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UNICEF INDIA

Documentation of Special Newborn Care Units in Orissa
Lessons Learned

Carolina Arcila, United Nations Mandated University for Peace
Vishal Avinashi, University of Toronto
Kristen Kappos, George Washington University
Shivraj Singh Negi, Indian Institute of Technology, Madras

In collaboration with
KIIT University
Bhubaneswar, India
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The views expressed in this case-study are those of the authors alone and do not necessarily reflect those of the interviewed participants; or the policies or the views of UNICEF and/or KIIT University.
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Finally, we want to express our sincere gratitude to the mothers and families who welcomed us into their homes and shared their experiences with us. Without their participation, our project could not have been completed.
**List of acronyms**

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>DEO</td>
<td>Data Entry Officer</td>
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<tr>
<td>DHH</td>
<td>District Headquarters Hospital</td>
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<td>GoI</td>
<td>Government of India</td>
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<tr>
<td>IMNCI</td>
<td>Integrated Management of Neonatal and Childhood Illness</td>
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<tr>
<td>IMR</td>
<td>Infant Mortality Rate</td>
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<tr>
<td>IV</td>
<td>Intravenous</td>
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<tr>
<td>NFHS</td>
<td>National Family Health Survey</td>
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<tr>
<td>NMR</td>
<td>Neonatal Mortality Rate</td>
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<td>NNF</td>
<td>National Neonatology Forum</td>
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<tr>
<td>NRHM</td>
<td>National Rural Health Mission</td>
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<tr>
<td>Rs.</td>
<td>Indian Rupees</td>
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<tr>
<td>SNCU</td>
<td>Special Newborn Care Unit</td>
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<td>WHO</td>
<td>World Health Organization</td>
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Executive summary

The challenge in achieving Millennium Development Goal 4\(^1\) and the National Rural Health Mission (NRHM) goal on reducing infant mortality is the reduction of the neonatal mortality rate. More than a quarter of child deaths worldwide in 2009 occurred in India alone.\(^2\) Orissa, a state in eastern India, lags behind other states in terms of child mortality indicators. At 65 per 1000 live births in 2009\(^3\), the infant mortality rate in Orissa is the second highest in India. Understanding that a child’s greatest risk for mortality is during the first 28 days of life (the neonatal period), the Government of Orissa aims to lower its IMR by reducing the number of deaths that occur within this period.

UNICEF has partnered with the Government of Orissa and the NRHM to implement an initiative targeted at saving newborn lives. The initiative has established Special Newborn Care Units (SNCUs) to build the capacity of government hospitals to provide care specifically to neonates. The first SNCU opened in 2007 in District Headquarters Hospital in Mayurbhanj district. To date, there are 16 functional SNCUs across various districts in Orissa.

This report primarily documents SNCUs at Capital Hospital in Khurda District and District Headquarters Hospital in Mayurbhanj District. It also includes highlights from in-depth interviews with mothers and families of SNCU patients post-discharge.

The establishment of SNCUs was generally a smooth process. UNICEF played a crucial role in supplying equipment for the first units, which provided nurse-led care for common neonatal problems such as birth asphyxia and low birth weight. Factors that went right during implementation of the initiative include positive working relationships, commitment and leadership shown by SNCU staff and partners; use of protocols; attention to breastfeeding; and attempts to focus on handwashing, hygiene and infection control. An initial problem was the lack of buy-in. This was overcome through collaborations with groups including the Indian Academy of Pediatrics and other pediatric specialists across India. Problems that remain to be solved relate to transportation to the units, high costs to the families, overstretched units, insufficient number of staff, lack of family centred care and a lack of emphasis on follow-up.

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1 Millennium Development Goal 4 aims to reduce the under five mortality rate by two-thirds, between 1990 and 2015.
Despite these issues, the SNCUs certainly have provided much needed services at the government level in Orissa. SNCUs have helped fill the gap between primary health centres and level III specialized care facilities. However, due to the lack of formal evaluations, the report cannot describe the impact of these units.

Interviews with health care staff, administrators and families have helped reveal major lessons learned related to the establishment and operation of SNCUs. In addition to improving the present day functionality, these lessons illustrate potential applications of the initiative beyond its original context such as establishing similar neonatal care units in other states or in designing and implementing other health interventions. The lessons learned illustrate the importance of:

1. An adequate number of trained staff
2. Family centred care
3. Systematic follow-up after initial interventions

Given that plans for expanding existing SNCUs and establishing 18 new units in Orissa by 2014 have been announced, planning, coordinating and learning from the past becomes of even greater importance.
An estimated 8.1 million children under 5 years of age died in 2009 worldwide—which is more than 22,000 children each day.\textsuperscript{4} A child’s highest risk of mortality is within the first 28 days of life, known as the neonatal period.\textsuperscript{5} Neonatal mortality contributes to 40 per cent of all deaths among children under 5 years of age and 60 per cent of all deaths among children under 1 year of age.\textsuperscript{6} The leading causes of neonatal deaths are birth asphyxia (23 per cent), preterm birth (27 per cent) and severe infections (36 per cent) (see Figure 1).\textsuperscript{7} The majority of these deaths are largely preventable by implementing simple, low-cost interventions. These lifesaving interventions include: drying and keeping the newborn warm; initiating exclusive breastfeeding as soon as possible after delivery; giving special care to low birth weight infants; and diagnosing and treating problems like birth asphyxia and sepsis.\textsuperscript{8} The outcomes are often dependent on timely care. Nearly 50 per cent of all neonatal deaths occur within 24 hours of delivery and nearly 75 per cent within the first week of life.\textsuperscript{9}

\begin{figure}
\centering
\includegraphics[width=0.5\textwidth]{neonatal deaths.png}
\caption{Estimated distribution of direct causes of neonatal deaths}
\end{figure}


South Asia accounts for the largest absolute number of neonatal deaths in the world.\(^ {10} \) India alone represents one quarter of all neonatal deaths globally.\(^ {11} \) While India’s neighbouring country Sri Lanka has been able to achieve a neonatal mortality rate (NMR) of 9 per 1000 live births,\(^ {12} \) India’s NMR is higher than the global average, at 34 per 1000 live births\(^ {13} \) compared to 24 per 1000 live births,\(^ {14} \) respectively. Similarly, the infant mortality rate (IMR) in India (50 per 1000 live births)\(^ {15} \) is higher than Sri Lanka’s (13 per 1000 live births)\(^ {16} \) and the global average (43 per 1000 live births).\(^ {17} \) The high NMR and IMR in India highlight the critical need for improved child health outcomes in the country. Yet while these aggregated statistics show great need at the national level, it is important to note that they mask inequities in mortality that exist across states in India.

Orissa, a rural agrarian state in eastern India, is among states with the poorest development indicators. Nearly half of Orissa’s 41.9 million population lives below the poverty line.\(^ {18} \) In 2001, the literacy rate in the state (64 per cent) was slightly lower than the national average (65 per cent), but with great gender inequity between the female literacy rate (51 per cent) and the male literacy rate (76 per cent).\(^ {19} \) Regarding child health, the IMR in Orissa was 65 per 1000 live births in 2009\(^ {20} \)—the second highest among states in India—

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\(^ {17} \) World Bank (2011) *World development indicators (subset)*. Access 7 June 2011. \(<http://www.google.com/publicdata/explore?ds=d5bncppjof8f9_&ctype=1&strail=false&nselm=h&met_y=sp_dyn_imrt_in&hl=en&dl=en>\).


\(^ {20} \) Registrar General, Government of India (2009) *Sample Registration System*. 
and the NMR was 47 per 1000 live births in 2007.\textsuperscript{21} Comparatively, in the southern state of Kerala, the IMR was 12 per 1000 live births in 2009\textsuperscript{22} and the NMR was 10 per 1000 live births in 2000.\textsuperscript{23} The high IMR in Orissa is particularly alarming because despite significant reductions in the IMR until the early 2000s, the rate has remained stagnant. Over the past five years, there has been an annual reduction of only two deaths per 1000 live births.\textsuperscript{24} This is mainly because the number of deaths that occur in the neonatal period has remained consistently high.\textsuperscript{25}

Many of the factors that relate to neonatal and infant mortality are well known and interrelated.\textsuperscript{26} Factors that relate to neonatal and infant mortality outcomes include societal level factors such as poverty, social systems and cultural practices\textsuperscript{27} (see Figure 2). For example, Scheduled Caste and Scheduled Tribe households, who are particularly vulnerable to poverty\textsuperscript{28} and have been historically marginalized, access and utilize health services disproportionately less compared to different segments of the population.\textsuperscript{29} This is important contextually in Orissa because 20 per cent of households belong to a Scheduled Caste and 23 per cent belong to a Scheduled Tribe.\textsuperscript{30} Factors that relate to neonatal and infant mortality outcomes also include household level factors, such as poor hygiene, lack of health information and inadequate nutrition.\textsuperscript{31} For example, studies have linked maternal anemia during pregnancy to low birth weight.\textsuperscript{32} According to National Family Health Survey (NFHS) 3, an estimated 68 per cent of women in Orissa are anaemic.\textsuperscript{33} Factors that relate to neonatal and infant mortality outcomes also include direct causes, such as congenital conditions.\textsuperscript{34}

\begin{footnotesize}
\begin{enumerate}
\item Registrar General, Government of India (2008) Sample Registration System.
\item Registrar General, Government of India (2009) Sample Registration System.
\item Registrar General, Government of India (2000) Sample Registration System.
\item Ibid.
\item Ibid.
\end{enumerate}
\end{footnotesize}
Strategy and implementation

At the state level, the Government of Orissa aims to reduce the IMR from 65 per 1000 live births to 50 per 1000 live births. The challenge for Orissa in the achievement of this target is reducing the number of deaths in the neonatal period. In alignment with this goal IMR and the significant need for improved child health outcomes in Orissa, UNICEF and the Government of Orissa have partnered to establish Special Newborn Care Units (SNCUs) in government hospitals across the state. Operationalization of SNCUs as part of improved access to quality facility-based newborn care is now a strategy for reducing the NMR recommended by the National Neonatology Forum (NNF), Indian Academy of Pediatrics, the Government of India (GoI), the Government of Orissa and UNICEF.

The concept of SNCUs evolved over time. The idea originated as a response to a challenge faced by implementers of the Integrated Management of Neonatal and Childhood Illness (IMNCI) initiative, a joint initiative between UNICEF and the GoI. In Orissa, when newborns needed care beyond what was provided at the community level, there were no government subspecialty care facilities available to newborns for referral.

35 IMNCI is a comprehensive strategy which aims to “reduce death, illness and disability, and to promote improved growth and development under five years of age.” See <http://www.who.int/child_adolescent_health/topics/prevention_care/child/imci/en/>. 
Staff could refer newborns to the government hospital’s general pediatric ward; however, these wards did not have specific newborn equipment, space or dedicated staff.

