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PREFACE

The updated Facilitator's Guidebook: Newborn Screening in the Communities is a product of a concerted effort of key newborn screening program implementers to come up with an up-to-date instructional material to facilitate easy teaching and learning process. The need to come up with a ready reference arises due to the evident need to support newborn screening facilitators when organizing and running newborn screening orientations. It standardizes the information to be communicated to all health workers.

This version contains new developments in the program, updated statistics and data, and recommendations on how to conduct the training orientation. This guidebook includes slide presentations, scripts, and additional notes that may aid the facilitator in delivering the presentation. The script is based on the usual lines delivered in previous orientations as well as valuable contributions from the newborn screening pool of speakers and input from the Newborn Screening Centers, Centers for Health Development, and Newborn Screening Continuity Clinics.

There are five sections in this guidebook:

Module 1 contains an overview of the general aspects of the screening program. It describes the history of newborn screening in the Philippines as well as its importance.

Module 2 presents the highlights of RA 9288 (the Newborn Screening Act of 2004) with an emphasis on the role of health workers and its implications on the health facilities in the country.

Module 3 is devoted to the procedures for implementing newborn screening in health facilities. The presentation includes the newborn screening flow of operations.

Elective Module 1 is optional for refresher courses. This module discusses the role of Newborn Screening Continuity Clinics (NBSCCs) in the national newborn screening program.

Elective Module 2 is also an optional course that discusses each of the disorders in the Expanded Newborn Screening Panel, along with their symptoms and treatment. This course is recommended if the need arises based on the training needs of the participants.

Each of the modules have two versions, one for face-to-face trainings, and another for online trainings. Use the module appropriate for your training's mode of delivery. If you want more information about newborn screening, particularly on the conditions included in the expanded newborn screening panel, you may go through the Fact Sheets for Doctors, NCNBSS Manual of Operations, or visit www.newbornscreening.ph for more resources and information.

We hope that using this guidebook will be beneficial to you. Any pertinent information (such as local policies) may be incorporated or updated as appropriate. In order to help you the most, we ask for your feedback while you use this guidebook. Every year, NSRC will update this manual to reflect the most recent information, address persistent issues, and give facilitators further guidance on any crucial aspects of the newborn screening program.

Thank you and stay safe!

Newborn Screening Reference Center Contacts:

National Institutes of Health

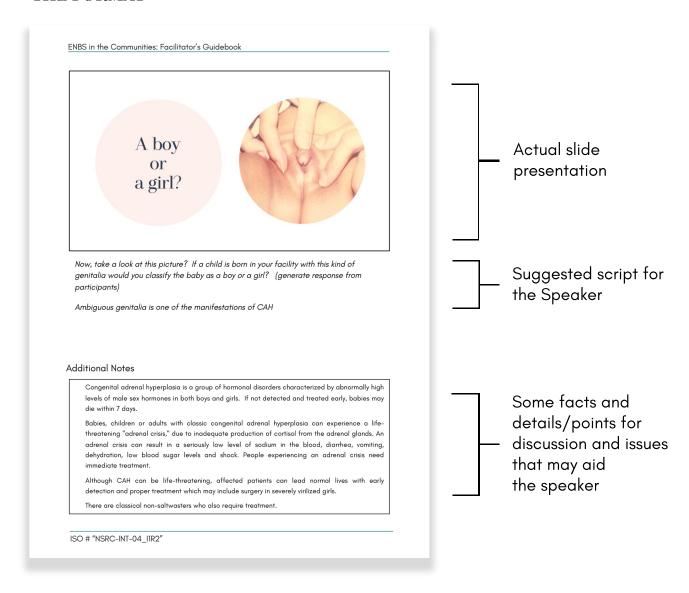
University of the Philippines Manila Email add: info@newbornscreening.ph

Newborn Screening AVP and Videos Inserts:

Year of Revision: 2023

HOW TO USE THIS BOOK

THE FORMAT



The suggested script for the speaker is in italics.

Additional notes for the speaker are written at the bottom of the page.

All points to be emphasized are in italic bold format.

This book comes with an 8-minute AVP to highlight steps for implementing newborn screening at the community level.

ACRONYMS

DOH Department of Health

DOH-RO Department of Health-Regional Office

ENBS Expanded Newborn Screening

HFSRB Health Facilities and Services Regulatory Bureau

IRR Implementing Rules and Regulations

LGU Local Government Unit

NBS Newborn Screening

NBSCC Newborn Screening Continuity Clinic

NCP Newborn Care Package

NIH National Institutes of Health

NSC Newborn Screening Center

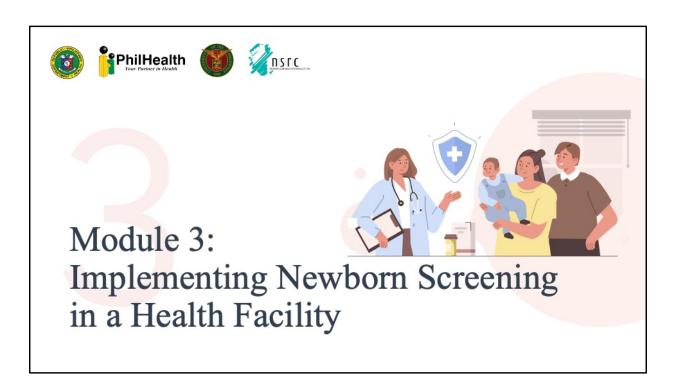
NSF Newborn Screening Facility

NSRC Newborn Screening Reference Center

PHIC Philippine Health Insurance Corporation

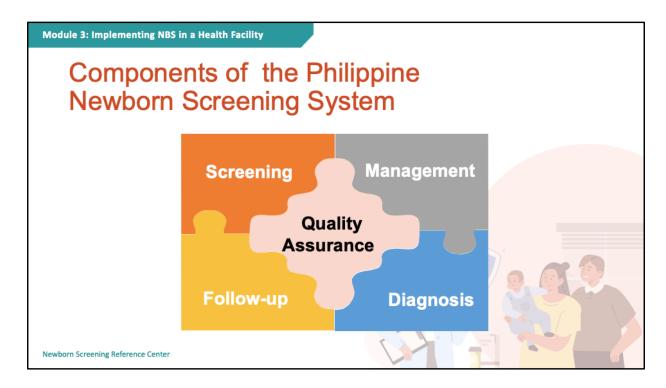
RHU Rural Health Unit





This last module of the training module covers topics on how newborn screening is implemented in a health facility. It will discuss the following:

- 1. Newborn Screening Flow of Operations and steps on how to start Newborn Screening in your health facility;
- 2. The Flow of Operations and the steps are already included in your orientation kit.



Newborn Screening is a system composed of the following components: The first component of this system is the screening. It involves all activities, resources and mechanisms related to the actual screening of newborns including collection, transport, testing, and releasing of results.

If found positive in one of the disorders, patients are followed up and recalled. Sometimes, if there are issues in the collected samples, the babies are recalled as well.

Screening is just screening. Children with positive screening results or outside the normal limits are subjected to confirmatory tests for proper diagnosis.

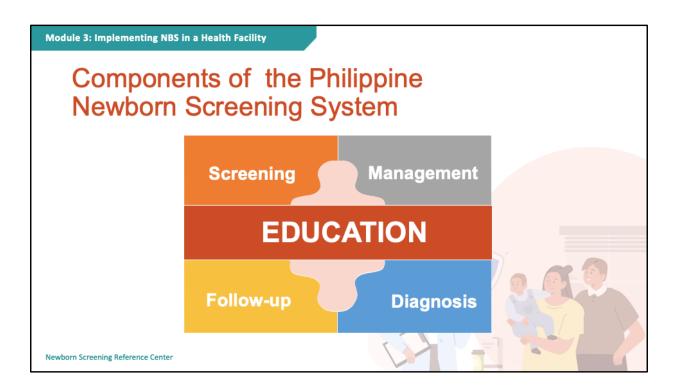
Long term management of children with the disorder is done by what we call NBS Continuity Clinics.

The fifth component is Quality Assurance and program improvement. Data are monitored and program protocols adjusted if problems are detected.

