

RESEARCH ARTICLE

# Satellite clinics of the Newborn Screening Continuity Clinic - Region 6: Establishment of a Community-Based Networking System in Western Visayas, Philippines

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## ABSTRACT

**Background:** With the increasing coverage of the newborn screening (NBS) program in the Philippines, the number of patients being followed-up has also been increasing. The NBS continuity clinics (NBSCCs) have continuously been creating strategies to improve long-term patient health outcomes.

**Objective:** This paper aimed to describe the establishment of a community-based networking system of satellite clinics.

**Methodology:** A document review of resources including powerpoint presentations, a local ordinance, Newborn Screening Reference Center database of statistics of the NBSCCs from 2015 to 2021 and a Department of Health - Center for Health Development memorandum was done.

**Results:** NBS satellite clinics were developed as a strategy for improving the tracking and long-term follow-up of patients confirmed for one of the conditions in the NBS panel. Satellite clinics offering long-term follow-up services were set up in hospitals strategically located in the provinces of the Western Visayas, especially in areas with a high number of patients. Capacity building activities were initiated among the established NBS satellite clinic core teams which were composed of doctors, nurses, and/or midwives. A total of 15 satellite clinics spread out across the six provinces of Western Visayas were established in 2017. By the end of 2020, the Western Visayas region had a total of 528 confirmed patients endorsed by the Newborn Screening Center Visayas (NSCV) and the recall rate increased from 62.77% in 2015 to 87.79% in 2020.

**Conclusion:** The establishment of satellite clinics provided a region-wide accessibility and availability of long-term follow-up services to the patients as seen by the increase in the patient recall rate. The benefits were seen especially during the implementation of strict border controls due to the pandemic which ensured the continuity of care of the patients in the region. This concept can serve as a model for other NBSCCs in the archipelago and for other regions across the Philippines.

**Keywords:** *satellite clinics, newborn screening continuity clinics*

## Introduction

Newborn screening (NBS) is an important public health program that allows detection of congenital conditions before the onset of symptoms, hence, lowering infant morbidity and mortality. It is a system consisting of six parts: screening, follow-up, diagnosis, management, evaluation, and

education [1]. Screening encompasses specimen collection, transport, and laboratory analysis. Specimen collection happens in the newborn screening facilities (NSFs), which include the hospitals and other birthing facilities where the neonate is born. The samples are sent to the newborn screening centers (NSCs) via couriers. After a positive

screening test result for any of the conditions screened through the use of dried blood spots from the newborns, babies are followed-up to undergo confirmatory tests. This is done by the NSC, which has a short-term follow-up team, in-charge of ensuring that cases are closed through confirmatory tests. If problems arise from following-up patients, the Department of Health (DOH) Center for Human Development assists in the recall. Once diagnosed, they are managed appropriately, followed-up or evaluated regularly and receive pertinent patient education. Education also includes that of parents, healthcare providers and policymakers. Evaluation refers to the long-term follow-up of patients and systems review of the program itself.

Fourteen strategic newborn screening continuity clinics (NBSCC) were initially established in the Philippines to ensure the long-term care of patients with confirmed diagnosis [2]. The NBSCC refers to an ambulatory clinic based in a tertiary hospital identified by the DOH to be part of the National Comprehensive Newborn Screening System Treatment Network. It is equipped to facilitate continuity of care of confirmed patients in its area of coverage in order to ensure good health outcomes. The DOH Administrative Order 2018-0025 further supports improvements in NBS infrastructure provided by RA 9288 or the Newborn Screening Act of 2004 [3]. In this Administrative Order, expansion of services and delivery network include setting up of continuity clinics and a provincial NBS referral system to further strengthen the referral and case management network. Currently, there is one NBSCC each in 13 regions and two NBSCCs in Region 6. The creation of a provincial-level referral system is congruent with the principle of universality embodied in RA 9288, and Republic Act 11223 or the Universal Health Care (UHC) Act.