Consequently, UNICEF became engaged in finding a solution to this problem. UNICEF received the help of a pediatrician, Dr. G. Sarangi, at District Headquarters Hospital (DHH) in Mayurbhanj district to develop a model for providing care to newborns in Orissa. DHH was already conscientious of newborns’ specific needs. It had isolated newborns from the general pediatric ward as early as 2005. As part of the model development, UNICEF and DHH staff reviewed their hospital’s labour room to see what type of patients needed newborn care. Low birth weight management and birth asphyxia were identified as the most common problems, allowing for targeted training and equipment. Using this information, the pediatrician suggested a model adapted from the Purulia Model—an successful model of newborn care developed in West Bengal—to the context in Mayurbhanj. Called the ‘Mayurbhanj model,’ the model shifted focus from pediatrician-focused care to nurse-focused care, and identified 4-5 key basic instruments necessary for caring for neonates with common illnesses.

At the beginning, pediatricians and gynecologists were hesitant to start newborn care units in Orissa. They felt there was a lack of trained doctors in neonatology; and there was a generalized discomfort related to handling neonates, as cited by Dr. A.K. Sen, UNICEF health specialist. UNICEF enlisted the help of the Indian Academy of Pediatrics as well as engaged physicians from Kalawati Saran Children’s Hospital in Delhi to help increase neonatalogy skills and knowledge, and comfort with specialized equipment.

The proposal for the first SNCU in Orissa was accepted in 2006. The doors were opened in DHH in Mayurbhanj district in February 2007 with significant support from UNICEF who provided funds for the equipment. DHH continued to receive support from health care professionals in Delhi, who provided guidance, visited the units and facilitated intensive training for nurses in Delhi.

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The hospital started seeing results from the SNCU. As illustrated by Dr. A.K. Sen, who stated, “The survival rate among newborns in the hospital had markedly improved. Low birth weight and asphyxiated babies were leaving the hospital, rather than dying.” Within six months of operation, UNICEF, Government of Orissa and National Rural Health Mission (NRHM) approved the establishment of 12 new SNCUs for the following year. There are currently 16 functional SNCUs across various districts in Orissa and there are plans to establish an additional 18 SNCUs by 2014, driven by NRHM.  

**Process**

**Problems during establishment**

The establishment of SNCUs was generally a smooth process; however, there were some problems faced when implementing the initiative. The first problem was related to buy-in, as reported by physicians and members of UNICEF Orissa state office. At the first mention of the SNCU concept in Orissa, physicians had reservations about implementing the initiative because there was a sentiment that staff lacked proper training and tools for handling neonates. The second problem was related to staffing. At the initiation of the SNCUs, physicians were asked to work in the newborn unit in addition to carrying out their regular clinical duties within the hospital. This led to an increase in workload for current physicians and made it difficult for both current physicians and for recruiting new physicians. At DHH in Baripada, for instance, two pediatric specialists were recruited to the hospital, but left shortly after starting their job. One of the aforementioned physicians cited quality of life as the primary reason for his resignation. He said, “The workload was too busy…I was covering the SNCU, Outpatient Department and Inpatient Department, seeing up to 100 patients per day. Some days I was in the hospital from 8:30 a.m. to 12:30 a.m. and then still had to attend to the calls from the units.” The third problem was related to the physical structure of the SNCUs. The SNCUs were established in spaces that had previously been other wards, rather than being established in spaces designed specifically for neonatal care. This has presented problems in the day to day functionality of the units. Nurses cite an insufficient number of electrical outlets in the unit; and both nurses and doctors cite the lack of central oxygen and suction as problems with the design of the unit. Also, related services such as laboratory and diagnostic imaging are often not in proximity to the unit, resulting in difficulties transporting sick newborns.

Many of the aforementioned problems have been recognized by UNICEF, NRHM and hospital administrators, and efforts have been made to address them. Buy-in, for example, was overcome by engaging multiple stakeholders. UNICEF and the Government of Orissa enlisted the help of the Indian Academy of

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37 Content for the ‘Strategy and implementation’ section were obtained primarily from an interview with Dr. A.K. Sen, UNICEF health specialist on 11 July 2011.
Pediatrics as well as other pediatric specialists who currently operate Newborn Intensive Care Units to discuss the management of sick newborns with physicians. The staffing problem has been addressed by having physicians that are primarily focused on SNCUs; however, it must be noted that this is short of the request for designated physicians exclusive to SNCUs. The problem related to the physical structure of the SNCUs is an ongoing problem, but one that is not being ignored. With SNCU expansions expected in DHH in Baripada and Capital Hospital in Bhubaneswar, there are ongoing discussions regarding the design of units.

**What went right**

There are several factors that have significantly contributed to the overall smooth implementation of the SNCU initiative. The positive working relationships, commitment and leadership displayed by SNCU staff and implementing partners have been integral in the functioning of the SNCUs. The Medical Officers interviewed cited very good working relationships and communication channels with UNICEF and the Government. The Medical Officers stated that decision making roles are clearly defined, which is believed to be a key contributing factor in the successful implementation of the initiative. Positive working relationships also exist among staff within the units themselves. The SNCU staff takes pride in their work and morale in the units is high. One of the nurses interviewed commented that there is a sense of camaraderie among staff members in the unit. Another nurse interviewed commented that good teamwork, good training and a safe work environment have led to the overall high staff morale. This high morale has led to a sense of job satisfaction among nurses, which is reflected in retention rates. All of the nurses interviewed had been working at the SNCUs since their inception. Leadership and commitment shown by the Medical Officers are also factors that have been integral to success. The Chief Medical Officers at both hospital locations are themselves pediatric specialists and have a good understanding of the needs of SNCUs, which is believed to be an asset for the success of the units. A doctor at DHH in Baripada stated that there is strong administrative support within the hospital and that the Chief District Medical Officer actively seeks feedback on how to improve the SNCU, rather than waiting for complaints.
Box 1: Case Study #1

Surrounding VP’s home are unplanned alleys, make shift houses, garbage and stagnant pools of water. Yet once you enter, the home appears spotless. Despite the large number of family members living in the same house (eleven persons including three children), the floors and sheets were impeccably clean and the walls seemed freshly painted. Cleanliness was a priority for both parents to ensure the health of their two daughters. Her mother cleans her clothing three to four times per day a day, changes her diaper regularly, disposes of it appropriately and bathes her with warm water once a day.

VP has been visited by an ASHA ten times. The ASHA weighs VP regularly and has educated VP’s mother on issues of immunizations, vitamin supplementation, malaria prevention, kangaroo mother care, child nutrition and sanitation and hygiene. VP’s mother knows how to identify warning signs regarding her daughter’s health and does not hesitate to take her to the doctor when necessary. VP was fortunate to have six months of exclusive breast milk.

After having spent 10 days at the SNCU in critical condition, baby VP is now 10 months and is stronger and growing up in a healthy household environment. VP, who is now learning to walk, is very alert and bounces around smiling to everyone in the room.

The units have implemented protocols for aspects of care, including intravenous (IV) fluids policy and keeping babies warm, which promote consistent management across SNCUs. Many of the adopted protocols help meet international standards set by reputable organizations, such as the World Health Organization (WHO). Attempts to focus on hand washing, hygiene and infection control are also being made, although basics—such as 24 hour water supply—are not available in all SNCUs. Attention given to breastfeeding is another practice going well at the SNCUs. Mothers are called to breastfeed their children approximately every two hours at the unit. This provides an opportunity for staff nurses to counsel mothers on breastfeeding with direct observation, including adequacy of milk and comfortable holds. The counselling seems to have made a positive difference post-discharge. Ninety-three per cent of mothers reported breastfeeding their child until six months of age, of which 71 per cent are exclusively breastfed until six months.
Tools used
Among the various existing standards for neonatal care, the SNCU initiative uses those set by the National Neonatology Forum (NNF), a body of health professionals solely working for the cause of neonatal health. The NNF standards have been applied in a toolkit for establishing SNCUs that was written jointly by the NNF, UNICEF and the WHO Collaborative Center for Training and Research in Newborn Care in New Delhi. The purpose of the toolkit, *Toolkit for Setting Up Special Care Newborn Units, Stabilisation Units and Newborn Care Corners*, is to support efforts of aforementioned stakeholders in planning and managing SNCUs. Also, ongoing monitoring efforts are in place at each unit in the form of various registries, including admission, medicine, complaint and daily census registries. This information is used to generate monthly reports given to NRHM, which provide quantitative information used to assess the performance of SNCUs.

What remains to be solved
While the SNCUs are providing new services to the people of Orissa, there remain several areas which can be improved upon. One of the Medical Officers himself admitted that the SNCUs are in their infancy.

Access issues
Approximately 50 per cent of newborns admitted to the SNCUs are outborn, meaning they were born outside of the hospital where the SNCU is located. While local physicians are suggesting sick newborns be transported to an SNCU, the responsibility to get the child from one health centre to the SNCU is still that of the parents. Among outborn patients’ families, 17 per cent of families surveyed brought their sick newborn by ambulance. The remainder came by hired vehicles, auto-rickshaws or buses. The average travel time was over an hour (76 minutes) with a maximum of 180 minutes. Travel time is critical, especially in cases where newborns require urgent interventions, such as oxygen.

Transportation is also important when transfer to another hospital is being considered. The SNCUs are accredited to provide basic services (e.g. oxygen, warmth and IV antibiotics); and if a child requires more advanced care (e.g. ventilatory support), then the next step would be to transfer to a level III facility. Few level III options exist in the state of Orissa, especially if one excludes costly private options. The decision to transfer a child has little to do with the physicians’ directives, but more to do with the parents’ ability to afford the services. One interviewed nurse said, “We support one’s decision (to transfer), but this has to be the parents’ responsibility.” The inability to transfer patients based on medical need is likely a contributor to the high in-hospital mortality rate of over 12 per cent (range 9 - 18 per cent).

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38 For more information on levels of care, visit <http://www.unicef.org/india/SCNU_book1_April_6.pdf>.
39 SNCU Meeting, Bhubaneswar, India. 6 June 2011. Powerpoint Presentation: “Role of SNCUs in Reducing NMR NBC week 2010.”
Cost factors

While it is understood that the operation of SNCUs is cost-intensive and government hospitals are not driven by profit, accessing services frequently causes families financial strain. Only a small amount of money goes directly to the hospital (as little as five rupees (Rs.) per bed per day), but there are other direct and indirect costs incurred by families that add up (see Table 1). Costs vary depending on the treatments received and the length of admission, but among families interviewed, total expenses (including indirect, but excluding lost wages) were up to Rs. 20,000, with an average of Rs. 6,800 per admission.