Additional Notes

Quality assurance is a process to check systematically if the services in the newborn screening system meets specific standards.





Finally, encompassing all the components in the Newborn Screening System is Education. This is the process of transferring information to relevant stakeholders. This include parents, physicians, policy makers, and the general public, making them informed on the significance of newborn screening to the life of a child and the need to take action to ensure that all newborns will undergo newborn screening.

Promoting Newborn Screening to parents should be done early for them to be able to save or prepare for the newborn screening cost of their baby.

Newborn Screening Flow of Operations

STEP 1: Motivating parents

STEP 2: Collecting samples

STEP 3: Handling and sending samples to the laboratory

STEP 4: Performing the test

STEP 5: Relaying/releasing results

STEP 6: Recalling patients

STEP 7: Managing/referring/ monitoring of positive cases

Newborn Screening Reference Center

Implementing Newborn Screening involves following a series of steps from motivation of parents to the management of patients.

Let us go through the steps of newborn screening.



Newborn screening starts at home or at your NSF with the NBS Team on the frontline.

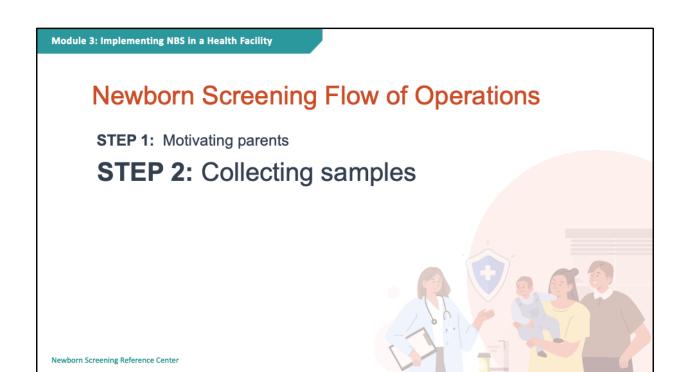
Step 1 is motivating the parents. It is the step where NBS implementers convince parents to have their babies screened.

It is important to motivate parents early enough to allow them to prepare for Expanded Screening. Not just financially but what it entails if the babies are found positive.

It is best done during prenatal visits, parents' classes, during home visits, or as early as during the conduct of pre-marriage counseling.

The NBS team members should know when is the best timing for parents to be informed and educated on newborn screening.

Posters, fliers, and audio video visual presentations are also important aids in making parents aware and informed of newborn screening.



Step 2 is collecting samples.

*You may run the following videos:

- NBS Sample Collection Video prepared by NSC-Central Luzon (https://www.dropbox.com/s/uonqdrr03cqsowy/NEWBORN%20SCREENING%20An o%20ang%20Iyong%20Pangarap%20para%20kay%20Baby.mp4?dl=0)
- Sending Good Sample (https://www.dropbox.com/s/frtwrl8nuvr6o8e/Sending%20Good%20Sample%20Ex plainer%20Video.mp4?dl=0)

Collection of Samples

Done in the participating health facilities:

- Hospital
- · Health Centers, Rural Health Unit
- · Lying-ins or birthing facilities

Or done at home by any of the following:

- Physician (consultants, residents, municipal health officers)
- Nurse
- Medical Technologist
- Midwife

There should be a person trained and designated to collect samples.

Newborn Screening Reference Center

Collecting Samples can be done either at home, in hospitals, health centers, Rural Health Units, Lying-ins or birthing facilities, which are enrolled in the program. These collecting facilities are referred to as NSF or newborn screening facilities. But sample collection should not be limited to the NSF alone. NBS team needs to come up with strategies to collect samples from babies who are delivered at home within their catchment areas.

Sample collection can be done by a physician (consultants, residents, municipal health officers), nurse, medical technologist or a midwife. The important thing is that there should be a health professional designated to collect samples. To address the issue related to fast turn-over of staff, make sure you have more than one personnel trained on newborn screening.



Collection of Samples

Samples should be collected at the:

- right time
- · right place
- right procedure/methods

Right time:

- · Baby is screened shortly after the 24th hour of life
- Baby had an adequate milk intake:
 Breastfeeding is strongly encouraged
- Before any procedure such as BT,TPN, or before putting baby on NPO

Newborn Screening Reference Center

In sample collection it is important to remember to collect at the right time, right place and using the preferred method.

Newborn screening is ideally done immediately after 24 hours from birth.

Baby should be feeding well. Breastfeeding is best for baby.

It should be taken before any procedure such as BT, TPN, or before putting baby on NPO for medical reasons.



Collection of Samples

A place in the health facilities should be designated for sample collection

Preferred method: Heel prick method

Newborn Screening Reference Center

Right place is a clean area where the sample can be taken. It can be at home or any health facility.

The preferred method is the Heel Prick Method.

The heel prick method is the preferred method over other methods of blood sample collection for newborn screening. Venous blood is used when there are other laboratory tests using blood samples are being done on the baby.

Additional Notes

The heel-prick method is the most preferred method of sample collection for newborn screening.

Venous blood is recommended only as an alternative when other blood works are to be performed. The reason why venous blood is discouraged is because it is more invasive and more traumatic to the newborn and blood collected from the veins has the tendency to over saturate the filter card.



Collection of Samples

Use BLACK or BLUE ball pen.
 Do not use pencil.

Fill out all items CLEARLY, LEGIBLY, and COMPLETELY.



 ALL of the information on the filter card is IMPORTANT for the interpretation of results and are critical for the immediate recall of patients with abnormal values.

Newborn Screening Reference Center

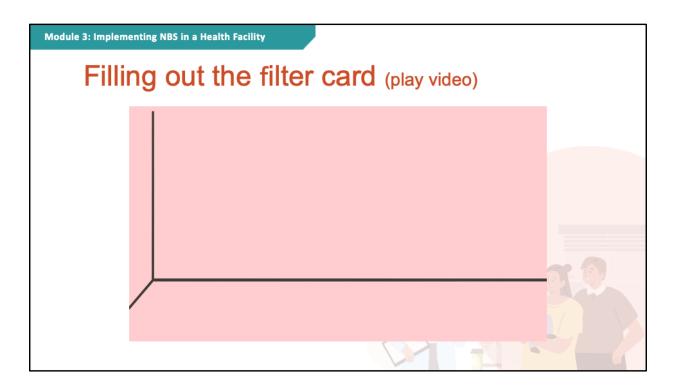
Another important point to remember in collecting the sample is to clearly, legibly, and completely provide ALL information asked on the filter card.

These data are all **important** in the **interpretation of results** and are **critical** for the **immediate recall of patients** who have positive results in the screening.

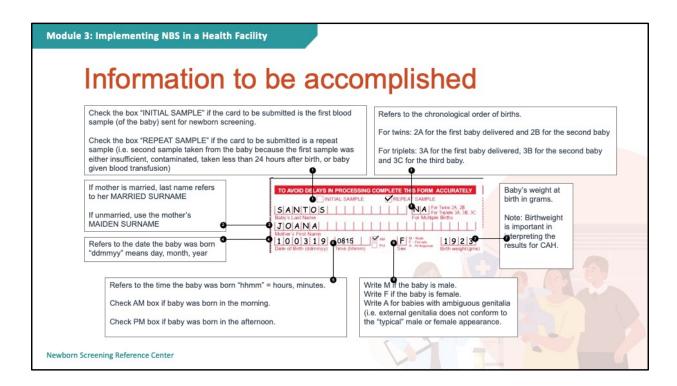
Module 3: Implementing NBS in a Health Facility									
NBS Filter Card									
6/300 9817 ⊃SN 104 81 909 S SNII. □ 104 909 SNII 1	TO AVOID DELAYS N PROCESSING COMPLETE THIS FORM ACCURATELY Salty's Last Name								
Filter Card	Information Card Detachable Stab								

The filter card is divided into 3 parts:

- 1. The filter card where blood spots are dropped.
- 2. The information card where data about the newborn are placed
- 3. The detachable stab, which is a requirement for PhilHealth claims

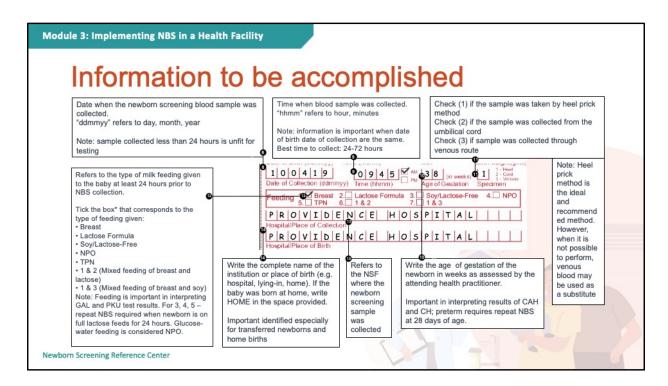


Here's a few reminders from NSC-NIH on how to fill out the Filter Card.