In the Philippines, the delivery of health services is devolved to the local government [4]. With the enactment of the Local Government Code of 1991, local government units were granted full autonomy and responsibility for managing and implementing their own health programs and services, with the DOH providing technical support. Under this set-up, provincial governments are given the responsibility for managing and operating primary- and secondary level hospital services through the district and provincial hospitals. Municipal governments, on the other hand, are mandated to provide primary care (Dayrit *et al.* 2018). The Philippines, an archipelago with 7600+ islands, is divided into 17 administrative regions with a total of 81 provinces. Region 6 or the Western Visayas (WV) region is in the central part of the Philippines between the Sibuyan and Visayas Seas. This region has a total land area of 20,233.2 square kilometers and

a population of 7,536,383 [5]. A regional NBSCC covering six provinces (Iloilo, Antique, Capiz, Aklan, Guimaras and Negros Occidental) was established to assist in tracking and improving patient health outcomes (growth, development, low mortality/morbidity), timeliness of care) of the increasing number of confirmed NBS cases across the region.[6]

The DOH Centers for Health Development (CHDs) are the local agencies responsible for monitoring and assisting in the implementation of the NBS program at the regional level [7]. These responsibilities are in line with the enactment of the National Comprehensive Newborn Screening System Treatment Network (NCNBSS) [8]. To scale-up NBS implementation in Region 6, the DOH CHD Western Visayas (DOH- CHD WV) through the Regional Development Council of Western Visayas released Resolution No. 2017-0007, also known as “Enjoining Local Government Units to Actively Support the Full Implementation of the Expanded Newborn Screening Program.” This Resolution recognized the urgent need to maximize resources for strengthening NBS service delivery in the region by establishing a province- and region-wide referral and management system for all positive NBS cases [9]. There is an urgent need because patients need to be recalled as much as possible and ensured that they get appropriate management. In addition, the patients being screened, saved, and needing regular monitoring are increasing in number. In 2016, prior to the release of this resolution, DOH-CHD WV started to map out potential satellite clinics situated in targeted hospitals in their region [9,10].

In Region 6, the West Visayas State University Medical Center (WVSUMC) in Iloilo City has been hosting the operations of the NBSCC since 2015. By the end of that year, the clinic had a total of 28 confirmed patients, which comprised 12.9% of the total endorsed patients of the national NBS program. In 2015, 177 of the 281 cases (63%) were recalled and seen at the NBSCC. The rest were unrecalled and lost to follow-up. Obsolete contact details and wrong/incomplete addresses were some of the identified barriers in the recall. The DOH-WV CHD has been closely working with the Newborn Screening Reference Center (NSRC) since 2016 to organize and develop provincial “NBSCC satellite clinics” throughout the region. These satellite clinics are strategically located clinics for patients within the area of coverage of an NBSCC which is more accessible to patients.

This study described and reviewed the newborn screening continuity clinic in the Western Visayas Region and the establishment of the “NBSCC satellite clinics” from 2015 to

2021. These clinics provide a possible model for implementation in other regions to strengthen service delivery and improve child health.

## Methodology

This is a qualitative descriptive study. The Western Visayas Region was chosen because the NBS Program team of DOH CHD WV pioneered the concept of the satellite clinics. A document review of resources provided by the DOH CHD-WV NBS program team was done. These resources include powerpoint presentations, a local ordinance, and a DOH CHD memorandum. Other resources were from the NSRC database of statistics of NBSCCs from 2015 to 2021. The study investigators analyzed the documents to come out with processes employed by the NBS Program team in rolling out the concept to identified facilities, including the flowchart of referrals from the community to the satellite clinics and to the NBSCCs.

Cross-validation was done with the NSRC database of statistics of the NBSCC in Region 6 from 2015 to 2021. The following steps were described: 1) conceptualization of the NBSCC Satellite Clinics; 2) Identification of the NBSCC Satellite Clinics; 3) trainings of healthcare providers; 4) endorsement and referral; and 5) monitoring and evaluation. These were then cross-checked by three more authors and reviewed by the rest of the authors. The review underwent two cycles before a final agreement was met.