Standard medications are meant to be provided free of cost unless they are not listed on the government register. However, families’ and nurses’ experiences indicate the medications are often out of stock and thus constitute the majority of expenses that parents have to bear. Forty per cent of the families interviewed in Bhubaneswar spent more than Rs. 5,000 on medication alone. None of the interviewed families in Khurda or Mayurbhanj mentioned that any medications were provided to them free of cost. At the SNCU Conference held in Bhubaneswar on June 6 - 7, 2011, one doctor directly stated that consumables and drugs are not being supplied according to protocol.

Table 1: Costs involved with admission to SNCUs

<table>
<thead>
<tr>
<th>Direct Costs</th>
<th>Indirect Costs</th>
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<tbody>
<tr>
<td>○ Admission charges</td>
<td>○ Transportation</td>
</tr>
<tr>
<td>○ Medications</td>
<td>○ Accommodation of the family</td>
</tr>
<tr>
<td>○ Laboratory tests</td>
<td>○ Food costs</td>
</tr>
<tr>
<td>○ Therapies</td>
<td>○ Lost wages</td>
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<tr>
<td>■ Phototherapy</td>
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<td>■ Blood transfusion</td>
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<tr>
<td>■ Oxygen</td>
<td></td>
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<tr>
<td>○ Supplies</td>
<td></td>
</tr>
<tr>
<td>■ Diapers</td>
<td></td>
</tr>
<tr>
<td>■ Milk substitutes</td>
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</tbody>
</table>

While there does exist some expense relief for ‘poor’ patients, the criteria for obtaining this is not even clear among the interviewed nurses. Despite some interviewed families earning a household income of Rs. 100 per day, none of the families mentioned that they knew about the expense relief program or were screened for eligibility. One interviewed family in Bhubaneswar left the SNCU against medical advice, stopping phototherapy for their child’s jaundice solely because of the high costs. The family noted that the health care team was aware of their reason for leaving and provided no alternative solution, signalling that cost covering
programs are not being effectively communicated to families. In fact, several interviewed families in Mayurbhanj district had to return to their villages and borrow money from friends and family in order to pay for their child’s hospitalization. The families (who are typically daily wage labourers) were unaware of the costs involved with the SNCU and none of them were offered financial relief.

Overall, there is a disconnect between the perceptions of cost and the reality. One Medical Officer discussed how poor families get free service and parents spend very minimal money as most items are supplied. One nurse estimated the cost to never exceed Rs. 2,000. Another nurse believed that 40 per cent of patients were covered under the cost relief program, while not one interviewed family was offered relief.

**Overstretched units**

The current supply of SNCU services is not close to meeting demand. In an intensive care setting, the expectation is one bed per patient and low staff to patient ratios to allow for close observation and rapid response. In the context of SNCUs, the statement ‘all beds are full at all times’ has little meaning. One physician at DHH in Baripada stated, “We have only 10 beds but our current census is about 30 newborns. We even have up to fifty babies at a given time. This means we have to triage the patients to see who is most in need of true observation and equipment, such as phototherapy and warmers. If multiple children require phototherapy, we would swap the different children providing two hours of light at a time.” The current system further highlights the lack of equipment and, more importantly, the significant workload on a fixed number of health care providers. One interviewed nurse stated, “If the kid is not connected to oxygen, then it is our preference for them to be with the mothers, and this clears up a bed.” While this seems appropriate, the reality of this means the “admitted” newborns are put on the floor in a hallway with their mothers, receiving minimal care. At the time of the DHH visit, thirty admitted newborns were being cared for by two on-duty nurses. With the prospect of more SNCUs being opened in Orissa, the workload may be reduced. However, this will take time, effort, coordination and skilled personnel.
Human resources problems

The best equipment and facility has little value unless there are appropriately trained individuals using knowledge and experience to guide their decisions. Providing good clinical care in an SNCU requires efforts from a variety of people including nurses, doctors and their full support teams, which involve hospital attendants, security personnel and DEOs. While the interviewed staff were without a doubt committed to their work, there is an increased need for more workers.

This was particularly evident for physicians, where a shortage of doctors with neonatology skills and interest was identified. At present, both DHH in Baripada and Capital Hospital in Bhubaneswar have 24-hour physician support provided by the same two or three physicians per site. One of the interviewed physicians stated, “Yes we provide 24-hour service, but it does mean many sleepless nights. Given I am on duty at least five nights a week, I often only now get 3 - 4 hours of sleep a night. But what am I to do as there is nobody else to provide these services? I come into the unit at least three to five times per day. This does take a toll on one’s personal health.” The sustainability has come into question and even resulted in service interruption in Capital Hospital, where physician night services were temporarily disrupted due to the physician shortage. Physicians who are posted to the SNCU often have hospital responsibilities beyond the SNCU. One interviewed Medical Officer said, “Doctors are not happy with the big workload and low remuneration. They leave and join private hospitals, which pay higher fees for their services.” Several solutions have been brought up by interviewees at the SNCUs, including having a neonatologist as a consultant with generalist doctors doing the day-to-day work, and having shift work for the physicians (which would require more positions).

While nurse retention rates are high, DHH has had difficulty filling new posts for nurses, which may be in part due to low salaries. The largest concern from the nurses was a unanimous theme that their salaries (Rs. 6,500 / month) were inadequate. The workload for nurses is high, as illustrated in the aforementioned nurse to patient ratio in DHH. A sufficient number of trained nurses are needed to reduce the workload burden and increase quality care to neonates.
In addition, the important position of DEO has been vacant for as much as two years at DHH in Baripada; and was also vacant at the time of visit to Capital Hospital in Bhubaneswar.

**Equipment maintenance**

Equipment such as warmers, oxygen concentrators, IV infusion pumps, phototherapy units and monitors are essential to the operation of an SNCU. While there has been little difficulty in obtaining the equipment, through discussion with multiple stakeholders it has become apparent that the maintenance of the equipment has not been well managed. At the SNCU Conference in Bhubaneswar, 10 of 12 SNCUs reported operating with non-functional equipment.

At DHH—the site of the oldest operating SNCU—nurses and doctors alike discussed the difficulty repairing equipment. One doctor stated, “We have a significant amount of non-functional equipment. There is no dedicated repair person and the people who try are often unqualified.” This is directly affecting patient care and safety of the treatments. The only cardiorespiratory monitor in DHH is out of service and there is only one operational IV infusion pump, despite many newborns receiving IV fluids and antibiotics. It is also affecting the education parents are receiving, as cited by an interviewed nurse who stated, “We also used to gather mothers in our common area to watch videos about breastfeeding and other topics, but now our computer is out of order.” Even in the ideal situation where all equipment is functional, there is no buffer or back-up equipment in case of malfunctions.

**Lack of family centred care**

In both DHH and Capital Hospital, mothers and families of SNCU patients stay nearby the unit in makeshift accommodation, which they cite as uncomfortable. In Capital Hospital, mothers have the option to stay in an area with other family members or in a room exclusively for mothers. Both areas are concrete rooms without beds and other basics, such as proper ventilation or access to clean toilets. Similarly in DHH, mothers and Hallway at the DHH SNCU which doubles as the step-down unit for mothers. Photo by: Vishal Avinashi.
families stay on the floor of a hallway, which doubles as the ‘step-down unit.’ An interviewed nurse stated, “We have no room for [parents]. They have to stay in the hallway, which gets wet when it rains; and is cold in the winter and hot in the summer.”

During interviews, the question “Would you like something to be changed at the SNCU?” was openly asked. One father shared his perspective saying, “We spent four days on the floor. That wasn’t very nice. The SNCU should also consider that the mother just gave birth and isn’t feeling great. She should be taken care of, too.” Similarly, a mother from Bhubaneswar explained, “Mothers are also human beings and should be treated as such. Mothers are very weak, increasing their possibilities of easily becoming ill...for a baby to be healthy the mother needs to be healthy and mothers at the unit are not being treated properly.”

In addition to the matter of inadequate accommodation, families are not allowed to spend time with their newborns outside of breastfeeding time. One mother suggested, “Mothers should be allowed to see babies more often.” Mothers are called to breastfeed their child throughout the day and must be available at all hours without making pumps or expressed milk storage an option. Several mothers were even scolded for not being available at the very moment they were told to feed their child.

When health education is disseminated during breastfeeding time, it is often only the mother who is present. This means that important health education may not be given in a family centred approach. Given the family dynamic observed during interviews, the value and importance of educating all members of the family on child health care—not just the mother—became apparent. While interviews reveal that mothers are the primary care providers for their children, questions related to maternal and child health were often answered by husbands or mothers-in-law. In these interviews where others were present, mothers often took a passive role. When directly asked about decision making related to the child’s care, it was revealed that mothers rarely made decisions on their own.

**Lack of follow-up**

A major problem of the current SNCU initiative is the lack of follow-up in the short term and the long term. At present, families are typically told to come back in 15 days, although 20 per cent of parents state they were not given any advice on follow-up. One father said, “The sister [nurse] said to bring the child if there were problems, but they did not tell us to come for a fixed appointment. We would have certainly come for an appointment if we were told. We would do anything for the baby.”
Box 2: Case Study #2

DK and CK are a husband and wife living in a rural village in Badasahi block in Mayurbhanj district, Orissa. Their home is a small one-room structure with mud walls, a thatched roof and an attached pen for their goats and cow. During the day, DK works as a daily wage laborer in the nearby fields and CK tends to daily household chores. In early 2011, DK and CK were eagerly awaiting the birth of their first child. CK gave birth to a son at Badasahi’s Community Health Center, the same place where she received regular prenatal care. The newborn weighed only two kilograms. At the recommendation of the physician who delivered the baby, the newborn was transferred by ambulance to the Special Newborn Care Unit (SNCU) in District Headquarters Hospital in Baripada, Orissa.

DK and CK stayed on the concrete floor in a hallway adjacent to the unit anxiously awaiting updates on their baby boy. CK was having difficulty breastfeeding, but was encouraged to continue and discharged home with their baby after five days in the SNCU. They were overjoyed to bring their newborn home even if they had to borrow Rs. 2,500 from family and friends back in their village to pay for their son’s hospitalization. Within 24-hours of discharge, the baby was described to have white spots in his mouth and visited a local doctor, who prescribed medication. Three days later, their baby died at home gasping for air. The parents knew their child was weak and received two blood transfusions, but still do not know what was wrong with their child. Reflecting on their experience, DK noted, “We would have done anything for the baby.” DK and CK still mourn the loss of their child and wonder what more they could have been done to save their son.