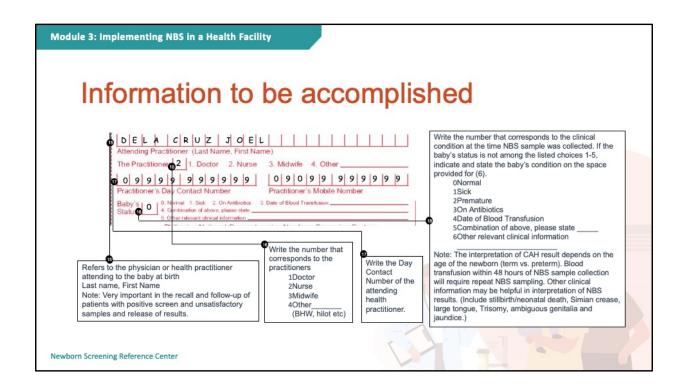
As mentioned, all data are important. Do not miss a single bit of information:

- 1. Indicate if it is an initial sample collection or a repeat sample collection. This information is important to prevent repeated inclusion of the patient's name in the list of patients for recall.
- 2. Write down the mother's surname in "baby's last name".
- 3. Specify if twin or triplets.
- 4. Write down the mother's first name. Newborns are identified by their mother's name.
- 5. Indicate the Sex if MALE, FEMALE, or AMBIGUOUS if you are not sure of the gender.
- 6. Specify Birth Weight.
- 7. Specify Date of Birth in ddmmyy (date, month, year) format
- 8. Indicate Time of Birth in ddmmyy (date, month, year) format



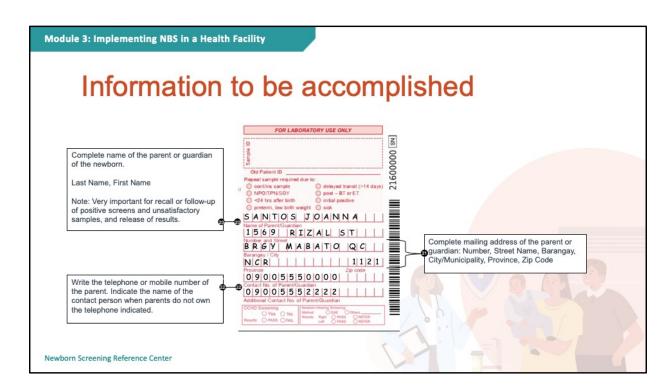
To avoid delays, complete the filter card accurately. Specify the following information:

- Age of Gestation in weeks
- Type of Specimen
- Date of collection in ddmmyy (day, month, year) format
- Time of collection in hhmm (hour, minute) format and specific whether it is AM or PM. This will inform the NSCs whether the newborn is at least 24 hours from birth at the time of collection.
- Feeding information is also very important esp. for PKU, Galactosemia, and other metabolic disorders included in the ENBS panel because these disorders are characterized by absence of certain enzymes that break down certain substances commonly found in milk products.
- In PKU for example, the baby does not have the enzyme that catalyzes the utilization of the essential amino acid phenylalanine. In GAL, the body lacks the capacity to process the sugar known as galactose, found in milk.
- Therefore, it is important that before the sample is collected, the baby should be fed and the type of feeding is properly recorded.
- Early latch-on is encouraged. Breastfeeding is best for baby.



Equally important are the following:

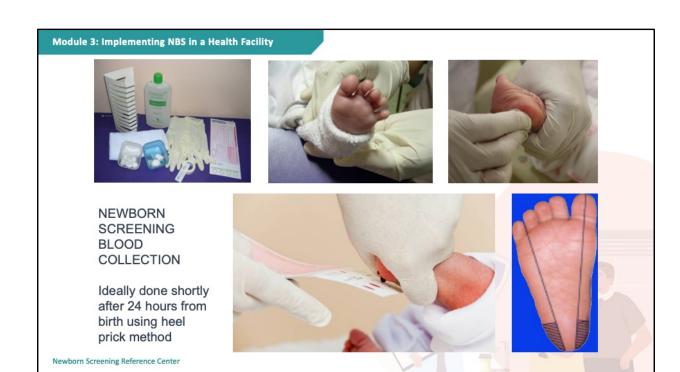
- 1. The hospital and place of collection
- 2. Attending Physician
- 3. Physician's contact number and mobile number. It is important that all possible contact numbers of the physician are available so the NSCs can easily recall the patients on-time in case of a screen positive result.
- 4. And, lastly, the baby's status whether normal, sick or premature, if on antibiotics, transfused, or combination of any, and other clinical relevant information as these are important in the analysis of test results. You may refer to the National Comprehensive Newborn Screening System (NCNBSS) Manual of Operations, Annex 23, uploaded at www.newbornscreening.ph



Make sure that filter cards you are about to use are not expired.



The filter card for the expanded screening has an orange sticker that indicates it is already for expanded screening.



You are now ready to collect the samples

- 1. Prepare the necessary materials
 - Alcohol
 - Dry and wet cotton swabs
 - Lancet (3mm tip)
 - Gloves
 - Micropore tape
 - Completely filled out filter card
 - Drying Rack
- 2. Gently massage the baby's heel to warm it. This will help increase blood flow.
- 3. To clean the heel, wipe with alcohol.
- 4. Dry with a cotton swab.
- 5. Prick the lateral side of the heel.
- 6. Apply intermittent pressure on the area surrounding the heel. Do not squeeze. Wipe the first blood droplet.
- 7. Wait for sufficient blood to form. Drop the blood on the filter card, filling each circle so that it is uniformly absorbed when viewed from the back side of the card. Do not superimpose the blood on top of another spot.



NEWBORN SCREENING BLOOD COLLECTION

Blood is dropped to a special filter card; blood spots are dried for at least 4 hrs in a drying rack; then sent to the laboratory

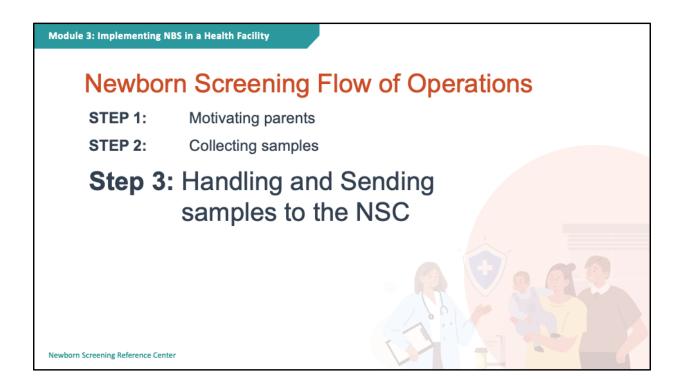


Newborn Screening Reference Center

Blood is dropped on the filter card.

- 9. Dry the filter card for at least 4 hours or until completely dried by placing it in a drying rack (refer to the photo on the screen). If you are drying 2 or more filter cards, place them in the drying rack in an alternating manner. Drying should be at room temperature without exposing it to direct heat or air (like an electric fan or aircon).
- 10. After drying, you may now send it to the NSC through your preferred courier.

Note: You may play the Sample Collection video produced by the Newborn Screening Center – Central Luzon after this slide



Now, the 3^{rd} step in the flow of operations of newborn screening is Handling and Sending samples to the NSC.

You already saw how samples are handled in the previous slide. But here are a few reminders .