## Results

### NBSCC patient profile

Majority of the patients in the NBSCC were endocrinologic cases (Table 1). A total of 420 patients, which was 79.5 % of

the total number of patients, had congenital hypothyroidism (CH). This was followed by Hemoglobin H disease in 27 patients (5.11%), congenital adrenal hyperplasia (CAH) in 22 patients (4.17 %), galactosemia in 21 patient and medium-chain acyl-coA dehydrogenase deficiency (MCAD) in 11 patients (Table 2). Most patients were > to 5 years old (196 patients), followed by >5 to 10 years old (108 patients). One hundred seven patients were < 1 year old while 36 patients were >10 years old.

### Conceptualization of the NBSCC satellite clinics

The NBSCC in WVSUMC in Iloilo City was set-up in 2015. Recognizing the difficulty in the follow-up of patients in the island provinces in the region, the concept of NBSCC satellite clinics was then formulated in 2016 in targeted hospitals in the islands. These institutions shall serve as a network of ambulatory clinics that can support the main NBSCC in the WVSUMC.

### Identification of NBSCC satellite clinics

With the aim of localizing long-term follow-up services, hospitals were identified in the different provinces of Western Visayas to serve as hosts for the NBSCC satellite clinics. The DOH WV-CHD embarked on a campaign to visit these hospitals, conduct presentations and talk with key people notably the chairs of the department of pediatrics and medical center chiefs to convince them to support the concept of a network of clinics for Region 6. Following the series of consultation meetings between the DOH WV-CHD, Newborn Screening Center Visayas (NSCV), NBSCC, individual medical specialists, and representatives of various government and non-government agencies (provincial/city health offices, Philippine Pediatric Society, and Association of the Municipal Health Officers of the Philippines), various hospitals were

**Table 1.** Breakdown of patients by age group and diagnosis as of December 2020

Age Groups	CH	CAH	PKU	GAL	MSUD	HbH Disease	β Thal/HbE	MCAD	GA I	3MCC	CIT	VLCAD	CUD	Grand Total
0 to 1	64	5	1	2	1	12	0	10	9	1	0	1	1	107
>1 to 5	160	3	0	6	8	15	2	1	0	0	1	0	0	196
>5 to 10	170	4	2	13	0	0	0	0	0	0	0	0	0	189
>10	26	10	0	0	0	0	0	0	0	0	0	0	0	36
Grand Total	420	22	3	21	9	27	2	11	9	1	1	1	1	528

CH – Congenital Hypothyroidism, CAH- Congenital Adrenal Hyperplasia, PKU – Phenylketonuria, GAL – Galactosemia, MSUD– Maple Syrup Urine Disease, HbH Disease – Hemoglobin H Disease, β Thal/HbE -β Thalassemia interacting with Hemoglobin E, MCAD – Medium-chain acyl-CoA Dehydrogenase Deficiency, GA I – Glutaric Aciduria Type 1, 3MCC- 3- methylcrotonyl-CoA carboxylase deficiency, CIT -Citrullinemia, VLCAD – Very long- chain acyl-CoA Dehydrogenase Deficiency, CUD –Carnitine Uptake Deficiency

**Table 2.** Summary of NBSCC Region 6 Patient Status from 2018 to 2020

	2018	2019	2020
ENDORSED	415	472	528
ACTUAL CENSUS	371	423	475
RECALLED	306	357	417
EXPIRED	10	10	15
UNRECALLED	65	66	54
LOST TO FOLLOW UP	12	11	11
DISCHARGED	22	25	27
PERCENTAGE RECALLED	82.48%	84.40%	87.79%
PERCENTAGE UNRECALLED	17.52%	15.60%	11.37%

