOU’LL GAIN INSIGHT, ENCOURAGEMENT, AND SUPPORT FROM THESE ANECDOTAL SUMMARIES OF SIMILAR EXPERIENCES.
Beyond the Guide...

- What are we missing?

Building Blocks Guide

Successful Electronic Messaging Project
Guide Review and Needs Assessment Process

1. Identify Participants
2. Distribute Questionnaires
3. Conduct Interviews
4. Assess Needs
Selecting Participants

- Early: Planning phase
- Middle: Engaged and Partially implemented
- Complete: In production with at least one messaging partner
Questionnaires

• **Designed to assess:**
  • The progress the state had made toward implementation of electronic data exchange.
  • The completeness of the information in the guide to support the requirements of data exchange implementation.
  • Additional support needed to meet the goals of electronic data exchange that were not included in the Guide.

• **Provided the opportunity to give structured and free text responses**
After receiving and reviewing the questionnaire responses, the JMC team scheduled interviews with the state respondents.

Interviews focused on probing deeper into the comments provided on the questionnaires and identifying state needs not originally identified in the Guide authorship.

Each set of interview questions were customized for the particular state.
1. **Lack of Project Resources**
   1. Project Management
   2. Training
   3. Staffing
   4. Tools

2. **Hospital Engagement**

3. **Software Limitations**

4. **Financial Resources**

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**Needs Assessment**

- **Successful Electronic Messaging Project**
- **Building Blocks Guide**
  - Resources
  - Hospital Engagement
  - Software Limitations
  - Financial Resources
Resource Needs

- Project Management
- Training
- Understaffing
- Tools

“We are in our third year of this project with very little progress... Having someone who is really going to be the project manager, to be able to put the project charters together, to be able to get a game plan, to keep the stakeholders on task. That is where we are lacking.”

“When we asked for help, we were directed to YouTube and printed documents. We need to have a basic training for NBS, HL7, etc. We need guidance on where to get the information. A “Lab Electronic Testing and Results for Dummies.”

“I definitely think that some “helpline” would be a great benefit, if possible.”
Resource Needs

- Additional tool – testing scripts
- Additional tool – Common NBS...
- Additional tool – lab system data...
- Variations between hospital...
- Lack of document sharing
- Lack of project cohesiveness
- Staff turnover
- Risk assessment
- Stronger Project Management
- Integration Engine training or SME
- NBS training or SME
- HL7 training or SME
- NBS Terminology training or SME
- Working with middleware

Number of States
Hospital Engagement

• Recruiting and maintaining hospital participation in messaging projects is challenging

“We had about eight hospitals that expressed great interest... Fast forward and ... people really started dropping off ...They just said, ‘I’m out, this is too hard, and it’s too much.’ So one by one, as they are looking at their staff and their schedule, they started dropping out.”
Software and funding Limitations

- Labs stated that hospital software was not sufficient to support messaging
- The financial resources needed to support an implementation are significant and labs struggled to find or allocate the funding.

“A lot of the hospitals could not handle the complexity of the HL7 message and ignored the OBXs... None of the EHR support staff were able to read and accommodate the PHII guide.”

Sought grant funding to support project

Limitations in hospital system
Next Steps

• Form a Technical Assistance Team for NBS ETOR implementation

• Author an Implementation Guide and Toolkit aimed at hospital stakeholders.

• Collect and publish return on investment data for hospitals and laboratories for implementation of NBS ETOR.

• Form a task force for identification of EHR modules, third party software or custom development available for NBS ETOR stakeholders to assist with implementing data exchange. Work with these partners to determine a standard NBS ETOR module for data exchange.

• Create a repository of funding opportunities and guidance on applying for funding.
• The Building Blocks guide provides a basis to address the needs of laboratories implementing electronic messaging for NBS

• Additional Needs identified during a needs assessment include:
  • Resources, hospital engagement, software limitations and financial constraints

• The needs of laboratories identified will provide the NBS community with direction and priorities for future initiatives
Thank you to the laboratories who participated in this assessment!

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