Step 3: Handling and Sending samples to the NSC

Proper handling is necessary to:

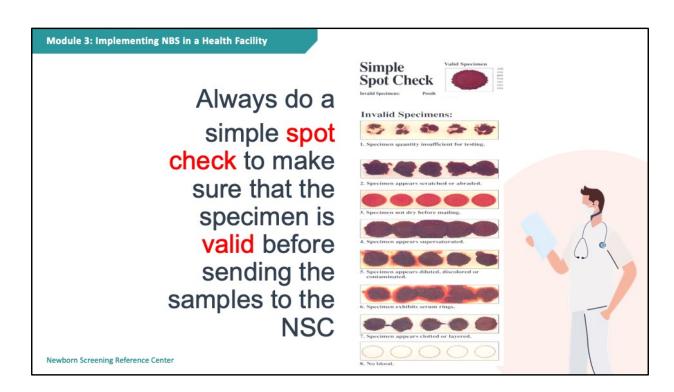
Prevent contamination and maintain integrity Immediate transport of samples ensures:

Prompt testing and analysis resulting to the timely diagnosis of baby's condition

There is a designated pick-up time **DO NOT BATCH SAMPLES!**

Newborn Screening Reference Center

Samples should be properly handled to prevent contamination. Check for validity and send the sample after it is completely dried for at least 4 hours and checked for validity. For samples collected by courier services, usually, there is a designated pick-up time. However, if the sample is to be sent to the NSC using other forms of transportation, it is also recommended that a specific time of transport should be established. When sending samples: send samples as soon as possible. Do not batch or hoard the samples. Document when specimens were sent out.



Before you send it to the NSC, make sure that the specimen is valid by visually observing the quality of the blood spots. Looking at the card, the correct sample is the one in the upper rightmost position. Those that follow are illustrations of invalid specimens. You may play the video on How to Spot Unfit Samples, produced by NSC-NIH https://bit.ly/UnfitSamples

Determining the Acceptability of Samples

Acceptable Samples

Unacceptable Samples

Samples are considered acceptable or satisfactory if they are adequate and are fit for NBS testing.

Unacceptable or
Unsatisfactory sample are
those samples that are either
rejected (due to insufficiency
or contamination) or those
that have questionable data
written on the filter card

Newborn Screening Reference Center

Samples should be properly handled to prevent contamination. Send the sample after it is completely dried for at least 4 hours and checked for validity. For samples collected by courier services, usually, there is a designated pick-up time. However, if the sample is to be sent to the NSC using other forms of transportation, it is also recommended that a specific time of transport should be established. When sending samples: send samples as soon as possible. Do not batch or hoard the samples. Document when specimens were sent out.

Handling & Transporting Samples

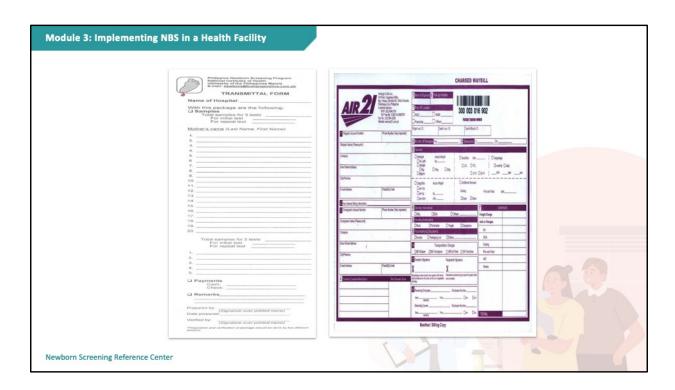
Preparing samples for transport

- Stack the dried filter papers in an alternate fashion
- Wrap the stacked samples in clean paper and place inside an envelope



Newborn Screening Reference Center

Make sure also that the dried filter cards are arranged in an alternate fashion as shown in the video. Wrap them in clean paper and place them inside an envelope.



Accomplish the transmittal form and air way bill properly and completely.

Transporting Samples

- Address the envelope to the Newborn Screening Center
- Arrange for regular pickup with the courier

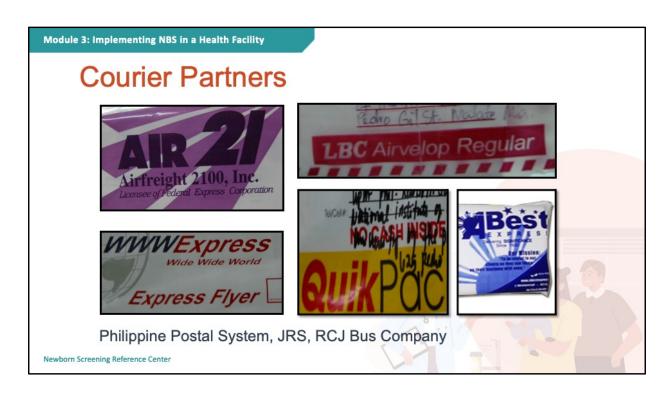


Newborn Screening Reference Center

If you send it through courier at the address of your NSC, always make sure that you remember the complete details of your NSC. In case you forget these details, please refer to the administrative mechanics sent to you together with the welcome letter.

For those who use courier services, arrange with the courier the schedule of regular pick-up of the sample.

As already stated in the previous presentation, there are seven NSCs now operating in the Philippines.



Here are few of our official courier services. Couriers are different for each NSC.

Additional Notes

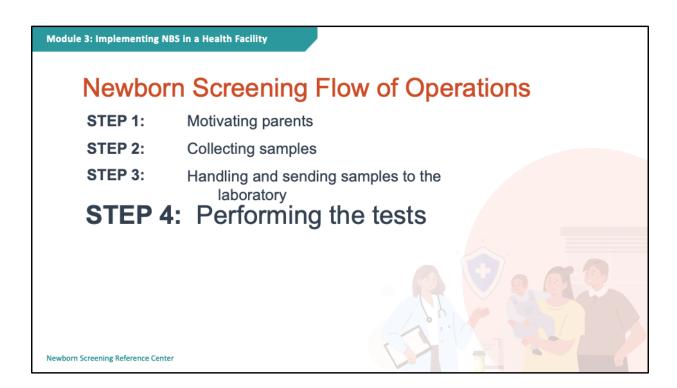
Other courier services that are also giving services to the newborn screening program are JRS, Aboitiz, and Abest. Provincial bus companies as well as airlines are also providing transport services. If your facility needs assistance in arranging with transport services, it may coordinate with the CHD or the NSC.



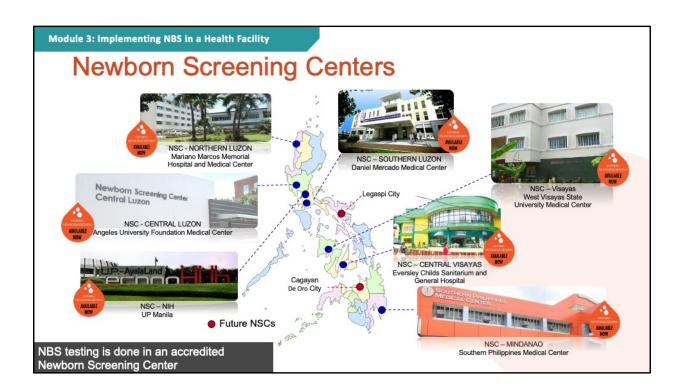


Those without courier services, please explore other means.

You can always ask the assistance of the NSC in case you are having a hard time finding a means to transport the sample. Couriers are different for each NSC.



After sending samples to the laboratory, tests are performed as shown in the video.



As mentioned, samples are sent to seven NSCs in the country:

NSC-CL - CAR and Region III

NSC-NL - Regions I and II

NSC-SL - Regions IVA

NSC-NIH - Regions IVB, V and MM

NSC-Visayas - Regions VI, VIII

NSC-Central Visayas - Region 7

NSC-Mindanao – Regions IX, X, XI, XII, Caraga, ARMM



Once the samples arrive at the NSC, samples are sorted. If fit for testing, numbered or accessioned, entered into the database, digitally captured, and then punched (3mm). Tests are performed by trained medical technologists



Results are available 7-14 working days after samples are received by the NSC. But if the sample showed positive screen or has an invalid specimen, the NSC staff immediately informs the hospital facility concerned about the result. The attending health practitioner will be alerted immediately to facilitate the recall, management and referral of screen positive patients.