- Notes:
1. Endorsed - patients confirmed with NBS disorder in the NSCs who are endorsed to the NBSCCs for long term care.
  2. Recalled – refers to families of patients whom the NBSCCs are able to make regular contact or communication, within a period of six months.
  3. Expired – patients who die while in the long-term care of CCs. Efforts must be done by the NBSCC to secure medical abstracts in order to ascertain the cause of death.
  4. Unrecalled – patients with non-working or erroneous contact information (phone number, address of residence); patients whom the CCs are unable to contact or communicate within a period of 6 months.
  5. Lost to follow up – unrecalled patients for more than 6 months and classified as lost to follow up by the DOH CHD. A certificate attesting to LTFU status coming from DOH is ideally needed.
  6. Discharged – patients ruled out as discharged or well-baby by an accredited specialist who exercised sound clinical judgment based on laboratory monitoring tests and physical examination of the patient. This should be properly documented by any records (ex. patient chart, patient profile form, emails) bearing the signature or name of the specialist who attested that the patient is indeed discharged from long term care.
  7. Actual clinic consults - patients who actually visit and consult with the CCs
  8. Actual Census - refers to the number of patients that the NBSCCs can realistically be able to recall. This excludes patients who have expired, were discharged, and are lost to follow-up.

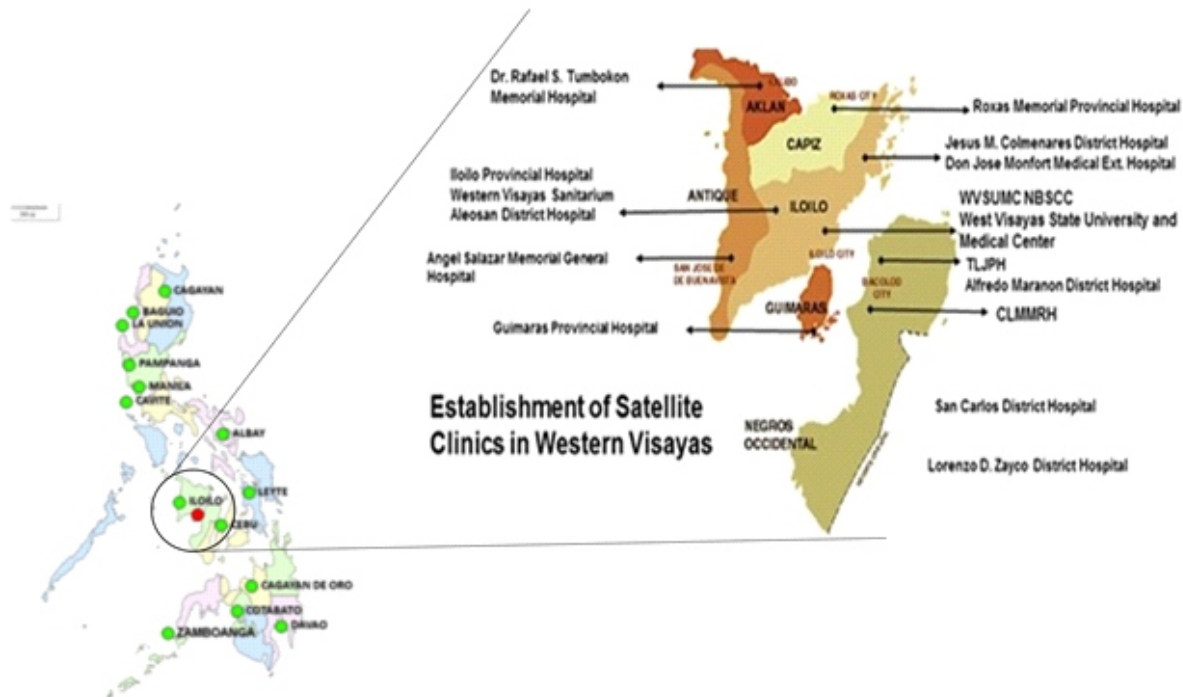
selected as hosts of satellite NBSCCs. Selections were based on, but not limited to, the following considerations: proximity of the hospital to areas with a high number of NBS cases, availability of affiliated pediatric consultants and access to basic laboratory/diagnostic work-ups. The rural health units (RHUs) and city health offices (CHO), as direct network of the NBSCC satellite clinics closer to the patients, were engaged to conduct recall and quarterly follow-up visits of the patients in their area to create demand for the NBSCC satellite clinics.