In DHH, those patients that do follow-up at the SNCUs are not given a specific appointment or a place for the child to be seen. The present system for follow-up is ad-hoc and is an additional responsibility placed on the physicians. Contacting families using the current registries is a challenge. At the time of the team’s visit to SNCUs, no phone numbers were kept in the registry in Mayurbhanj, and in Capital Hospital only 13 per cent of patients registered had a written phone number (although the trend was improving with time).
One interviewed doctor stated, “UNICEF guidelines do suggest follow-up, but we are unable to provide these services because of such a high patient load.” Of the seven families interviewed in Mayurbhanj district, none returned to the unit for follow-up, although the physicians estimate a 50 per cent follow-up rate. In Capital Hospital, only 42 per cent of patients had gone for a visit to any health care worker when their baby was well, but not necessarily to the SNCU. The one SNCU which is a positive outlier for good follow-up rates is Subarnapur, which describe their follow-up rates at nearly 90 per cent.\(^{40}\)

According to SNCU staff, reasons for low follow-up rates include large referral area, parents feeling their child is now healthy in combination with their many other household responsibilities, transportation difficulties and economic constraints (e.g. lost wages). One interviewed mother said, “No, we did not take baby for follow-up. We couldn’t afford for the baby to go back to the SNCU.” One interviewed doctor stated, “Daily wage worker will not want to take a day off work unless the child has a significant problem. Wealthy families will get care from private pediatric specialists to follow-up their children and often receive follow-up more than necessary.”

**Need for quality assurance**

Quality assurance processes are necessary for ensuring minimum standards of quality are being attained in health care facilities. In the SNCUs, however, monitoring efforts are in place to provide only descriptive data on the units, rather than quality assurance. Descriptive data—such as the number of admitted newborns, gender of admitted newborns and mortality among admitted newborns—are generated from multiple registries. It is unclear how much analysis of gathered data occurs or what decisions get made based on the presented data. When asked whether there was a difference between inborn and outborn mortality outcomes, an interviewed nurse replied, “Probably yes, but there is no proper documentation on it.” This evident gap in data gathering and analysis likely exists because the post for the DEO has not been filled for at least two years in both DHH and Capital Hospital. Nurses have partially filled the void, possibly taking them away from more suitable clinical duties.

There is a need for uniform registry keeping across all SNCUs, as currently the registry systems vary. For example, based on the SNCUs visited, it was found that one of the units collected data on caste, while the other did not. Even within the same registry, the categories of data collected differed. In addition to descriptive data collection, it is important to also have monitoring for quality assurance in SNCUs. This was evident from one doctor who commented that units focus on volumes of patients and not on quality.

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\(^{40}\) SNCU Meeting, Bhubaneswar, India. 6 June 2011.
Establishment of the SNCUs has led to significant advancement in services provided for neonates at the government level in Orissa. This means that intermediate level neonatal care is now available to poorer families. As a result of the initiative, there is now dedicated trained staff and newborn-specific equipment to better care for sick neonates at the hospitals. All of the families interviewed were admitted to these units at the recommendation of a doctor, which shows a high level of awareness of SNCUs among health care professionals. This may be aided by the high percentage of institutional deliveries (96 per cent, as indicated by the telephone survey). The improvement in institutional capacity at the district level is important considering the high incidence of birth asphyxia, low birth weight and severe infections. SNCUs have helped to fill the gap between the primary health care centres, which provide basic resuscitation, and level III specialized centres. In the next few years, certain SNCUs will be expanded. This expansion is necessary considering the very high levels of usage and high bed occupancy rates in the existing units.

The expansion of SNCUs has occurred over a very short duration, which reflects stakeholders’ confidence in the program and the demand for services. However, it was not clear whether formal evaluation of the projects has been carried out or if objective data exists demonstrating the initiative’s impact. One necessary piece to properly evaluate these units will rely on long term outcomes of the patients post-discharge, including complication rates and survival rates.
Lessons learned

Sufficient number of trained staff
A common theme identified in interviews was that the SNCUs were overstretched in terms of human resources. Although the number of staff is based on the number of beds available, the number of newborns per unit often exceeds the number of beds per unit. With such high demand for services in the units, the number of trained staff in the SNCUs is insufficient to keep up with the high workload.

The shortage in human resources is evident when speaking to the interviewed physicians, who cite demanding shifts, frequent on call duties and other clinical duties beyond their SNCU responsibilities. Increasing the number of physicians trained in neonatology, especially those dedicated exclusively to the SNCU, is vital for improving the service delivery in the units. A sufficient number of trained physicians are needed to reduce the workload burden of the current physicians, provide increased care to neonates, increase the amount of time that physicians can spend giving updates to families and improve follow-up services. Where medical and nursing colleges exist, efforts should be made to increase students and junior trainees’ exposure to basic newborn care management as well as increase formal training opportunities to develop more neonatologists in Orissa.

The human resource shortage in the SNCUs extends beyond physicians. While nurse retention rates are high, Mayurbhanj has had difficulty filling new posts for nurses, which may be in part due to low salaries. A sufficient number of trained nurses are needed to reduce the workload burden, enhance record keeping, increase quality care to neonates and improve the interface between the unit staff and patients’ families. Further, a sufficient number of DEOs are necessary for managing data, monitoring the unit and assessing performance. Security personnel and hospital attendants are also necessary to provide security and cleanliness in the unit, which are critical for the safety and health of neonates and their families.

Having units with a sufficient number of trained staff is especially important considering the growing demand for the units and the upcoming plans for expansion. If hospitals are having trouble filling posts currently, expanding the SNCUs without increasing the number of trained staff could further overstretch the units. This could be detrimental to the quality of service provided to patients and result in negative health outcomes.

Family centred care
Being considerate of the needs of mothers and families of babies at the SNCU is a first step toward family centred care. The SNCU stay for families is full of emotions and stress. Feelings of sadness, frustration,
anxiety and worry were prominent among the families interviewed. In addition to worrying about their child, being away from home and family, having financial worries and having unmet responsibilities are all part of the mothers’ and families’ reality in the SNCU.

With an average stay of nine days, waiting on the concrete floor without privacy, clean water, proper ventilation or clean bathrooms are less than ideal conditions for mothers who have just given birth. Given that maternal health and wellness are associated with the ability to bond, breastfeed and provide appropriate care to their child, attention to maternal needs at SNCUs should be considered a priority. Setting up cots in the mother’s room, adding fans for ventilation and installing a water filter near the unit would make the maternal experience at the SNCU better. Providing material for families to read and look at in relation to child care would also be beneficial to the family and the future wellbeing of the baby.

Education targeted to families is another step toward family centered care. The health care education that is provided to mothers at the units should also be provided to all family members. Involving all family members is important because interviews revealed that mothers rarely made decisions related to the child’s care on their own and that mothers-in-law are often cited as the most knowledgeable about child care. In addition, there seemed to be a gap between the information that is provided at the SNCU and what happens when the baby is brought back home. Although the interviewed mothers recalled the “headings” such as the importance of nutrition or good hygiene, they did not remember what each of those issues meant. Having more family members actively participate in an education session at the SNCU may help encourage healthier choices in relation to child care at the household level.
Follow-up

Keeping the newborn alive in the SNCU is only part of the solution towards a healthy and able population. It is overly simplistic to think that inpatient survival is equal to outpatient survival; or that survival is equal to health or quality of life in the long term. The first part of knowing whether a child is alive post-discharge is being able to contact that child. Mobile phones are relatively ubiquitous and while every family may not have their own, a relative or a community health worker, such as an ASHA, should. Without any exceptions, a tracking system should keep the complete address including block, panchayat, village and mobile information, which can be used to contact the family. Registries should be standardized across all SNCUs to allow for consistent and comparative data. Some private health centres in Orissa provide parents a direct phone line to a health care worker on call in the Neonatal Intensive Care Unit for the family who is being discharged. Communication should be bidirectional, allowing for families to have a contact number of a health care worker in the SNCU at least for the first month of life.

Phone follow-up can be an initial point of contact, but is not a substitute for detailed examination of the child. All patients who were admitted should be advised to return for a check-up at fixed points for visits when the baby is well, unless issues arise prior to their appointment. Barriers to follow-up, including lack of transport (or lack of funds for transport), should be addressed as well as considering a system of reimbursement after the child has visited a physician.

Pediatric specialists should also be engaged at a more local level, especially for children who are not deemed as high risk. One doctor who works at a Community Health Centre stated, “Follow-ups are very important, but for those coming from the district hospital, we don’t know what the problem was, what treatment has been carried out and what advice has been given. There should be some feedback which comes about these patients
and then only can we help. Otherwise we have to follow-up our own patients.” Proper discharge information must be provided to other health care workers—including diagnosis, medical history, treatments, procedures and follow-up—if others are to be involved. The available network of pediatric specialists who are comfortable with newborn care needs to be identified, expanded, trained and utilized.

The SNCUs should have physical space and human resources dedicated to the follow-up of high risk children and ensure they are connected with appropriate multidisciplinary services.

**Potential applications**

The establishment and operation of the SNCUs since 2007 has highlighted some important lessons. Given that plans for expansion and scaling up have already been announced, SNCUs will be in a growth phase for the years to come. Lessons learned from the current operation should help ensure that old problems do not recur.

Lessons such as having adequate human resources, family centred care and follow-up, can also be applied to establishing neonatal care units outside the context of Orissa; and to designing or improving related health programs in Orissa or other states. Example of related health programs include programs to monitor and promote growth of children as well as the mother’s health before and after pregnancy, health awareness days in schools, immunization programs and integration of alternative methods of health care into government health care services. These programs seek to bolster the capacity of the health care service providers at each level of care and focus on improving access to all.

**Beyond the SNCU**

- With program implementation, institutions are generally aware of the direct costs, but can overlook the indirect ones. From a families’ perspective, they often only see the total costs, which can be a barrier towards accessing these programs, even if the programs would benefit them overall. While certain programs have policies to reduce the cost burden to poor families, the objective and verifiable eligibility criteria should be clearly outlined and publically communicated

- Health care programs using doctors and nurses should maximize their skills allowing them to work on clinical care and reduce their administrative work as much as possible. The administrative tasks can be delegated to others, including unit clerks and data managers. Salaries and benefits of health care providers should be commensurate with qualifications and experience and be competitive with the private sector. While it is easier to expand physical infrastructure, increasing the number of specialty trained health care professionals may be difficult. Specialized training systems or vertical training
programs should be implemented when possible. For existing health care professionals, knowledge can be enhanced by facilitating the organization and attendance of continuing medical education training modules.

- Health education should not be limited to clinics or hospitals nor should information exclusively come from doctors or nurses. There is a vast network of allied health care workers (such as ASHAs, Urban Social Health Activists, Anganwadi Workers, Yashodas, Auxiliary Nurse Midwife and Female Health Workers who work in communities across India which should be capitalized upon to provide (public) health education.

