

Newborn Screening Contingency Plan Update



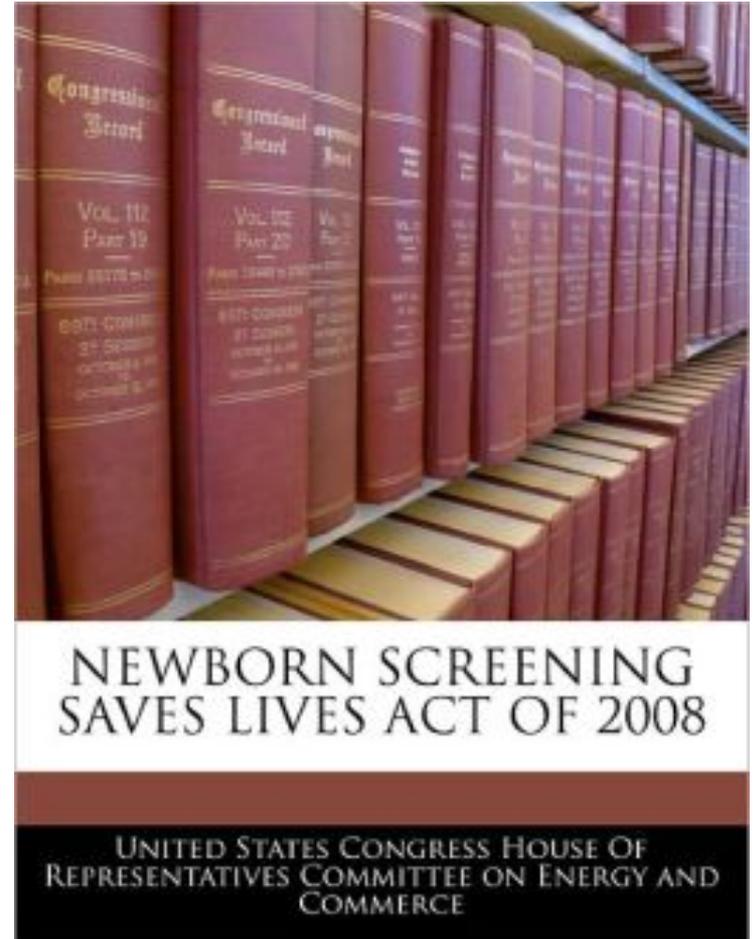
Scott Shone, PhD
APHL NBSGTS
St. Louis, MO – 3/1/16



Background

- Newborn Screening Saves Lives Act of 2008
 - Directs CDC – with HRSA and State Agencies – to develop a national NBS contingency plan for use by a state, region, or consortia of states in the event of a public health emergency.
- 2008 – CDC/HRSA Workshop
 - Federal partners; State public health programs (including newborn screening programs, state labs, maternal child health programs); State emergency preparedness programs; and Clinicians
- 2010 – Current plan published

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Background, cont'd

Strategic Objectives of Current Plan

1. A framework for specimen collection is established.
2. Specimens are shipped to the designated newborn screening laboratory site.
3. Specimens are processed.
4. Screening results are reported to the newborn screening follow-up program and physicians and families.
5. Positive diagnostic screening results are confirmed.
6. Availability of treatment and management resources is ensured.
7. Families are educated about newborn screening.
8. Carry out other activities determined appropriate by the HHS Secretary.

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Background

- Newborn Screening Saves Lives Reauthorization Act of 2014
 - The plan shall be updated as needed and at least every five years.



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113TH CONGRESS
2D SESSION

S. 1417

IN THE HOUSE OF REPRESENTATIVES

JANUARY 31, 2014

Referred to the Committee on Energy and Commerce

AN ACT

To amend the Public Health Service Act to reauthorize programs under part A of title XI of such Act.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

2

1 **SECTION 1. SHORT TITLE; TABLE OF CONTENTS.**

Project Goal: Assess and update the Newborn Screening Contingency Plan

With a focus on addressing gaps in laboratory and clinical follow-up

Objectives:

1. Seek stakeholder input on the current plan with regard to gaps in laboratory and clinical follow-up. (Public Comment)
2. Convene representative stakeholders and subject matter experts to draft content and review updates. (Advisory Committee)
3. Provide a final approved guidance document for dissemination.