Newborn Screening Flow of Operations

STEP 1: Motivating parents

STEP 2: Collecting samples

STEP 3: Handling and sending samples to the laboratory

STEP 4: Performing the tests

STEP 5: Relaying/Releasing

results

Newborn Screening Reference Center

After performing the tests, how are the results relayed and released?

Step 5: Relaying of Results

Two steps in the relay of NBS results:

- Relaying NBS results from the NSC to NSF or collecting health facilities
- Relaying NBS results from collecting NSF to parents

Newborn Screening Reference Center

There are 2 steps in the relay of NBS results

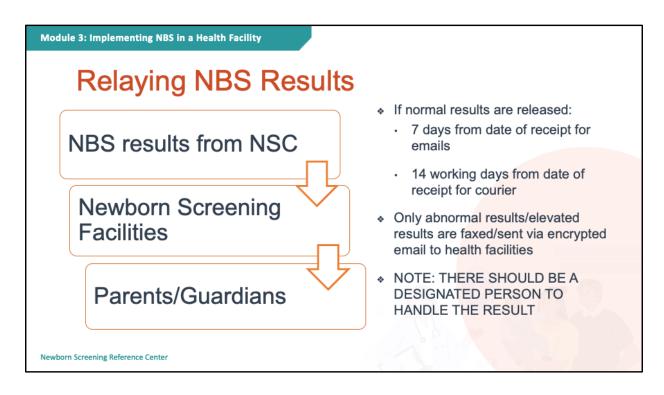
- 1. Results are released from the NSC to the NSF, YOUR health facility
- 2. From your health facility, the NBS result is relayed to parents

Relaying is done immediately.

Additional Notes

- Q. Most of our patients are from far-flung places and are transient only in our city. Tracking newborns will be extremely difficult.
- A. The NSF-NSC may ask the assistance of the CHD-NBS Coordinator in tracking hard-to-track- down patients





These are very simple and easy steps, If you also have completed the information required in the filter card, there should not be any problem in relaying the result.

If normal, results are released 7 days from date of receipt for emails and 14 working days from date of receipt for courier. In some cases especially from hard to reach areas where courier is not available, results are also released via postal mail and his could take up to 3 weeks for postal mail. Only abnormal results/elevated results are faxed/sent via encrypted email to health facilities

THERE SHOULD BE A DESIGNATED PERSON TO HANDLE THE RELEASE OF RESULTS

As a reminder, it is very important to verify contact details when filling the filter card. We have cases of lost to follow up due to wrong addresses and contact details.

Relaying NBS Results

In relaying ENBS results <u>from NSC to collecting health</u> <u>facility</u> and <u>to parents</u>, the following should be taken into consideration:

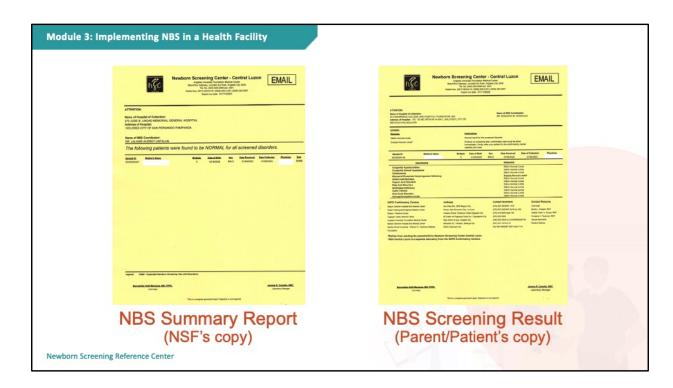
- What department/unit/office is in charge of receiving the result?
- Who is in-charge in receiving and releasing ENBS results?
- What should the person-in-charge do after receiving the result? To whom will it be given?
- When and how are ENBS results released to parents?

Newborn Screening Reference Center

In relaying the ENBS results, some things must be taken into consideration:

- 1. What department/unit/office is in-charge of receiving the results?
- 2. Who is in-charge of receiving and releasing the ENBS results?
- 3. What is the protocol after receiving the results from NSC?
- 4. When and how are ENBS results released/relayed to parents?

Your health facility must establish a system to effectively implement ENBS. It is also important that you assign or designate an NBS Coordinator in your health facility.



Here is a sample of ENBS Summary Report released to the Newborn Health Facility, and the sample ENBS Screening Result Form given to parents.

Newborn Screening Flow of Operations

STEP 1: Motivating parents

STEP 2: Collecting samples

STEP 3: Handling and sending samples to the laboratory

STEP 4: Performing the tests

STEP 5: Relaying/releasing results

STEP 6: Recalling patients

Newborn Screening Reference Center

Newborn Screening Flow of Operations



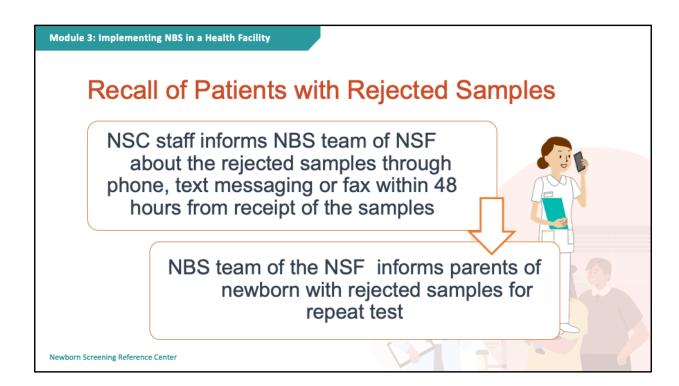
 Every baby with a positive screening must be recalled for confirmatory tests and management

- Types of Recall
 - Recall of patients with rejected samples
 - Recall of patients with elevated results

Newborn Screening Reference Center

It is time to recall patients with rejected samples and with elevated or positive results.

Every baby with a positive screen result must be recalled for confirmatory testing and management.



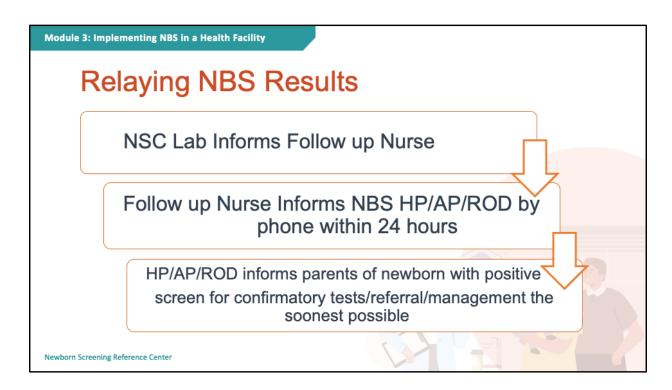
How to recall patients with rejected samples?

The staff informs NBS team of the health facility about the rejected samples through phone, text messaging or fax within 48 hours from receipt of samples. Reasons for rejections of sample is relayed as well.

The NBS team of the Newborn Screening Facility then informs parents of newborn with rejected samples for repeat test.

The repeat test has no extra charge.

To avoid sending in rejected samples, make sure that samples are collected properly. Contamination and insufficiency are the most common reasons of rejection. Improper collection will cause a delay in treatment or patient management. The parent may also decide against returning for repeat testing as a result of the hassles.



How do we recall patients with positive screens?

The NSC lab informs its follow-up nurse.

The follow up nurse informs NSF by phone within 24 hours.

The NSF informs the parents of newborn with positive screen for confirmatory tests/referral management.