- When programs require equipment, budgetary allotments should be made to purchase equipment and maintain them. Proper maintenance is dependent on having the money for repair, the appropriate tools and parts and access to appropriately trained people.

- All programs related to health should have regular evaluations and routine quality assurance measures. The standards should be developed communally a-priori by professionals involved in the field. While it is best for evaluation to be done externally, all people have a role in ensuring quality on a daily basis. Computerized systems may enhance this process.

Next steps

The expansion of existing units and scaling up of SNCUs is ongoing. The expansion of the SNCUs should not take away the focus from providing access to safe and timely deliveries (including caesarean sections) or appropriate neonatal resuscitation at the community level. Although the SNCU is intended to be nurse-driven and deal with a few common problems, presently there is a heavy reliance on physicians who are dealing with newborns with the full spectrum of diagnosis, acuity and complexities. There is a want among several interviewed physicians and nurses for more equipment, training and even for becoming a level III facility in Capital Hospital and DHH. While having tertiary level newborn referral centres have a role in the future, basic provisions such as 24-hour water and electricity need to be in place. The expansion of SNCUs may be limited, as pediatric specialists are already overworked and in many regions the post has remained vacant for years. Given that doctors and nurses are busy caring for neonates, having a designated health educator available at the SNCUs (such as a Yashodas) could relieve some of their workload. As a result doctors and nurses will be more able to focus on their clinical duties caring for the sick newborns.

In addition to verbal health information given at the SNCUs, booklets could be provided to reinforce (but not replace) the information provided by the health educator. This booklet should be standardized, written in simple, non-technical local language (Oriya) and include images on how to take care of newborns. This can
serve as a reference for families while at home and promote good child care practices at the household.

It would be beneficial if systematic follow-up is made part of the mandate of the SNCUs and adequate budgetary and human resource allowances are made for it. The follow-up system should track mortality rates as well as describe and provide services to those with disabilities resulting from the underlying problems which caused the children to be admitted to the SNCU. This follow-up can be done at a community level or at the SNCU at scheduled appointments, depending on the child’s problems. Regarding tracking patients and collecting data, new software has been designed specifically for the SNCUs. The initial steps prior to its implementation include ensuring that there are functional computers in all SNCU sites and having a trained person to enter the data. While this can help keep track of the discharged infants and their outcomes, it does not independently equate to quality follow-up for the children or reduce the pre-existing barriers. A private hospital in Orissa has exemplified a unique method of follow-up by bringing a member of the health care team to the child at the time of their regularly scheduled immunizations to avoid multiple visits. Many ideas for ideal models of follow-up exist, including having periodic phone calls to families, arranging ambulances for transportation or having weekly high risk clinics; however, all rely on having more doctors available. Capital Hospital seems to be ahead in terms of having multidisciplinary services, such as Retinopathy of Prematurity screening and hearing screening, and are keen to have occupational therapists and physiotherapists as part of their SNCU team.

In addition, providing access to ambulances could facilitate rapid care and treatment in cases of emergency. Ambulances should be available to all communities and individuals at no cost to encourage their use. Family centred care is the ideal model for pediatrics, which should include neonates, particularly those who are receiving true level II care. While at the SNCUs, fathers and mothers should be allowed to spend time with their newborn child so long as they follow hand washing protocol and the newborns are not critically unwell. Options for pumping and storing expressed milk should be made available to allow mothers some flexibility, including sleeping throughout the night or going home to tend to her other children for a short period.

While growth seems inevitable for the SNCUs, documentation, review and analysis should be part of the process at each step of change. This will slowly allow the culture of objective evaluation to be imbedded in the SNCU which can lead to the provision of high quality care.
References


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Annexure I

Recommendations

*Human resources*

- For Special Newborn Care Units (SNCUs) with high volume, staff positions should be exclusively for the SNCU and should not involve other hospital duties. Ideally all staff positions will be on a shift basis for patient safety.
- Administrative duties should be delegated away from nurses and physicians to allow them to focus on clinical care.
- Staffing (nurse to patient ratios) should be based on the number of patients, not the number of beds, although these should be the same. All admitted babies should have their own bed.
- Staff salaries should be commensurate to those offered by the private sector facilities for similar skills.
- Data Entry Officers (DEOs) are important members of the SNCU team. Full efforts should be made to recruit and retain DEOs.
- Equipment repairs should only be done by individuals with appropriate training.
- The available network of pediatric specialists who are comfortable with newborn care needs to be identified, expanded, trained and utilized.
- Where medical and nursing colleges exist, efforts should be made to increase student and junior trainees’ exposure to basic newborn care management as well as increase formal training opportunities to develop more neonatologists in Orissa.
- If the model is meant to be nurse-driven, increased autonomy and responsibility should be given to the nurses.
- Health education should not be limited to clinics or hospitals nor should information exclusively come from doctors or nurses. There is a vast network of allied health care workers (such ASHAs, Urban Social Health Activists, Yashoda workers, Anganwadi Workers, Auxiliary Nurse Midwife and Female Health Workers) who work in communities across India which should be capitalized upon to provide (public) health education. In the case of SNCUs, Yashoda workers would be a good resource to help with health education while the newborns are admitted.

*Family centred care*

- Appropriate space, hygienic supplies, clean water, clean bathroom access and a decent place to sleep should be made available to mothers who should be seen as relevant to the needs of the newborns. Even setting up cots in the mother’s room, adding fans for ventilation and installing a water filter near the unit would make the maternal experience at the SNCU better.
- While procedures require sterility and good hand washing practices are paramount in decreasing nosocomial infections, consideration should be given to allow core family members to visit and even hold their newborn during certain times of the day. Most level II newborns can tolerate touch and even benefit from it. This allows a wonderful opportunity to provide updates on the newborns.
- Education should be provided to families and not just mothers. All family members should be included in an active, participatory way.
• Booklets related to caring for newborns at home should be provided to families to reinforce the health education provided in the hospital. They should use simple, non technical language in Oriya and contain images.
• Consideration should be given to providing discharged families a way to contact a health care worker knowledgeable in neonatal care.
• Options to express milk and store expressed breast milk should be made available in SNCUs particularly for gavage or spoon fed newborns.

Follow-up

• Systematic follow-up should be made part of the mandate of the SNCUs.
• The follow-up schedule for newborns being discharged should be consistent across all SNCUs.
• All newborns discharged from the SNCU should have discharge cards with relevant medical history including diagnosis, medical history, treatments, procedures and follow-up
• Not all patients require follow-up at the SNCU. Patients who are deemed complicated and high risk (which can be defined collectively ahead of time) should be followed at the SNCU, but should still have access and support from local pediatric specialists.
• Specific space and human resources (including multidisciplinary services) should be provided to high risk children for follow up.
• Low risk children, for example jaundiced term babies, can and should be followed up by local community pediatric specialists.
• Barriers to attending follow-up, such as cost to follow up, at SNCUs should be addressed.
• Multidisciplinary services should be provided to those who have (or are at risk of) complications related to the conditions that led them to be in the SNCU.

Access and costs

• Ambulances should be made more widely available for the transport of sick newborns from one health centre to an SNCU. The ambulances should have trained personnel who can perform basic newborn life support and have oxygen and newborn specific equipment.
• From the perspective of the health care provider, the recommendation to transfer a patient to a higher level facility should be primarily based on the clinical status of the child.
• All medications on the standard registry should be provided in SNCUs free of cost.
• Operational funds to the individual SNCU beds should be increased.
• Programs of cost relief at the hospital should be publically announced and advertised. Staff should be aware of the ideally objective and verifiable eligibility criteria and help screen families.
• At the time of purchasing, budgets for equipment should include money for repair and should factor in the life cycle costs.

Infrastructure

• When planning for an SNCU, units should be made to have adequate supplies including 24 hr water, electricity (installed generators), adequate power outlets, good ventilation, and ideally central oxygen and suction. The location should ideally be in close proximity to the labour and delivery wards.
• Equipment allotment should be standardized for each unit and based on the number beds. The amount of equipment should include a buffer accounting for repair and breakdown.
• Functional computers with internet connectivity should be made available in all SNCUs.
• Step down units should be separate and should not double as breastfeeding areas.

Unit operations

• Strict attention to hand washing must be paid as all level of staff were witnessed not washing their hands between patient contact and some families also entered the SNCU without being asked to wash their hands.

Quality control and assurance

• The same admission criteria, protocols and registries should be used in all SNCUs across Orissa.
• The acquired data should be sufficient to easily contact a family post discharge (e.g. mobile number).
• The data gathered presently for monthly reports should be enhanced to include information such as the presence of non functional equipment.
• Families’ perspectives on their experience in the SNCUs should be regularly sought and should serve as a quality indicator. Other quality indicators should be developed communally and used throughout the state.
• Systems that track government supply of essential medications should be in place.
• Survival rates and complication rates obtained from follow up visits should be reported and tracked.
• Ensure data collection and data analysis is happening in each unit and at the state level. Data analyzed should be posted publically for all to see.
• Units should undergo full evaluation to allow full commentary on the impact of SNCUs in Orissa.
Annexure II

Method of investigation

Methodology

Review of the SNCUs was done from several different angles, including from the hospital perspective and from the families’ perspective. The project was observational in nature and used mixed methods. While there are more than a dozen operating SNCUs, our project focused on two sites: District Headquarters Hospital, in Baripada, Mayurbhanj district and Capital Hospital in Bhubaneswar, Khurda district. Both these units have large volumes of newborns and have been established for at least two years, allowing for the description of two stable units. Our team was also privileged to be part of a two day meeting in Bhubaneswar, sponsored by UNICEF, where representatives from each of the functioning SNCUs in Orissa provided status updates and shared their problems.

To better understand the establishment and operation of SNCUs, our team primarily spoke with a variety of health care workers and administrators including physicians, nurses and medical officers. Dr. A. Sen was also a key informant who provided historical and contextual information of how UNICEF has been involved in the initiative to date. A total of 21 interviews were performed, including five interviews with pediatric specialists, nine with nurses, three with medical officers and five with others including attendants, security officers, Yashodas and members at UNICEF. While each key informant semi-structured interview was tailored for a specific position, the general questions were similar. See Appendix 2 which provides a template for interviews with physicians.

An attempt was made to provide quantitative data on infants who were discharged from the SNCUs and estimate survival. The planned method was performing a 5 – 10 minute phone survey of discharged babies in Oriya, which would provide the status of the child along with basic demographics. However, a significant limitation to the completion of this research was the fact that no phone numbers were provided in the admission/discharge registry at DHH in Baripada. In Capital Hospital of the 1587 listed patients in the registry, only 210 had mobile numbers listed (13 %). Of those with mobiles, our team could contact only 98 people. After excluding those not interested (12), those with babies transferred (2) and those babies who died while in the SNCU (9), we were left with 71 consenting respondents. The telephone survey questions can be seen in Appendix 3. Analysis of this data has not been presented as it is underpowered to show a statistical difference.