Advisory Committee

Co-chairs: **Debbie Badawi, MD**, Chief, Child and Adolescent Health Unit, Maryland Department of Health and Mental Hygiene; and **Scott Shone, PhD**, Program Manager, Newborn Screening Laboratory, New Jersey Department of Health

- Newborn screening programs
- Public Health Labs
- Regional Collaboratives
- Family Voices
- Newborn screening HIT
- Metabolic Specialists
- Title V
- AAP
- AMCHP
- APHL
- ASTHO
- CDC
- HRSA
- March of Dimes
- NACCHO

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Committee Purpose

1. Provide content expertise, draft content and review updates
2. Provide guidance on a public comment survey and help disseminate the survey
3. Participate in Committee calls and meetings
4. Develop and assist in dissemination of the updated plan and any resources

Timeline



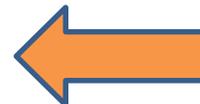
Dec 2015 – Advisory Committee Orientation & Kick-off Call ✓

Jan. 2016 - Advisory Committee Call ✓

Jan. – Feb. 2016 – Public Comment Survey Open ✓

Feb. 27, 2016 – In-person Advisory Committee Meeting

- Recommendations for updates to the plan and resources
- Dissemination plan for updated CONPLAN and resources



March – June 2016:

- Incorporate recommended updates
- Circulate updated draft to Advisory Committee for final review/comment
- Finalize updates



June 2016 – Submit final product

June and beyond – Disseminate and promote updated plan and resources





Meeting Framework

1. Develop a clear outline of updates to be made, including new content and updates and/or drafting language or edits to the text
2. Develop clear next steps in terms of what needs to be addressed and coordinated in order to complete recommended updates by June 2016 (with consensus on roles and tasks going forward).

Outcomes: List of recommended updates and completed action plans



Survey Overview:

- Open from Jan. 12 – Feb. 15, 2016
- Included background/demographic questions and guiding questions
- Comment could be provided in general, or on specific sections of the current plan
- Widely disseminated by partners, Committee members and organizations

Background Information

Respondents were asked general background information about their experience with emergencies affecting NBS, status of NBS contingency plans, familiarity with their state and the national CONPLAN, and familiarity with EMAC.

Background questions were tailored by stakeholder audience:

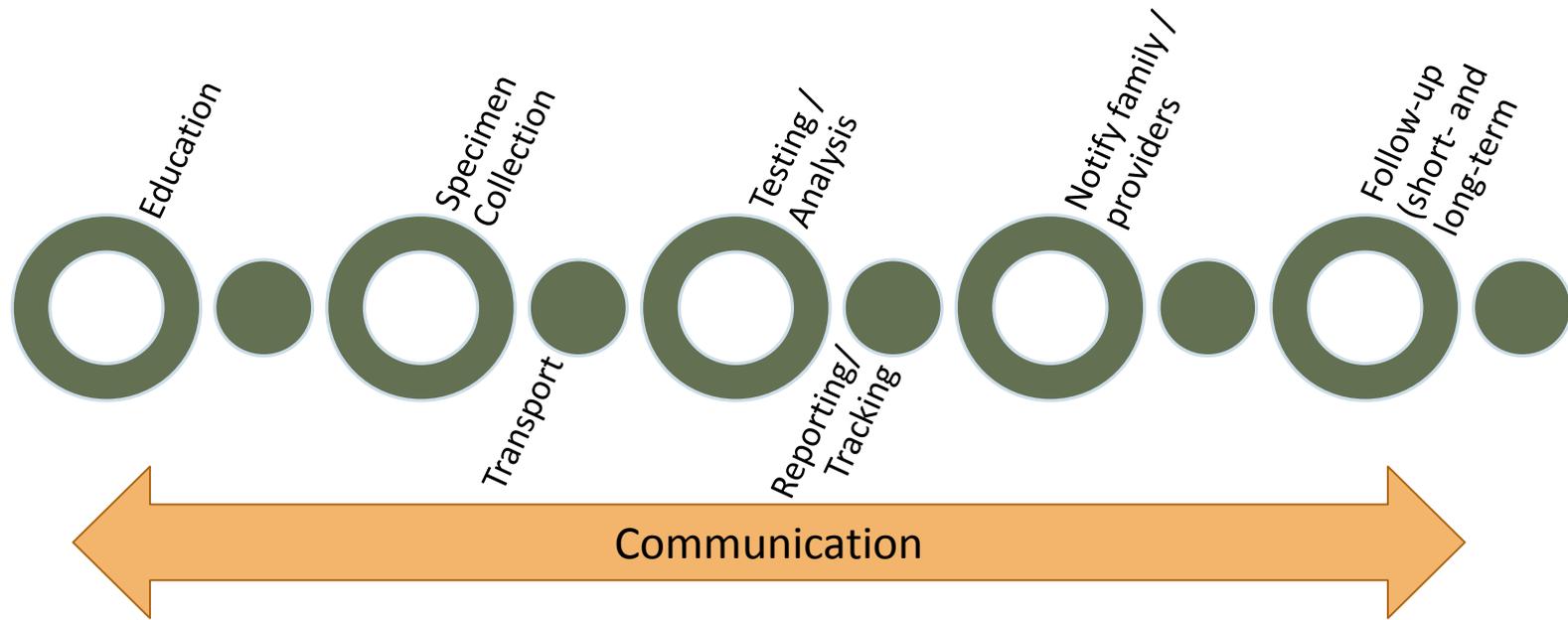
1. State/Territorial Newborn Screening Programs; Labs; MCH/CYSHCN Programs
2. Other stakeholders – Hospitals, Physicians, Specialists, Preparedness Programs, Local Health Depts., Families and Consumers, etc.

Public Comment - Themes

- General Comments
 - Components of a CONPLAN
 - Considerations for the Committee
 - Addressing Gaps in Follow-up
 - Helpful Resources and Formats
 - “Beyond on the Plan”
- Comments Specific to the Current Document



Plan Components



- Vulnerability Assessment
- Planning Assumptions
- Essential Functions
- Preparation Documents
- Training and Exercise
- Funding guidelines
- MOUs
- Case Examples
- How to connecting with other states / supports



