New Disorder Readiness Scale (updated April 2020)

The NewSTEPs New Disorder Readiness Scale is intended to track progress toward full implementation of screening for a new disorder, as well as to provide data to NewSTEPs on how long the different phases and milestones of the implementation process take, and how these timelines vary by disorder, program and other variables.

Timing of activities and milestones achieved may differ by disorder. Therefore, we request that you complete a separate scale for each new disorder. If you are initiating implementation for more than one disorder, please complete a new scale for each. Here are some general notes for completing the tables:

- Phases 1, 2, and 4 represent implementation activities and Phase 3 represents education related activities.

- Your state may not need to conduct each activity/milestone listed. If the activity does not apply to your state, please check "not applicable" for that line.

- Start and completion dates are estimates. NewSTEPs would like to capture whether the activity takes three months or twelve months, and as such, exact dates are helpful, but not required. If you are unsure, please use the first of the month.

- If a required activity has not yet been initiated, please mark "not started." If preparations for an activity have been initiated, please select "started" and enter the month and year preparation was initiated.

- Use the notes field to capture feedback or other information that is important to understanding the time required to complete a given activity.

For more information and instructions on how to complete the New Disorder Readiness Scale, including clarification about the activities/milestones included, please see the New Disorder Readiness Scale Guide.

Date Started: _____   Update 1 Date: _____   Update 2: _____   Update 3: _____   Update 4: _____

Please complete the table below for the following disorder _____.

	Activity/Milestone	Not started	Date started (MM/DD/YYYY) *if exact day is unknown use 1st of the month	Date Completed/ Implemented (MM/DD/YYYY) *if exact day is unknown use 1st of the month	Not Applicable	Notes
Phase 1 — Authority to Screen	**Approval/Authority to Screen**					
	Obtain approval from the NBS Advisory Committee (from initial presentation/meeting to final approval).					
	Obtain approval from the Board of Health/Commissioner/other leaders (from initial presentation/meeting to final approval).					
	Other approval authority activities.					Specify:
	Mandate/approval to start screening/ state approves disorder for NBS.	███████	███████			

NewSTEPs New Disorder Implementation Project

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	Obtain approval from the Board of Health/Commissioner/other leaders (from initial presentation/meeting to final approval).					
	Other approval authority activities.					Specify:
	Obtain approval from the Institutional Review Board (IRB) to initiate pilot testing, if needed.					

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	Other approval authority activities.					Specify:
	Approval of Funding					

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Obtain approval from the Board of Health/Commissioner/other leaders (from initial presentation/meeting to final approval).					
Other approval authority activities.					Specify:
Develop a budget to show costs for screen, including laboratory testing, follow-up, information technology, etc.					

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	Other approval authority activities.					Specify:
	Obtain approval by NBS Advisory Committee for increase in funding.					

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Other approval authority activities.					Specify:
Obtain approval by the State Budget Authority.					

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Obtain approval from the Board of Health/Commissioner/other leaders (from initial presentation/meeting to final approval).					
Other approval authority activities.					Specify:
Other funding activities.					Specify:
Approval for fee increase.	■■■■■	■■■■■			

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	Other approval authority activities.					Specify:
	Fee increase implemented.	███████	███████			

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Phase2—Lab&Follow-upLogistics	**Laboratory**					
	Establish the Algorithm					
	Identify screen methodology/assay for					
	Please specify the methodology for (first-fifth) testing. (select one from dropdown menu) • MS/MS					

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Laboratory					
Equipment					
Identify the need for additional					
Identify laboratory space, modify space, and install needed equipment.					

NewSTEPs New Disorder Implementation Project

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NewSTEPs New Disorder Implementation Project

Phase2_Lab&Follow-upLogistics (vertical text)

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Laboratory					
Equipment					
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NewSTEPs New Disorder Implementation Project

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Equipment					
Identify the need for additional					
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P h a s e 2 _ L a b & F o l l o w - u p L o gi st ic s	**Laboratory**					
	Equipment					
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Follow-Up					
Develop staffing plan and ensure adequate staffing.					
Develop and gain buy-in on short-term follow-up protocols for abnormal screens.					
Develop and gain buy-in on long-term follow-up protocols for abnormal screens.					
Identify medical specialists and/or treatment center to work with/ refer to and establish contract/agreement to follow infants with abnormal screens.					
Overall Follow-Up Readiness	Check Box if your NBS Follow-Up program is ready to screen for this condition.			Yes, we are ready	
Earliest start date and latest completion date of follow-up readiness activities.	■			■	
Information Technology					
Disorder is Integrated into Laboratory Information Management Systems (LIMs) for Testing & Reporting					
Describe and develop specifications for LIMs.					

Phase 2

Activity/Milestone	Not started	Date started (MM/DD/YYYY) *if exact day is unknown use 1st of the month	Date Completed/ Implemented (MM/DD/YYYY) *if exact day is unknown use 1st of the month	Not Applicable	Notes
Identify required coding changes and implement changes to the LIMs.					
Validate the changes to the LIMs and re-test as needed.					
Disorder is Integrated into Follow-Up Reporting System					
Describe and develop specifications for the follow-up reporting system.					
Identify required coding changes and implement changes to the follow-up reporting system.					
Validate the changes to the follow-up system and re-test as needed.					
Disorder is Integrated into Electronic Order Protocol					
Describe and develop specifications for the electronic order protocol.					
Identify required coding changes and implement changes to the electronic order protocol.					
Validate the changes to the electronic order protocol and re-test as needed.					
Disorder is Integrated into Electronic Results Protocol					

_Lab&Follow-upLogistics

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Describe and develop specifications for the electronic results protocol.					
Identify required coding changes and implement changes to the electronic results protocol.					
Validate the changes to the electronic results protocol and re-test as needed.					
Other IT Activities					
Other IT activities.					Specify:
Overall IT Readiness — Check Box if this disorder is integrated into all applicable IT systems for your NBS Program (LIMs, follow-up reporting system, electronic ordering, electronic reporting, etc.)				Yes, we are ready	
Earliest start date and latest completion date of IT readiness activities.	■			■	

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Education for Families					
Identify and modify family education materials to be state specific.					
Initiate a strategy for family education materials and create own family education materials.					
Identify or create measures to track impact of family education materials.					
Family education materials are distributed.			███		
Education for Providers					
Identify and modify provider education materials to be state specific.					
Initiate a strategy for provider education materials and create own provider education materials.					
Identify or create measures to track impact of provider education materials.					
Provider education materials are distributed.			███		

Phase3_Educat

NewSTEPs New Disorder Implementation Project

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io n	**Education for the General Public**					
	Identify and modify education materials for the general public to be state specific.					
	Initiate a strategy for general public education materials and create own education materials for the general public.					
	Identify or create measures to track impact of education materials for the general public.					
	Education materials for the general public are distributed.			■		

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Phase 4 – Full Implementation	**Screening**					
	Pilot population testing (if outside lab is conducting pilot test, please describe in the notes).					
	Implement statewide screening (including follow-up, reporting, and education) for select population(s).	■	■			
	Implement statewide screening (including follow-up, reporting, and education) for all newborns.					

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