A total of 22 household interviews took place with mothers and families who previously had a child in the SNCU in either DHH or Capital Hospital. The average duration of an interview was approximately 70 minutes. The approach by which the families were identified differed depending on the site. In Capital Hospital, at the end of
the phone interviews, the participant was asked whether they would be interested in a more in depth interview. If so, the address was noted and a time convenient to the family was scheduled.

In DHH, given that there were no phone numbers in the registry, our sample of families was a sample of convenience. Physicians in Community Health Centres (or Primary Health Centre) within different blocks, who would contact nearby ASHAs to see if they knew anybody who was admitted to the SNCU, were visited. The team would then meet the ASHAs, who would take the team members directly to the house of the previously admitted child.

Although the approach to the contact families differed depending on the site, written consent was obtained from all families and the questions asked through the translated semi-structured interviews were the vastly the same (see Annexure V).

Notes were taken during all interviews and then later transcribed into full text. All information gathered has and will continue to be treated confidentially. The content of the interviews has been entered into Microsoft Excel and the data file is encrypted and password protected. The transcribed information was then analyzed and organized into broad themes.

**Ethical considerations**

In understanding the sensitivity of the issues discussed (such as the death of a child), our team has paid particular attention to interviewing in a compassionate, culturally sensitive and ethical manner. Doing so involves paying attention to participants’ rights, privacy and confidentiality. Consent forms were obtained from all participating families either verbally and/or in writing to guarantee their willingness to participate in the project. (See Annexure VI for consent form). In addition, the project objectives were made clear and articulated in Oriya in simple non-technical language. Participants were told that they had a right to refuse participation, refuse answering certain questions, ask questions at any time or leave the study at any time. It was stated that no direct benefit will come to the study participants. Verbal and/or written consent was obtained for use of all photographs (see Annexure VII for photo consent form). The methodology used was inclusive, non-discriminatory and allowed for a degree of flexibility in accommodating participants’ needs.

**Challenges and limitations**

Despite efforts to provide the most accurate and reliable information possible, our team faced several challenges and limitations which may have influenced our results and conclusions.
First of all, this ‘lessons learned’ document should not be considered a formal evaluation of SNCUs in Orissa. While our team’s project was supposed to focus on SNCUs throughout Orissa, the data was primarily gathered from only two sites, which strongly shaped our teams’ viewpoints and make the results less generalizable towards other SNCUs. Also, while the project calls for the document review of SNCUs, very few written documents were shared or found on the establishment and operation of SNCUs, leaving a heavy reliance on verbal history. Despite best efforts, not all key stakeholders were interviewed. In our case, we were unable to have an in-depth interview with a member from the NRHM involved with SNCUs.

Having no one on our teams who spoke Oriya, the dominant language of the participants, we had to rely and trust our translators who were not directly a part of our research. The accuracy and sensitivity of the questions asked may not have been translated or disseminated effectively by the translators. Although the consent forms were explained in Oriya, unfortunately the consent forms were not translated into Oriya in time for our field work, leaving participants to sign documents in a foreign language. Also, there were no local ethics committees which could review or approve our protocol from an ethical point of view prior to field work.

In term of participant selection, in Capital Hospital, there was likely selection bias towards those with increased means given that the families had to own a mobile phone. While we intended to select in-depth interviews based on caste, gender of child and child survival in a case-controlled manner, the small sample size caused us to interview all willing families.

In DHH, resulting from the lack of phone numbers in the registry, the team were brought unannounced by ASHAs to families. In these circumstances where there are people at your doorstep, it may have been more difficult to turn down the interview and possibly made for a less comfortable environment even if the families did consent. While the ASHAs were most helpful to connecting our team to families, their presence may have also affected responses, especially on topics such as health education or health seeking behaviour.

Time, particularly in the field, was also a major limitation for the team. We were on a fixed time schedule that hindered our ability to make adjustments in our research plan. Having little time also hindered our ability to build rapport and creating trust with the participants. There was no opportunity to sit and drink tea with the participants before asking them sensitive questions about the state of their babies. Being able to spend more time in the field would have been very beneficial and helpful to us, particularly the Mayurbhanj team who only got to complete 5 out 10 planned days in the field.
One of the challenges we faced was with the target audience. Despite having designed a questionnaire focusing exclusively on mothers, most of the time it was husbands and mothers in law who answered the questions in the interview. Overall we were able to successfully complete our research, yet it is important to highlight our limitations.
Annexure III

Physician interview

1. What is your name? How long have you been working in this position?
2. How did you hear about this position? What other work do you do outside of the SNCU?
3. How far away do you live from the SNCU?

Establishment of the SNCU.

4. Please walk us through the process of establishing the SNCU. What were the steps?
5. Were there any challenges encountered during the establishment of the SNCU?
   a. If yes, how were these challenges addressed?
      i. Were these challenges overcome?
         1. If yes, what did you do to overcome them? If no, why were they not overcome?
6. What went smoothly when establishing the SNCU?
   b. What factors do you think led to this?
7. What do you think about the government’s recommended outline for SNCUs (staff wages, unit size, etc.)?
8. If you were to establish another SNCU, how would you do it differently?

Maintaining the SNCU.

Funding

9. Where does funding for maintaining the SNCU come from?
10. Is the funding sufficient for maintaining the SNCU (e.g. equipment repairs, number of staff, staff wages)?
11. How do you address funding issues, if any?

Staffing

12. Who staffs the SNCU (e.g. one surgical doctor, two nurses, one cleaning, etc.)?
   c. Is this number adequate?
   d. Is the unit overstretched in terms of service delivery? (Both in physical capacity and human resources capacity).
      i. If yes, describe.
13. Are you able to offer 24 hour services?
   e. If yes, is this sustainable? If not, what are the challenges?
14. How is staff retention?
15. How do you address staff turnover?
16. How is staff morale?
   f. What factors do you think have led to this overall sense of morale?
   g. Is there anything that would improve staff satisfaction from the status quo?
17. Have you thought of ways to make the SNCU more efficient?
18. Have you ever bought up any ideas at meetings about how to improve or solve the problems at the SNCU?
   h. How were they taken by others?
   i. How were they taken up by the managers?
Equipment
19. What is the current state of your equipment? List functional and non-functional items.
   j. Why is this the case (for non-functional items)?
   k. How is this affecting the SNCU?
20. What is the current system for maintaining and repairing the equipment?
21. Is there any equipment that the SNCU does not currently have, but that you think would improve the unit?
22. Regarding the use of equipment, is there training on how to use it?
23. Did you personally receive any training on using equipment that is pertinent to your job tasks?
24. How does the SNCU deal with power cuts?
25. What is the availability of lab support? Is it available 24-hours?

Record Keeping
26. Please describe the current patient record keeping system.
27. Have you encountered any challenges with your current record keeping system?
   i. If yes, please describe the challenges you have faced.
   ii. How did you address these challenges?
   iii. Were you able to overcome these challenges?
28. Are you planning to upgrade your current record keeping system?
29. What do you think of the idea of the offline tracking software for follow up purposes?
30. Is the SNCU considered to be part of the hospital?

Government Relations
31. Describe the communication channel between the SNCU and the government.
32. Up to what level of government officials do you communicate with and what is their behaviour?
33. From which government offices do you need cooperation from?
34. Is it clear which operational decisions are to be made by you or by the government?

Challenges
35. What challenges have you encountered in the day to day maintenance and functionality of the SNCU?
   m. How have you addressed these challenges?
   n. Have you been able to overcome these challenges?
      i. If yes, what did you do to overcome them? If no, why were you not able to overcome them?

General questions about the SNCU

SNCU-Specific Questions
36. Do you think that residents in your district are aware of the SNCU?
37. Do you promote the SNCU in the community?
   o. If yes, how?
38. What is your catchment area?
39. What is the furthest that someone has traveled to the SNCU?
40. Do you think your centre is maximally utilized?
41. On average, what percentage of beds is filled at the SNCU?
42. Does your SNCU provide consultations (e.g. to babies in the hospital nursery)?
43. Are there standard admission, treatment and discharge criteria?
44. Describe the unit’s working relationship with ASHAs and Anganwadi workers?

Baby- and Family-Specific Questions
45. Do you find a difference in outcomes between babies who are inborn vs. out-born?
46. Where do patients’ families stay when their baby is in the SNCU?
47. Are any accommodations made for mothers to ensure that they are near their baby to promote breastfeeding?
48. What information and updates do you provide to families while their baby is receiving services at the SNCU?
   
   p. Describe how this information and updates are disseminated.
   q. Who disseminates the information?
   r. How do you address possible language barriers?
49. What do parents have to pay for from the pocket?
50. How much would you estimate that an average family pays from pocket (on direct health expenses)?
51. If a family is unable to pay, how do you address this?
   s. How often do you estimate that this happens?
52. Is cost to families a factor in your prescribing habits?
53. How would you describe the satisfaction level of families whose babies are patients at the SNCU?
54. Can you provide any insight why families leave against medical advice?
55. Are there other pressures to discharge babies that go beyond medical indications?
   t. What do you think the causes are?
   u. How often do you estimate that this happens?
56. How does the SNCU address abandoned babies?
   v. What do you think the causes are?
57. What measures do you take to make sure that everyone feels welcome at the SNCU?
58. Is there anything done to make the unit baby-friendly (e.g. colors and noise in the unit)?

Transfer, Discharge and Follow Up
59. What is the number of discharges per day?
   v. Who decides this?
   w. Where is the record keeping process for this?
60. What information do you provide to families at the time of discharge?
   x. Who disseminates the information?
   y. Describe how this information is disseminated.
   z. Was it demonstrated?
61. What advice is given to mothers on the following?
   aa. Breastfeeding?
   bb. Keeping baby warm?
   cc. Identifying warning signs regarding their baby’s health?
   dd. Beyond these three, is there any additional information that should be included in the discharge papers?
   ee. How do you address possible language barriers?
62. What is the advised follow up for patients?
   ff. How do you decide which children require follow up?
   gg. Who makes these arrangements?
63. Are there any follow up clinics?
   hh. What would you estimate to be the attendance rates at these clinics?

64. What is the ideal model of patient follow up?

65. If a patient is transferred, how do they get there?
   ii. Whose responsibility is it to arrange it?

66. Do you anticipate any changes in the SNCU in the next five years?

67. Is there anything important that we have not discussed here that you would like us to know?
Annexure IV

Phone interview

Phone Interview

Good day. How are you? My name is (interviewer name) and I’m calling from (hospital name) Hospital. I am calling about (child’s name/mother’s child) who was in the hospital in (month/year). Can I speak to (mother’s name) please?