The DOH-WV CHD successfully identified NBSCC satellite clinics in every province in the region (Figure 1). The recognized satellite clinics are in the Outpatient Department of the following provincial hospitals: Dr. Rafael S. Tumbokon Memorial Hospital in Aklan, Angel Salazar Memorial General Hospital in Antique, Roxas Memorial Provincial Hospital in Capiz, and Dr. Catalino Gallego Nava Provincial Hospital in Guimaras. The provinces of Iloilo and Negros Occidental, being both geographically large and populous, have NBSCC satellite clinics institutionalized in several local government unit (LGU) hospitals. The identified facilities in Iloilo are as follows: Aleosan District Hospital, Iloilo Provincial Hospital, and Jesus M. Colmenares District Hospital. On the other hand, the NBSCC satellite clinics in Negros Occidental are in the following hospitals: Teresita L. Jalandoni Provincial Hospital, Alfredo E.

Marañon Memorial Hospital, Lorenzo D. Zayco District Hospital and San Carlos City Hospital (DOH RO VI, 2017). All DOH hospitals were engaged as NBSCC satellite clinics – Western Visayas Sanitarium and Don Jose S. Monfort Medical Center Extension Hospital (Iloilo Province), Western Visayas Medical Center (Iloilo City) and Corazon Locsin Montelibano Memorial Regional Hospital (Negros Occidental).

#### *Trainings of healthcare providers*

Efficient NBSCC satellite clinic operations warrant the establishment of a long-term follow-up team composed of a designated pediatric consultant, OPD nurse, and NBS coordinator. The goal is to prepare the team to later on be a continuity clinic itself. The establishment of training needs and objectives was done. The goal is to equip the team in the management of patients. Development of training content, target recipient, training delivery including identification of trainers were done. Each team received training in managing the various NBS disorders. The trainings were conducted by the DOH-Center for Health Development Region 6, in coordination with the Newborn Screening Center-Visayas. Trainings include long-term follow-up, management, and referral system. This was participated in by the representatives of the hosts of the satellite clinics. Short- and long-term recall



**Figure 1.** Map of Western Visayas and location of the satellite clinics in the region.

protocols, referral algorithms, NBSCC satellite clinic operation protocols, recording and reporting mechanisms, and lines of communication were discussed and streamlined among the host hospitals. For patient management, lectures on the management of endocrine, metabolic, and hematologic disorders were provided by selected pediatric specialists. Developmental and nutritional assessments, which are part of patient monitoring, were also reviewed.

#### *Process of endorsement and referral*

The NBSCC-WVSUMC relays confirmed cases to the NBSCC satellite clinics and to the RHU/CHO nearest to the patient's place of residence. Likewise, the provincial/city health offices are furnished with the list of patients endorsed to the RHU/CHOs. This is because the RHU/CHO, being the primary healthcare facility in the patient's place of residence, can help in looking for the patient and assisting the family to go to the satellite clinic. The satellite clinic staff, on the other hand, check-up on the patients and communicate with the NBSCC regarding patient status. These collaborations help facilitate the recall of patients. The active tracking of patients, especially unrecalled patients, is done by the RHU/CHO assigned through their rural health midwives and barangay health workers.