Recall of positive screens

Each participating institution should <u>establish an</u>
<u>effective system</u> in the recall of patients with elevated
and rejected samples

- Designate a person to take charge of the recall
- · Define process in the recall of patient
- Define strategies in the recall of patient
- Establish proper documentation for prompt recall

Newborn Screening Reference Center

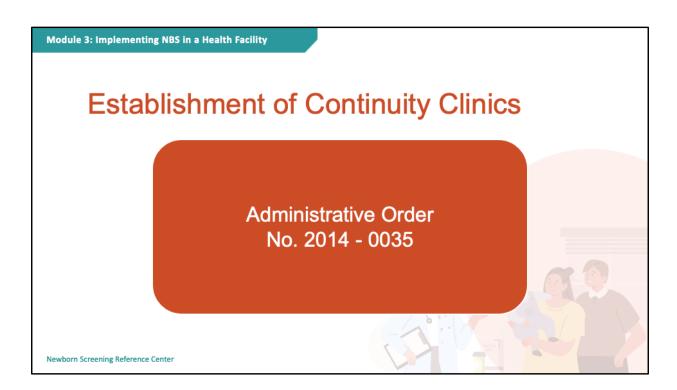
Just like the collection of samples, Each health facility should <u>establish</u> an <u>effective</u> <u>system</u> in recalling of patients with elevated results and also for rejected samples.

Designate a person to take charge of the recall Define the process in the recall of patient Define strategies in the recall of patient Establish proper documentation for prompt recall

Additional Notes

- Q. Who pays for the repeat sample, if there is an elevated result or invalid specimen?
- A. Repeat sample collection for an elevated result is free of charge for parents. However, invalid specimen are charged to the collecting facility.
- Q. Who pays for the confirmatory test?
- A. For metabolic and hemoglobin disorders, confirmatory test is included in the Php 1,750. For Endo and G6PD deficiency, confirmatory tests are care of the parents.
- Q. Considering the volume of patients who deliver in our institution (being a high risk referral center), how is tracking of patients be guaranteed?
- A. The motivation part is very important to parents in realizing their responsibility to promote their child's right to health through newborn screening.
 - The NSF and NSC may seek the assistance of the CHD NBS Coordinator in tracking difficult cases.





DOH Administrative Order No. 2014 – 0035 was released to provide policies and guidelines for the setting-up and implementation of NBS Continuity Clinics and Birth Defects Continuity Clinics for referral and management of all screened-positive newborns.

These clinics were established in line with the growing number of referrals and patients being managed and the implementation of an expanded screening. This will strengthen the treatment and referral network and ensure the capable management of confirmed positive cases.

Note: For more information regarding the roles and responsibilities of Continuity Clinics, please refer to the Elective Module

Newborn Screening Flow of Operations

STEP 1: Motivating parents

STEP 2: Collecting samples

STEP 3: Handling and sending samples to the laboratory

STEP 4: Performing the tests

STEP 5: Relaying/releasing results

STEP 6: Recalling patients

STEP 7: Managing/ Referring/ Monitoring

of Positive Cases

Newborn Screening Reference Center

Lastly, all positive cases must be managed, referred to specialists, strictly monitored and consistently followed-up.

Prompt recall of patients would mean prompt management of babies thereby





saving them from possible mental retardation and death.

Never give up on any case!

Should there be difficulty in recalling patients, you may seek the assistance of DOH Center for Health Development



Newborn Screening Reference Center

Prompt recall of patient would mean prompt management of babies thereby saving them from mental retardation and death

Never give up on any case! All cases are extremely important!

You may also seek the assistance of DOH Center for Health Development should you encounter any problem in recalling patients.

Step 7: Managing/Referring/Monitoring of Positive Cases

Prompt and appropriate management of positive cases is essential in saving babies from the consequences of the disorder

Newborn Screening Reference Center

This step is very important as it is essential in saving babies from further complications.

What to do for patients with positive newborn screen?

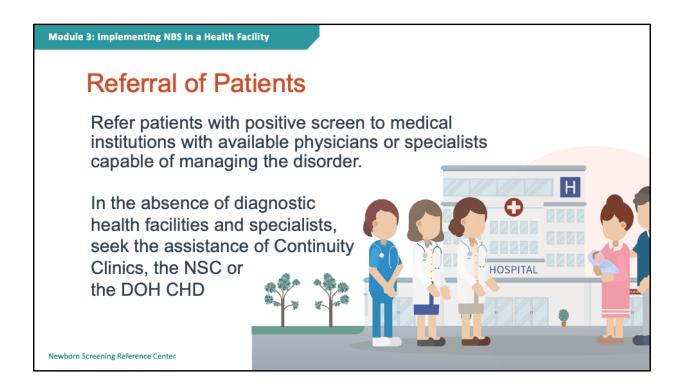
- 1.Recall patient
- 2. Facilitate confirmatory testing
- 3. Check if confirmatory test is done
- 4.Follow-up results for confirmatory test
 - · If positive refer the patient to specialist
 - If negative inform AP and close the case

Newborn Screening Reference Center

What do you do for patients with positive newborn screen?

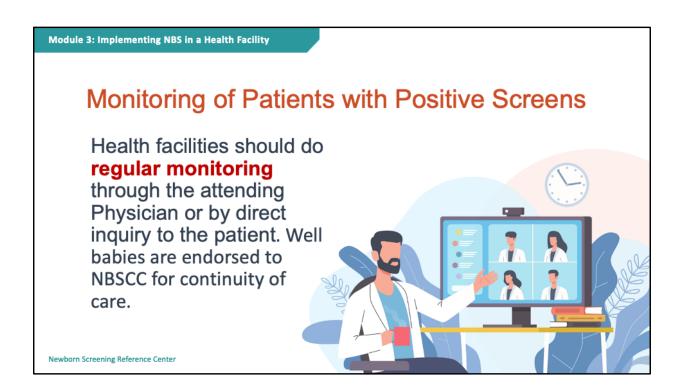
- 1. Recall patient and check their clinical status
- 2. Facilitate confirmatory testing
- 3. Check if confirmatory test is done
- 4. Follow-up results for confirmatory test, if found positive refer the patient to specialist, otherwise inform the attending physician and close the case.



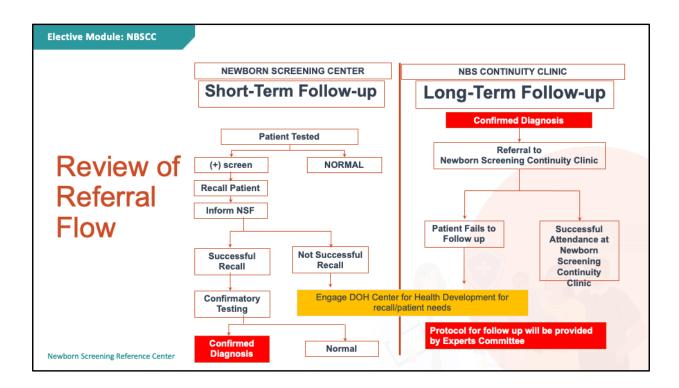


How to refer patients?

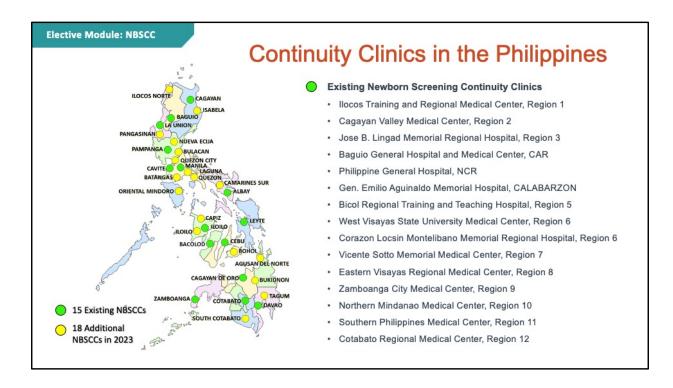
Refer them to medical institutions with available physicians or specialists capable of managing the disorder. In the absence of diagnostic health facilities and specialists, seek the assistance of Centers for Health Development or the NSC.