--------(If not, how could I get a hold of her?)--------

We would like to ask you some questions to follow up on the baby. This information is very valuable to us and will be used to make improvements to the SNCUs in hopes that more newborn lives can be saved. We promise to keep your responses confidential and you can ask questions or stop me at any time. Your thoughts are very valuable to us. This will only take five to seven minutes. Would you be willing to participate?

--------(If No – is there a better time that we can talk?)--------

(Name of person being interviewed)

1. What is the name of the child who was admitted to the SNCU? NAME_________________

2. Is this a boy or girl? Sex: F M

3. Which caste or tribe do you belong to? Caste/Tribe

4. Under what category is it placed? SC/ST OBC Other? SC ST OBC Other

5. What is your highest level of formal education you completed? _______________________

6. How old were you when you gave birth to (NAME)? Age _______________________

7. Did the delivery happen at home or at the hospital? Home Hospital

8. While pregnant with (NAME), how many check-ups from a health care worker did you go to? Prenatal # _______________

9. How much did (NAME) weigh when HE/SHE was born? BW _______________________

10. What was going on with (NAME) that required them to go to the SNCU. (What symptoms)? Symptoms: _______________

11. Were you given an explanation or diagnosis of what happened to (NAME)? What was it? Dx _______________

12. How far away was the SNCU from where you had the baby? Distance__________ Mode_____________ Time _______________

13. How old was (NAME) when he/she arrived to the SNCU? Days or Hours _______________
14. How long did your baby stay in the SNCU?  
Duration (days)_________  

15. When discharged, were you advised to go for follow up with the SNCU?  
Were you able to attend the follow up?  
Advised  
Attended  

16. Is (NAME) alive today (if No, continue to next section)  
Alive  

17. How old is (NAME) now?  
Current Age __________  

18. Since discharge, has (NAME) seen a health care provider?  
HCP  

19. How many times has he/she had visits for routine follow up  
(If 0 go to 21)  
# well visits __________  

20. Who did (NAME) see for the well visits?  
Who ___________________  

21. How many visits were made for times when (NAME) was  
unwell? (If 0 go to 24)  
# unwell visits__________  

22. What were some of the reasons?  
Why?___________________  

23. Who did (NAME) see?  
Who ___________________  

24. Was (NAME) breastfed? (If NO go to 28)  
BF  

25. How many months was (NAME) breastfed for?  
Duration ____________  

26. When did (NAME) receive liquids other than breastmilk?  
Liquid intro __________  

27. When did (NAME) receive solid foods?  
Solid Intro ____________  

28. Thank you for your information. Is there anything else you  
wanted to share with us?  
Other__________________  

20. Sorry to hear that. Would you mind sharing what  
happened? (including symptoms, when, where)  
Death__________________  

21. How old was (NAME) when he/ she died?  
Time/Death ____________  

22. How many visits were made to a health care worker  
for times when (NAME) was unwell (if 0 go to 25)?  
# unwell visits__________  

23. What were some of the reasons for the visit?  
Why?___________________  

24. Who did (NAME) see?  
Who ___________________  

25. How many times has he/she had visits for routine follow up?  
(If 0 go to 27)  
# well visits__________
26. Who did (NAME) see? Who ________________

27. Do you feel anything could have done to help prevent the Prevent ________________
   death of your child?

28. Was (NAME) breastfed? BF Y N
   (If NO go to 32)

29. How many months was (NAME) breastfed for? Duration _____________

30. Did (NAME) receive liquids other than breastmilk? When? Liquid intro ____________

31. Did (NAME) receive solid foods? When? Solid intro ____________

32. Thank you for your information. Is there anything else Other _____________
you wanted to share?

Thank you so very much for talking to us. The information you gave us is very valuable. We would be interested in hearing more about your thoughts and experience at the SNCU. We know your time is valuable but we believe the information you share will help save newborn lives. Would you be willing to further talk to us in person within the next few days? We are willing to meet you at your home or any other place that is convenient to you to talk more in depth.

**IF YES**

“Great. What is the best way to contact you? We will contact you at this number to further discuss this meeting and what it involves and at that time we can set up a time and place that works for you”

**IF NO**

“No problem. Thank you very much for your time and sharing your thoughts”
Annexure V

Family interview

A. General Family/Kinship Related Information:
1. How many individuals are there in your household/family?
2. Description of Child’s Family.

<table>
<thead>
<tr>
<th>Name (Mention Relation to the Head of the household)</th>
<th>Member 1</th>
<th>Member 2</th>
<th>Member 3</th>
<th>Member 4 and others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date of Birth</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age when married</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. How long have you been living in this place?
4. Where have you spent most of the time of your life? (In a hamlet, village, town or city).
5. How far is your house from an all-weather road? ____ kilometers
6. Are there any smokers in the household? Do they smoke inside the house?
7. Which one of the following possessions does your household have?

<table>
<thead>
<tr>
<th>Electricity</th>
<th>Bank Account (Independent or Joint)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gas Stove</td>
<td>Pressure Cooker</td>
</tr>
<tr>
<td>Cooler</td>
<td>LPG connection</td>
</tr>
<tr>
<td>Satellite TV</td>
<td>Electric Fan</td>
</tr>
<tr>
<td>Cooler (grass)</td>
<td>Radio or Transistor</td>
</tr>
<tr>
<td>Air Conditioning</td>
<td>Television</td>
</tr>
<tr>
<td>Refrigerator</td>
<td>Mobile Phones</td>
</tr>
<tr>
<td>Landline Connection</td>
<td>Computer</td>
</tr>
<tr>
<td>Car</td>
<td>Bicycle</td>
</tr>
<tr>
<td># of rooms</td>
<td>Motorcycle or Scooter</td>
</tr>
</tbody>
</table>
B. Household Environment and Facilities Issues:
1. Where do you get your drinking water from?
2. How do you store water in your household?
3. Do you treat water before consumption?
4. Where is the water source located and how is it replenished?
6. Where do you cook?
   ● If indoors, how is the kitchen ventilation designed? (Window/Exhaust/Ventilator or something else)
   ● What kind of fuel do you use?
8. On average, how many meals do you eat in a day?
9. Where do you defecate?
   ● If you use a toilet, What kind of a toilet
   ● If you use a toilet, how often do you clean it?
   ● What kind of a disinfectant do you use to clean it? Do you share it with other households?
10. If you practice open defecation, how far from the household do you go?
11. Describe your hand washing practices after defecation?

C. Nutritional Issues
1. How often do you consume these items?

<table>
<thead>
<tr>
<th></th>
<th>Daily</th>
<th>Weekly</th>
<th>Occasionally</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Milk or Curd</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pulses or Beans</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Green Vegetables</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Vegetables</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fruits</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eggs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chicken/Fish (any other meats)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. Are you able to consume them by choice when wanted/needed or are their any constraints (monetary/customary or others). OR If you don’t eat meat/egg then is it by choice (customs, traditions)?

D. Maternal Education
What is the highest grade you have completed?
E. Physical Exertion Issues:

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Mother</th>
<th>Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nature of Work (daily wage labour or fixed income) Include physical labour specifically</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seasonality of Work (all round year or for a few months)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

F. Income/Social Mobility Issues:
1. How much is your family spending on daily living expenditures? ____ Rupees per day.

G. Gender:
1. Do you think male and female babies, have different requirements of nutrition, health care and upbringing?
2. Do you have different expectations for boys and girls with regards to domestic chores? (Washing, dishes, cleaning)?

H. Independence:
1. Who makes decisions regarding following things in the home. (For Women)

<table>
<thead>
<tr>
<th>Activity</th>
<th>On your own</th>
<th>Husband</th>
<th>Jointly with Husband</th>
<th>Other Family Members</th>
<th>Jointly with Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily Expenditures</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child Health Care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maternal Health Care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Travelling outside the house</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

I. Health
1. How do you get knowledge of different health related topics and issues?
   • Do you read any newspapers or magazines? In which languages do you read them?
   • Do you listen to the radio? In which languages do you listen to the radio?
   • Do you watch television? In which languages do you watch television?
2. What is your perspective on modern medicine?
3. How do they compare to the traditional methods of cure and healing?
4. Is there any health worker/care giver in your social circle?
   • Within Family
   • Within Relations
   • Family Friend
   • Friend of Friend
   • As a Neighbor
5. Does anyone suffer from any chronic diseases in the household? Does it have any financial impact on the family?
6. How do you meet expenditures on different health care issues? Are you always able to meet the expenses out of your own pocket or do you sometimes have to take a loan or sell/pawn something?
7. How far is the nearest health centre/clinic (both distance (km) and time)?
8. Is this the facility you go to for your health care needs?
9. How far is the nearest hospital (both distance (km) and time)?
10. Is this the facility you go to for your health care needs?
11. Do you access only government health care centres or private ones as well?
12. What kind of transport do you normally use for travelling to the health care centre or hospital?
   - Two Wheeler (cycle/scooter/motorcycle)
   - Three Wheeler (Cycle Rickshaw/Tempo/Hand drawn Cart)
   - Animal Drawn Vehicle or on an Animal (Specify the Animal)
   - Car/Jeep/SUV
   - Bus/Truck/Tractor Trolley
   - On Foot
   - Something else (Specify)

J. Mother Related Issues:
1. Overall how is your (the mother’s) health?
2. Mother Height:
3. Mother’s Weight:
   | Number of Child births ( for mother) | Number of surviving children |
   | Age and number of children who did not survive | Reason / symptoms |
5. Did the mother have any health problems prior to pregnancy?
6. What methods do you generally use for the following issues? If possible please also tell us about any traditional practices that you follow with regard to these issues.
   - Family planning
   - Birth spacing
   - Delaying/avoiding pregnancies.

K. Ante Natal Care:
1. When did you discover that you were pregnant? Was it planned?
2. What role did the father play in during pregnancy?
3. How many months pregnant was mother when she went for the first health check-up?
4. How many health check-ups did you get before delivery?
5. Tell us about your experience of your visit to any health care facility while pregnant, including topics discussed and results of the visit? Tell us about:
   - Delay in getting to the facility.
   - Time spent waiting to meet the health care worker/provider/professional.
   - Diagnosis and information about the disease/problem given.
   - Information about facilities available.
   - Behaviour of staff.
   - Respect for privacy shown.
   - Language barriers in communication.
   - Cleanliness of the facility.
   - Breakup of the money spent on treatment.

6. If the mother did not receive any health check-ups, then reasons for that?
   - Did not feel necessary.
   - Reasons of customs and traditions.
   - Cost issues.
   - Distance and transport issues.
   - Quality issues with the services given.
   - Time constraints.
   - Family constraints.
   - Lack of knowledge.
   - No visits by the health worker.
   - Any other reason.