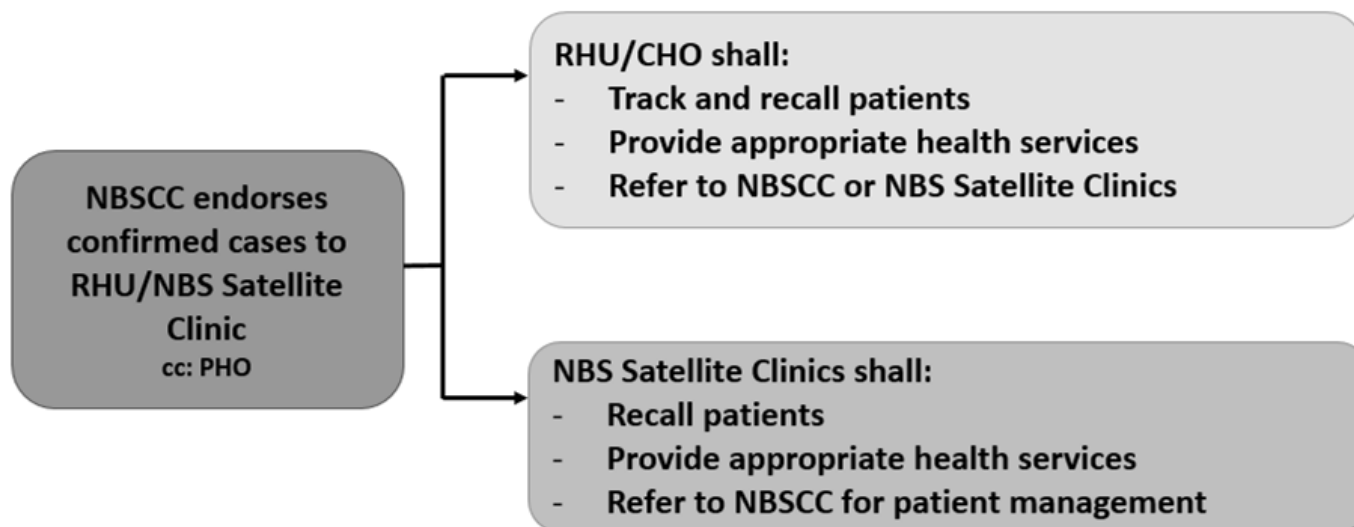
NBSCC services have been incorporated into the infrastructure of the host facility of each of the NBSCC satellite

clinics that includes setting-up a consultation schedule specific for NBS cases [9]. The NBSCC satellite clinics are responsible for the recall of patients and provision of appropriate health care services that include but are not limited to documentation of the anthropometric measurements, PEDS evaluation, provision of medications, referral to NBSCC or specialist and patient counseling (Figure 2). Anthropometric data, assessment findings and follow-up consultation schedules are documented on a standard form.

When complications are identified, patients are immediately referred to the NBSCC -WVSUMC or to the nearest specialist who can address the issues at hand. Patients without identified complications are managed by the satellite clinics and scheduled for an annual consultation with the NBSCC-WVSUMC or identified specialists. A roster of specialists was established which included names of pediatric specialists (endocrinologists, hematologists, neurologists, neonatologists), clinic addresses and schedule and contact details. Specialists agreed to be available as needed.

#### *Monitoring and evaluation*

As part of the establishment of NBS satellite clinics, other indicators of need were assessed. A 2017 data report showed that of the 379 patients confirmed to have an NBS disorder in the region, 158 (41.6%) were from Negros Occidental. As a result, the Corazon Locsin Montelibano



**Figure 2.** Flow of endorsement from the NBSCC to the rural health units (RHU) or city health office (CHO) and satellite clinics. The Provincial Health Office (PHO) also receives a copy of the endorsed patients.

Memorial Regional Hospital (CLMMRH) was identified as the 2nd NBSCC in the region providing local NBS services in Negros Occidental. CLMMRH is a DOH hospital with a roster of specialists i.e. geneticist, neonatologist, pediatric hematologist, and developmental pediatrician. Thus, it was already equipped to facilitate the continuity of care of confirmed patients in its area of coverage as required in the DOH Administrative Order No. 2014-0035 [2]. The salary of the continuity clinic nurse assigned in CLMMRH is to be provided by the Newborn Screening Center Visayas for the first two years, and by the DOH-WV CHD, thereafter. Currently, the CLMMRH is a fully operational NBSCC.