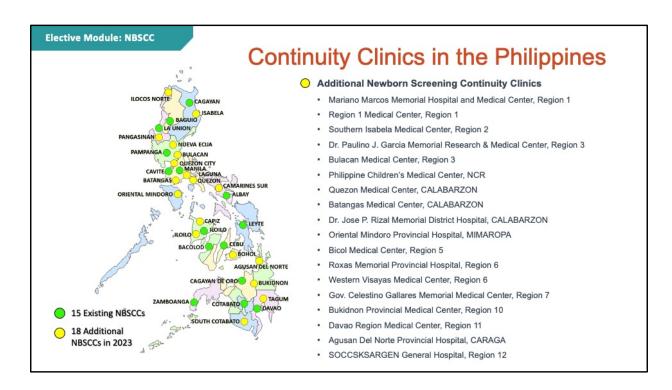
Health facilities should do monitoring regularly through the Attending Physician or by direct inquiry to the patient.



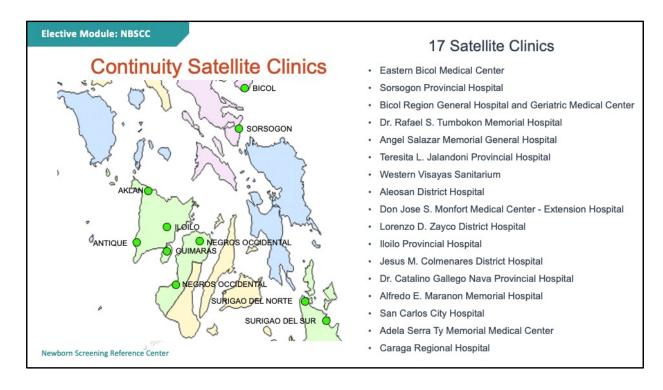
The Newborn Screening Centers' (NSCs') role currently extends to the confirmation of the diagnosis and the referral to a specialist for long-term treatment. With the establishment of the NBS Continuity Clinics, the patients diagnosed by the NSCs will be turned over to the NBS Continuity Clinics for long term care and monitoring. The network of NBS Continuity Clinics will definitely improve the quality of life for our diagnosed patients.



These continuity clinics are located in tertiary and government hospitals in 14 regions. Mimaropa region is being handled by PGH NCR; Caraga region is being handled by SPMC Region 11 and; ARMM is being handled by CRMC Region 12.



In 2023, 18 new continuity clinics were added from the initial 15 continuity clinics.



These satellite clinics function as a network of medical facilities to assist the NBSCCs in patient management. The satellite clinic's host facilities integrate NBS clinic services into their OPD services.

Contact details of the continuity and satellite clinics are available at https://www.newbornscreening.ph/index.php?option=com_content&view=article&id =205&Itemid=85

NOTE: The presenter/facilitator may include in the presentation their region's continuity clinic and/or satellite clinic team members' composition and clinic schedules.

Newborn Screening Flow of Operations

STEP 1: Motivating parents

STEP 2: Collecting samples

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STEP 6: Recalling patients

STEP 7: Managing/referring/ monitoring of positive cases

Newborn Screening Reference Center

So again, to sum up:

- Motivate the parents
- Collect the samples properly
- Efficiently handle and send samples to NSC
- •Tests are performed by the NSCs.
- •Results are relayed to the health facility
- •Health facility releases the results to parents
- •Patients with rejected samples are recalled.
- •Patients with positive screen results are recalled for confirmatory tests
- •Patients confirmed with the diagnosis are referred for treatment.
- •And lastly, all patients with confirmed diagnosis must be monitored.

It is a complete system – comprehensive, integrative, sustainable and collaborative.

HOW TO START NEWBORN SCREENING IN YOUR HEALTH FACILITIES?

Newborn Screening Reference Center

STEP 1: Inform management on how to set- up or to include NBS as one the services of the health facilities

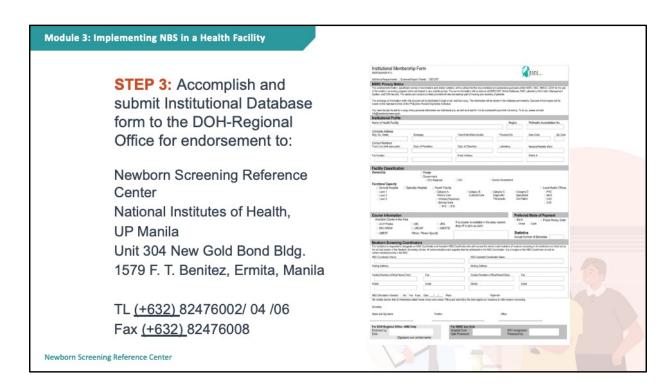
STEP 2: Organize a NBS Team which may be composed of:

- a. NBS Coordinator
- b. Administration group
- c. Accounting group
- d. Follow-up group

Newborn Screening Reference Center

Here are our easy steps, if you are not the decision-maker in your health facility, inform management of your interest to set- up or to include NBS as one the services of the health facilities.

Organize a NBS Team composed of NBS Coordinator and Assistant Coordinator.



The form must be accomplished, endorsed by the DOH-CHDs, and submitted to:

Newborn Screening Reference Center National Institutes of Health, University of the Philippines Manila Unit 304 New Bond Gold Bldg. 1579 F. T. Benitez, Ermita, Manila TL (+632) 82476002/04/06 Fax (+632) 82476008

 ${\it Email: info@newbornscreening.ph}$

Private facilities must attach a copy of any of the following permits: DTI, Business, Mayor's Permit

NOTE: Endorsement from the Center for Health Development (formerly DOH-Regional Office) is a prerequisite for the assignment of facility codes to the applying health facilities.

Reference: Department Memo 2018-0167 Application of all Health Facilities to become Newborn Screening Facilities.

Newborn Screening Reference Center

If application is submitted to the NSRC, it will be forwarded to the Department of Health – Center for Health Development following Department Memo 2018-0167 Application of all Health Facilities to become Newborn Screening Facilities. Endorsement from the DOH-CHD is a prerequisite for the assignment of facility codes to the applying health facilities. Or you may want to send your form through email or directly to the DOH-CHD.

Once endorsement is received, NSRC will send the following to the applicant:

- a. A welcome letter indicating the facility code.
- b. Administrative mechanics including how to order the NBS Specimen Collection Kit.

STEP 4: Prepare and send a PURCHASE ORDER of NBS Specimen Kit to NSC

Mechanics in Preparing Purchase Order (PO) for NBS Specimen
Collection Kit

a. All orders for the NBS Specimen Collection Kit must be in Purchase Order (PO) of the requesting health facility

Newborn Screening Reference Center

Prepare and send P.O. of NBS Specimen Kit to NSC.

Here are the mechanics you have to be reminded of:

a. All orders for the NBS Specimen Collection Kit must be in P.O. form for the requesting health facility

Additional Notes

- Q. What does a kit contain?
- A. Filter card, lancet, transmittal form and parent result form. Upon placing an initial order, the kit includes a drying rack, spot check poster, 2 NBS posters.



STEP 4: Prepare and send a PURCHASE ORDER of NBS Specimen Kit to NSC

b. The duly signed and approved P.O. must be sent through courier or mail to:

Newborn Screening Centers

- Northern Luzon
- -Visayas
- Central Luzon
- -Central Visayas
- Southern Luzon
- -Mindanao

- NIH

Newborn Screening Reference Center

The approved P.O. must be initially sent to the NSC through fax and the original copy mailed.

Five (5) sets of ENBS Specimen Collection Kit is the minimum allowable order.

STEP 4: Prepare and send a PURCHASE ORDER of ENBS Specimen Kit to NSC

- c. Minimum allowable order per P.O.: 5 sets of ENBS Specimen Collection Kits (P1750/kit).
- d. Ordered supplies will be sent/transmitted by NSC through courier of your preference with the Original Sales Invoice.

Newborn Screening Reference Center

Ordered supplies will be sent/transmitted by NSC through courier of your preference with Sales Invoice in triplicate form.

Original copy of sales invoice retained and forwarded to accounting department who received the goods. The duplicate copy is sent back to the NSC.

Person in-charge of receiving the ordered supplies must immediately inform NSC of any discrepancy in the delivery within the day of receipt. Otherwise, it shall be deemed received in good order and condition.

Delivery of orders is within 7 working days upon receipt of the PO from health facility.

Newborn Screening Reference Center

The person-in-charge of receiving the ordered supplies must immediately inform NSC of any discrepancy in the delivery within the day of receipt. Otherwise, it shall be deemed received in good order and condition.