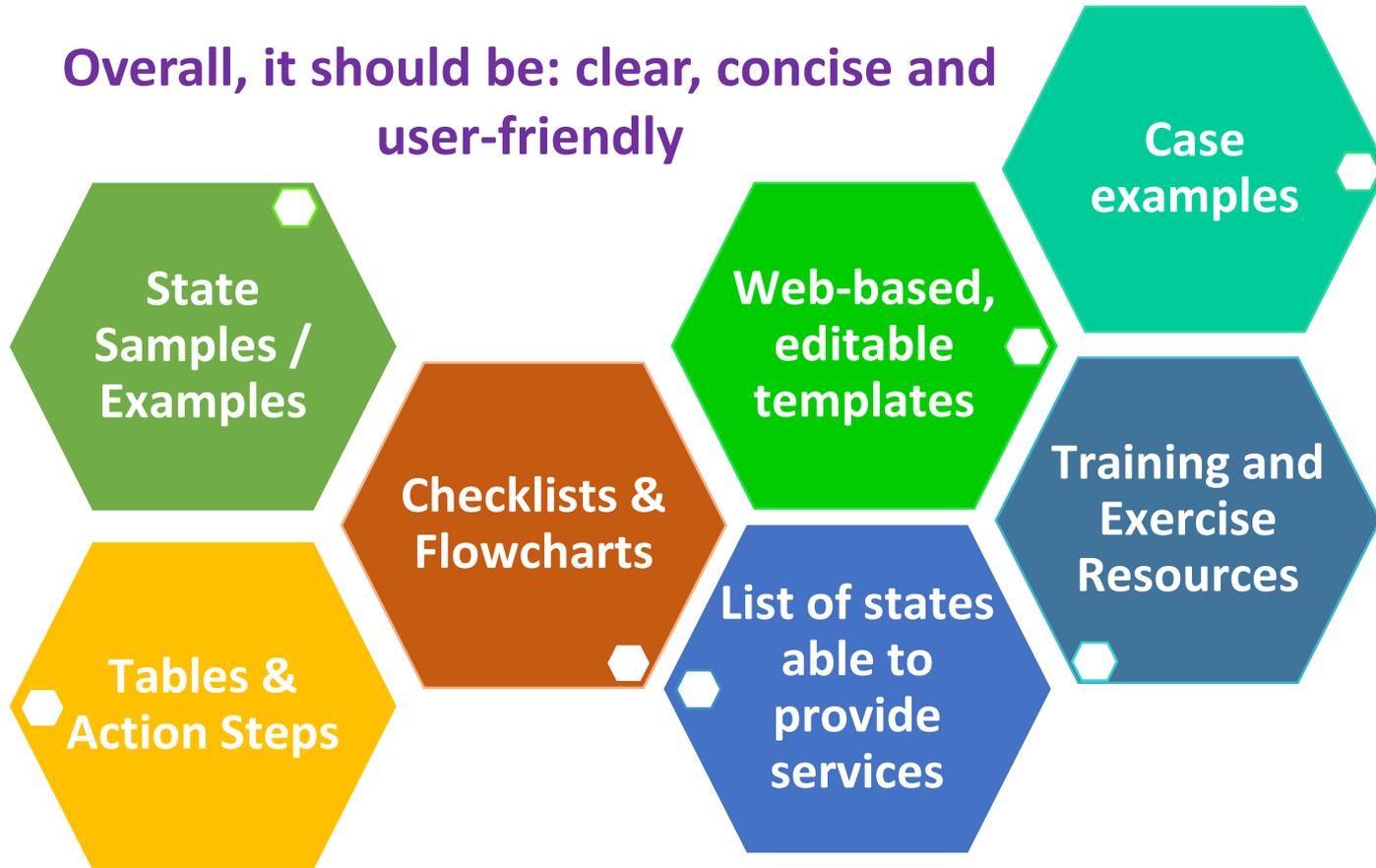
OTHER CONSIDERATIONS

- ❖ Point-of-Care
- ❖ EMAC
- ❖ Statutes and Privacy Concerns
- ❖ Technology
- ❖ Differences in State Panels
- ❖ Facilities near State Lines
- ❖ Language Barriers
- ❖ Risk of delayed response
- ❖ Competing Priorities
- ❖ Minimize Redundancy
- ❖ Centralize operations and communications



HELPFUL RESOURCES / FORMATS

Overall, it should be: clear, concise and user-friendly



Contingency Planning ≠ Preparedness



Contingency Planning ≠ Preparedness

Contingency Plan: a plan designed to take a possible future event or circumstance into account.

Preparedness: a continuous cycle of planning, organizing, training, equipping, exercising, evaluating, and taking corrective action in an effort to ensure effective coordination during incident response.

Bring NBS to Emergency Planners





Plan MUST be Usable

Best Practices Resources



Lack of collection cards

- Plan to obtain card from national stockpile



Primary courier not operating

- Identify alternate courier for transporting specimens



Reagent storage fails

- Alternate source for reagents



LIMS Server Crashes

- Establish manual reporting method



Treatment center is evacuated

- Other local, state or regional options

NBS Contingency Planning Process Map
EMAC Mission Ready Packages

Wisdom from The Lorax

“It’s not about what
it is, it’s about what
it can become.” —



Wisdom from The Lorax

**“UNLESS someone like you
cares a whole awful lot,
nothing is going to get
better. It’s not.”**