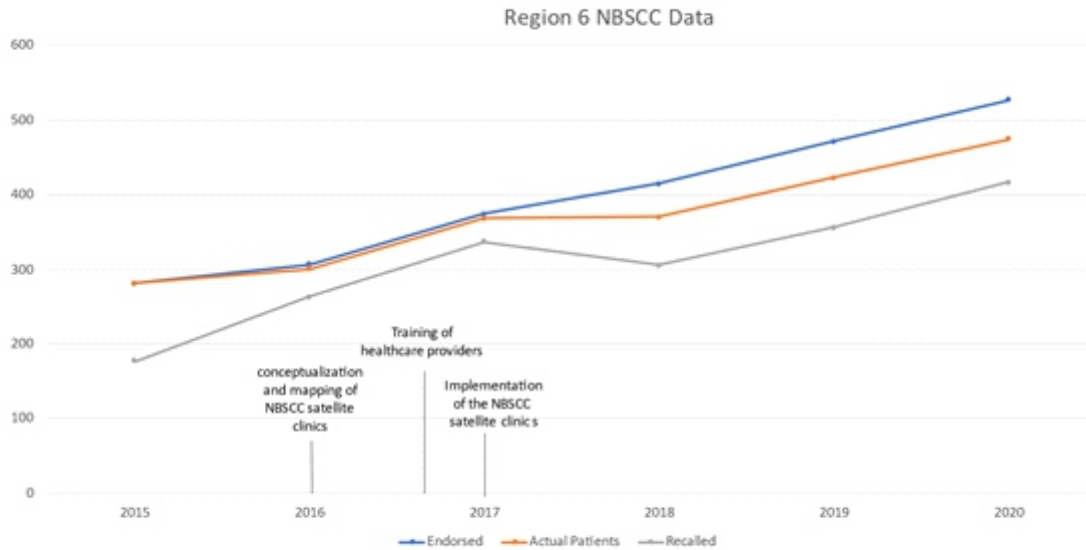
To ensure sustainability of the satellite clinics, regular consultation meetings are conducted to address implementation concerns. Likewise, the DOH CHD WV, NBSCC- WVSUMC, NSCV and representatives from the provincial/city health office (P/CHO) conduct onsite monitoring visits to evaluate the operations of the clinics and provide necessary technical assistance. The NBSCC-WVSUMC monitors quarterly the feedback of patient cases and status. Currently, the NBS program has a comprehensive tool called the Philippine Performance Evaluation and Assessment Scheme (PPEAS) being used to evaluate the various components of the Philippine NBS system. Annual external audits and program implementation reviews of the NSCs, DOH CHDs and NBSCCs are being done by evaluators led by the NSRC with invited evaluators to represent stakeholders from other NSCs and DOH CHDs. These activities identify gaps in service provision and develop and

initiate recommendations for quality improvement. An example of an identified gap is the huge volume of patients in certain regions which necessitates additional clinics to augment the staff of a lone NBSCC for that region and bring access to health care closer to the patients.

*NBSCC data before and during the COVID-19 pandemic*

There were 15 satellite clinics spread out in the six provinces of Western Visayas. The total number of endorsed patients and the actual census of patients being monitored and followed-up have been increasing through the years (Figure 3). In 2015, the recall rate was 62.77%. By the end of December 2020, a total of 528 endorsed patients were included in the Western Visayas Region, 187 % more than the endorsed patients in 2015. Despite the increase in number, the continuous efforts of the NBSCC and the establishment of the NBS satellite clinics, the recall rate has increased to 87.79% (Table 2).

While the establishment of the NBS satellite clinics was seen as an opportunity to increase region-wide access and availability of long-term follow-up services to the patients, community engagement and awareness, local support and shift of health priorities had continuously challenged and affected the implementation of NBS referral and management strategies. A lot of people had to be on board (doctors, nurses, midwives, etc.) who must stay motivated to join and commit to the endeavor. During the initial stages of implementation, the number of cases needing consultation at the satellite clinics was relatively low. As such, demand generation activities to