Delivery of orders is within 7 days upon receipt of the P.O. from the health facility.

NSC will send NBS Specimen Collection Kit based on the quantity indicated in your P.O.

Terms of payment:

• Walk in

• 45 days from receipt of the sales invoice

Payment:

Made through the following:

• Bank to bank

• Check

• Cash

• Postal Money Order

NSC has given the health facility a payment term of 45 days from receipt of sales invoice but it can be up to 60 days for PHIC accredited facilities. Coordinate with NSC for specific details.

Payment can be made through bank to bank transaction, check and cash.

For validated deposits slips:

Should be sent to NSC for proper recording and posting. Invoice No. must be indicated in the deposit slips

Any unpaid account after the given term: shall be imposed an interest charge of 2% per month until fully paid

Newborn Screening Reference Center

All bank to bank transactions are supported with validated deposit slips. After transaction has been made, please fax the deposit slip immediately to NSC for proper recording and posting. The invoice number must be indicated in the deposit slips.

Any unpaid account after the given term, a 2% per month interest will be imposed until fully settled. Please pay on time to avoid delays!

Policy for the NBS specimen collection kit:

- ♦ NBS Specimen Collection Kit = one newborn
- Only filter cards due to the following will be replaced
- for free:
 - POSITIVE SCREENING
 - CONTAMINATION
 - TAKEN <24 HRS. FROM BIRTH
 - LATE TRANSMITTAL
- Submit a list of these patients.

Newborn Screening Reference Center

NBS Specimen Collection Kit is good for one newborn. NBS kit includes filter card, a lancet, pink brochure and transmittal form. For first order, poster and drying rack are included in the kit.

Only filter cards used for repeat sample due to positive screening will be replaced for free. A list of patients with second/repeat cards should be submitted.

However, in the meantime, filter cards that were rejected due to reasons of Contamination, insufficient sample taken less than 24 hrs. FROM BIRTH, and LATE TRANSMITTAL (samples sent to the NBS Lab > 10 days from date of collection) upon evaluation of the laboratory will be replaced once for free.



STEP 5: Inform all sections concerned about the forthcoming availability of newborn screening in the health facility

STEP 6: Prepare an Advocacy and Promotional plan for the following:

- a) Administrators
- b) Professionals / Health Practitioners
- c) Expectant parents, guardians/patients
- d) Growing numbers of confirmed positive patients

Newborn Screening Reference Center

After the P.O. is sent to NSC, inform all sections concerned about the forthcoming availability of newborn screening in the health facility.

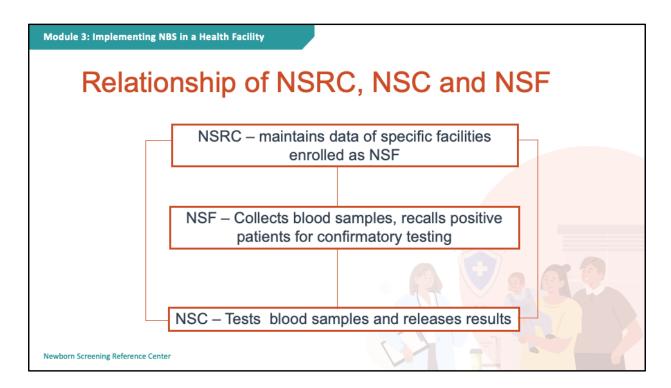
Prepare an advocacy and promotional plan for your administrators, professionals, health practitioners, expectant parents, guardians and patients.

As soon as the health facility receives the ENBS specimen collection kit, it may start offering expanded newborn screening services.

Sample leaflets and posters are available for sale.

<u>Please show sample poster and leaflets</u>

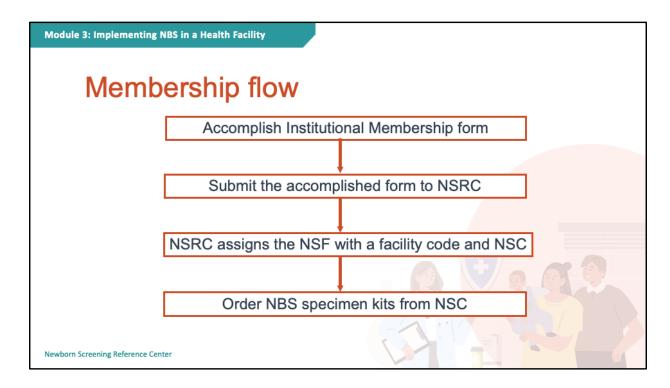




The Newborn Screening Reference Center is the technical arm of the DOH in the implementation of the Newborn Screening Program. In its most specific terms, NSRC maintains data of specific facilities which are considered eligible to collect specimen for newborn screening. It acknowledges NSFs and classifies NSF as active or inactive.

NSF or newborn screening facilities are the health facilities conducting sample collection for newborn screening. They are the frontline institutions in the implementation of the National Comprehensive Newborn Screening System. The NSF submits sample collected to NSCs.

NSC or the Newborn Screening Centers are the laboratories where blood samples are processed, analyzed and in cases of elevated results, the center recalls patients. Equally important to finding a screen positive patient is recalling the patient for confirmatory test. NSCs follow up patients with positive results and ensure that proper management for the patients are carried out.



How does one facility become a NSF? First of all, the facility should prepare itself. Its preparation should consist of organizing an NBS team with an NBS coordinator to oversee the NSF operations. This would include, but not limited to, collection of samples, release of results, prompt recall and follow-up of positive cases. Please remember that only trained health practitioners may do the sample collection.

Once organized, the coordinator or any designated person accomplishes institutional membership forms secured from the NSRC or the DOH-CHD. Private facilities must attach any of the following permits: DTI, Business, or Mayor's Permit.

Once received as discussed in the previous slide, application will be forwarded to the Department of Health – Center for Health Development for endorsement. Once endorsement is received, .NSRC acknowledges the application by sending a welcome letter together with the assigned facility code, NSC assignment, and administrative mechanics.

As soon as one is assigned an NBS code, the facility is now ready to order the ENBS collection kit from the designated NSC.

Quiz Question no. 5

What were established in 2014 to address the growing number of patients being managed by the program?

NBS Continuity Clinics

Newborn Screening Reference Center

Quiz Question no. 6

What is the preferred method to collect the newborn screening blood samples?

Heel Prick

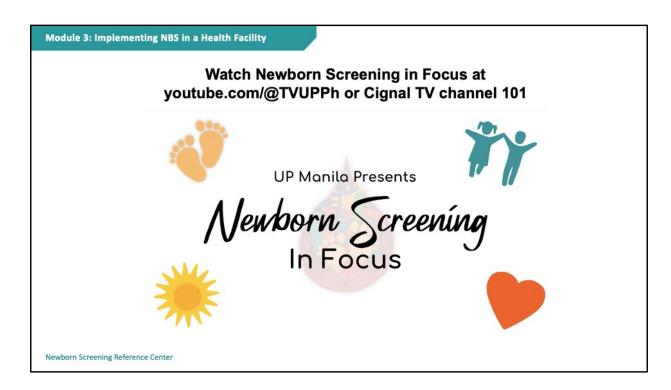
Newborn Screening Reference Center

*You may run the Newborn Screening@ 20 AVP after this slide



For more information about newborn screening, you can visit the newborn screening resource/portal site:

www.newbornscreening.ph



Newborn Screening in Focus is a video series that uncovers the wonderful story of Newborn Screening in the Philippines, zooming in on what makes Newborn Screening a comprehensive program for every Filipino.

NBS in Focus features the humble beginnings of the Newborn Screening Program and its evolution into a national health program. The series also presents the very process of newborn screening from the moment the child is born, and into the continuing care available for newborns confirmed to have a disorder included in the panel. Features and management of the disorders from the newborn screening panel are also discussed in individual episodes. Finally, the series presents the Newborn Screening program network, and how the program managed to give quality service despite the limits brought about by disasters such as the COVID-19 pandemic.

Watch the live airing of NBS in Focus every Saturday 7-8 pm at Cignal TV 101 or online at youtube.com/@TVUPPh.