**Figure 3.** The number of endorsed patients, actual census and number recalled patients of NBSCC Region 6 from 2015 to 2020 and the significant milestones in the region

popularize the NBS Satellite clinics were organized to increase health service utilization. Localization of information, education and communication activities, continuous dialogues with the NSFs, and engagement of the RHUs and P/CHOs to conduct active tracking and referral were done. Furthermore, local engagement with the P/CHOs was strengthened yielding LGU support to realign resources for NBS case management. The NBSCCs have formed various linkages through Memoranda of Agreement with P/CLGUs for patient support. However, the dynamism of health priorities resulting to shifts in resource allocation to address more immediate health concerns such as Measles-Rubella-Polio, Dengue and COVID-19 created disruptions in the delivery of long-term follow-up NBS services. Nevertheless, the organization of the referral and management network in the Western Visayas formalized through DOH WV CHD Order No. 35, s. 2020 (Long-Term Follow-Up Care for Confirmed Newborn Screening Cases in Western Visayas) provided alternative service points for NBS cases and prevented displacement of NBS-related services [11]. During the pandemic, when the healthcare efforts primarily shifted towards response to this global concern, the efforts of the continuity clinics in providing quality service continued despite the challenges. Coordination with the satellite clinics was done to assure the delivery of services to patients despite the limitations brought about by the pandemic. Continuity clinics utilized telemedicine consultations to ensure that the medical needs of the patients were addressed.

The benefits of the “NBSCC satellite clinics” during the implementation of strict border controls during this time of the

pandemic have been seen. They have helped ensure the continuity of care of the patients in the region. The patients who were not seen in the NBSCC in the WVSUMMC were referred to the nearest satellite clinic for consultation and follow-up. The environment in the satellite clinics now has been very dynamic. There should always be a regular evaluation for areas where improvement of the delivery of services can be done. There should also be a balance of expectations against the real deliverables considering the status of the healthcare system brought about by the pandemic.

## Discussion

One of the components of effective public health program implementation is an innovation to develop an evidence base for action. Innovation has long been recognized as an essential component of public health strategies and program development [12] The introduction of NBSCC satellite clinics in the Western Visayas Region appears to be a logical strategy for addressing the geographic disparity in care provision for NBS patients. Since adherence to regular follow-up and treatment may be affected by a patient's travel time, the localization of NBS follow-up services in satellite clinic provides an obvious patient benefit. This was evident in the recall rate of the region, which increased after the introduction of satellite clinics.

The involvement of rural health units (RHUs) and city health offices (CHOs) has facilitated community involvement. The RHUs are managed by the municipal governments while

the CHOs are overseen by the city governments. Both the municipal and city governments provide primary care services that include preventive and promotive health services and other public health programs such as newborn screening [13]. The RHU and CHO form part of the network that are relied upon through the mandate of the DOH CHD VI. These were enjoined through an ordinance of the Regional Development Council of the National Economic and Development Authority Region 6 to actively support the NBS program in the region.

Prior to the establishment of the satellite clinics, the RHUs and CHOs regularly contacted and scheduled patients for follow-up visits, which created part of the need for satellite clinics. The implementation of the satellite clinics in the region during the pandemic showed its value by providing uninterrupted long-term follow-up care. This would have been more difficult if there was just one NBSCC in the entire region.

As the newborn screening program in the Philippines progresses over time, it has developed a more comprehensive system of follow-up of patients who need long-term care. This system is unique to the country and has never been done in any newborn screening program in the world.

## Conclusion

With the increasing number of patients being confirmed to have a condition included in the newborn screening program, the NBSCC has been seeing more and more patients through the years. In addition, a lone NBSCC per region may be far for patients outside the province of location of the NBSCC. Hence, the establishment of satellite clinics provided a region-wide accessibility and availability of long-term follow-up services to the patients as seen by the increase in the patient recall rate. The benefits of the “NBSCC satellite clinics” was seen especially during the implementation of strict border controls due to the pandemic. It has helped ensure the continuity of care of the patients in the region. The concept also serves as a model for other NBSCCs in the archipelago and for other regions across the Philippines.

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## Conflicts of Interest

The authors declare no conflict of interest.

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