7. Tell us about the dietary habits/nutrients taken during pregnancy. Did you change your diet after you discovered that you were pregnant?

8. Where there any lifestyle changes made after becoming pregnant, in terms of physical work, daily routine, living conditions within the household and movement?

9. Did the mother take any immunizations/medicines during pregnancy? Did you take vitamins or supplements (iron / folic acid)/prenatal vitamins?

10. Did you visit any homeopathic, ayurvedic or any other alternative medicine practitioner during pregnancy? What were the issues and what was the diagnosis and medication given?

11. Please describe any problems during pregnancy and what kind of treatment was taken? Tell us about the diagnosis and the facility which provided these treatments and/or the worker who administered them?

L. Delivery Related Issues:
1. In which place did the mother give birth? Why did you choose that location?
2. If the delivery was in hospital, how was mother taken to hospital?
3. Who assisted/supervised the process of delivery?
4. If not delivered under trained supervision, then reasons for the same
   - Did not feel necessary.
   - Reasons of customs and traditions.
   - Cost issues.
   - Distance and transport issues.
   - Quality issues with the service given.
   - Time constraints.
5. If not delivered in a medical facility, then reasons for the same.
   - Did not feel necessary.
   - Reasons of customs and traditions.
   - Cost issues.
   - Distance and transport issues.
   - Quality issues with the service given.
   - Time constraints.
   - Family constraints.
   - Lack of knowledge.
   - Absence of a health worker or any other reason.

6. If the baby was delivered within a medical facility then what were the factors that led to that decision? (May involved costs, expert supervision, safety, health, other)

7. If the baby was premature then by how many weeks?

8. How much did your baby weigh when it was born?

9. From your perspective why did the baby need to go to the SNCU?

10. Please describe your experience at the SNCU?
    - Before taking your baby to the SNCU, had you heard about them before?
    - If yes, what did you know about the Units?
      i. How and when did you find out about the Units?
      ii. Who told you about the Units?
      iii. If the person had been to a SNCU before, did they share their experiences with you?
      iv. How was this information given to you (i.e. written, oral)?
      v. Did anyone in particular recommend or advise you to take your baby to a SNCU?
      vi. When you were advised that you had to go to a SNCU, what was your reaction? What was the baby’s father reaction?
      vii. Can you share with us any expectations that you had (if any) when you decided to take your baby to the SNCU? Were they met?
      viii. Please describe to us what happened from the moment you came in to the SNCU, until your baby was discharged?
      ix. During your time at the SNCU, how did the staff treat you? Do you have any stories you would like to share with us?
      x. Can you describe what the staff’s (i.e. Doctors and Nurses) attitude at the SNCU was towards you and your baby?
      xi. During this whole process, were you feeling any emotions (positive or negative) that you would like to share with us?
      xii. While at the SNCU, did you feel like you were treated with respect?
      xiii. Do you think that your baby’s health is better or worse as a result of you bringing him/her into the SNCU? In what ways?
      xiv. If (you are in a similar situation once again) you could do it all over again, would you bring your baby back to the SNCU? If not, what would you do instead?
      xv. If you were to tell anyone about the SNCU, would you recommend it to them?
Overall, how did you find your experience at the SNCU? Can you tell us about it?
Was there an incident in particular that made you have a negative or positive experience?
If you could change anything at the SNCU that could have improved your experience, what would it be?

11. How much do you think you spend out of pocket when the baby was admitted to SNCU? Give us details on the money spent?
12. Did you know about those expenditures?
13. How did you meet them?
14. Did you have to take any loan or sell/pawn something to finance that expenditure?
15. Was mother covered under any health insurance? How much did they cover?
16. If you were to give advice to another mother on how to keep their baby healthy after bringing them home, what would you tell them?

**M. BEHAVIORS:**

1. When did you start breastfeeding your baby?
2. How did your child receive milk while in the SNCU?
3. For how long did you feed it exclusively on breast milk?
   - If stopped then reasons for the same.
   - Did you provide any other liquid besides breast milk?
4. How did you feel about coming home with your child from the hospital?
5. Tell us about the customs, practices and rituals that are typical to mother and baby after a child birth in your community.
   - child/mother isolation
   - drying
   - belly hot iron
   - honey
6. Tell us something about your practices regarding child and maternal care on these issues

<table>
<thead>
<tr>
<th>Umbilical Cord Care</th>
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<tbody>
<tr>
<td>Skin to skin contact</td>
<td></td>
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<tr>
<td>Cleaning and Hygiene of the baby</td>
<td></td>
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<tr>
<td>- How do you manage excretion by baby?</td>
<td></td>
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<tr>
<td>- How often do you change clothes?</td>
<td></td>
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<tr>
<td>- How do they treat/wash baby’s clothes?</td>
<td></td>
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<tr>
<td>- How do you clean baby’s surroundings?</td>
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<tr>
<td>- How often do you bathe the child?</td>
<td></td>
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<tr>
<td>- When did you first bathe the child?</td>
<td></td>
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<tr>
<td>- What water is used to bathe your baby</td>
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</tbody>
</table>

**Immunizations**

**Keeping the Baby Warm**
Nutrition for Baby

Nutrition for Mother

Keeping household environment clean

N. Post Natal Follow-Up/Health Care:

1. Prior to coming home, what advise were you given about health care follow ups for your child?
2. Were you and your child visited at home by any health care worker after child was born? When was it that they came? How many times did they come? When was the last visit? Tell us about your experiences? How did they interact with you in terms of:
   - Language
   - Advice given
   - Sensitivity shown to patient
   - Respect for privacy

3. Did you take the baby for a health check up after birth (after getting discharged from SNCU)? When was it that you went? How many times did you go? When was the last visit? Tell us about your experience? How did they interact with you in terms of:
   - Language
   - Advice given
   - Sensitivity shown to patient
   - Respect for Privacy

4. How much did you spend out of pocket for each of the visits?
5. If no follow up, please explain.
6. Other than the scheduled follow up visits, have you consulted any health care worker/professional for any of the problems with the health of the baby, then please tell us about the:
   a. Timing of visit (in relation to child)
   b. Person who you consulted
   c. Symptoms
   d. Diagnosis
   e. Treatment prescribed / advice given
   f. How much did you spend out of pocket for each of the visits?
   g. Were you and your family able to follow those medical treatments / advices?

7. Does your baby have a birth certificate or birth registration?
8. If the child died then can you tell us about the events surrounding the death?
   - What symptoms did the child have, for how long, how old was the child at this point?
   - What health care services were received?

9. How long after being released from the hospital / SNCU did the baby die?

O. Education, Information and Communication Issues:
1. Did you receive any information from a health care worker/professional on these issues prior to the child being born; if yes then what information did you get/receive. Also when did you receive the information?

<table>
<thead>
<tr>
<th>Topic</th>
<th>Information Provided</th>
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</thead>
<tbody>
<tr>
<td>Family Planning</td>
<td></td>
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<tr>
<td>Breast Feeding - importance and the adequacy</td>
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<tr>
<td>Immunization (mom and child)</td>
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<tr>
<td>Vitamin supplementation (including iron)</td>
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<tr>
<td>Malaria Prevention / bed net use</td>
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<tr>
<td>Importance of good nutrition</td>
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<tr>
<td>Treatment of Health Problem such as sexually transmitted infections</td>
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<tr>
<td>Importance of Pre Natal Care</td>
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<tr>
<td>Supervised delivery</td>
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<tr>
<td>The harms of Smoking, and drinking alcohol in pregnancy</td>
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<tr>
<td>Skin to Skin contact</td>
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<tr>
<td>Child Nutrition</td>
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<td>Sanitation and Hygiene</td>
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<tr>
<td>Oral Rehydration in case of diarrhea</td>
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<tr>
<td>When to visit hospital when in labour</td>
<td></td>
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<tr>
<td>How know when baby is sick</td>
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</tbody>
</table>

2. What changes did you make to your household/behaviour/lifestyle according to the advice/information?

**P. Role of Family in Raising Child:**

1. Who takes care of the child most of the time?
2. What kind of roles and functions does the father play in bringing up the child?
3. If your child was ever sick or showed unhealthy symptoms, how did the father react?
4. If mother is the primary care giver, who takes care of the child when she is not available (ex. sick, working)?
5. Who in your family is the most knowledgeable when it comes to maternal and child care?
6. Who according to you plays the most crucial role in bringing up a child?
Annexure VI

Research consent form

Research Consent Form

TITLE OF RESEARCH PROJECT: Documentation of Special Newborn Care Units (SNCUs) in Orissa

SUPERVISOR:  Dr. A.K. Sen, UNICEF
             Dr. Nandini Sen, KIIT University

CO-INVESTIGATORS:  Carolina Arcila, UNICEF Intern
                  Vishal Avinashi, UNICEF Intern
                  Kristen Kappos, UNICEF Intern
                  Shivraj Singh Negi, UNICEF Intern

PURPOSE OF THE RESEARCH

The purpose of this study is to get a better understanding of what happens to the babies after they have gone through a Special Newborn Care Unit (SNCU) in Orissa as well as to better understand the maternal and family experience of the SNCUs.

So far, information has been kept on those admitted to SNCUs until the time of discharge. Very little is known about what happens beyond the hospital period.

It is hoped that this interview will lead to a better understanding of how these units and family experiences’ can be improved. Also, it will help inform us whether the SNCUs are contributing towards keeping sick children alive beyond the hospital period.

It is important for the participant to know that there are no right or wrong answers.

Participant Selection
Participants have been selected among the many patients who have been discharged from a SNCU. Participants have not been selected individually.

Potential Harms
There is no direct harm to taking part in this study. However, questions related to infant survival, education levels, caste and personal health information will be asked about and can stir strong emotions.

Potential Benefits to Individuals
There is no direct benefit to the participant or the participant’s child.

Potential Benefits to Community
The information obtained in this interview provides much needed details to improve the services and know what areas need improvement at the SNCU.
Confidentiality
We will respect the participant’s child’s privacy as well as that of the participant’s household. No information will be used that can identify the participant’s family or child.

Reimbursement
No money or gifts will be provided for participating in the interview.

Participation
Participation in the study is voluntary. Participation involves answering questions from the interviewers with the help of a translator. It is estimated to take 90 minutes. The participant has the right to not answer certain questions and/or to end the interview at any point in time. Participation will not have a positive or negative impact on the participant’s family’s current or future ability to obtain health services. The participant has the right to inquire about the study at any point in time.

The interviewers will take notes and may record the conversation during the interview in order to not lose any valuable information provided by the participant.

Conflict of Interest
The Investigators and Co-Investigators have no conflict of interest to declare.

Consent
I confirm that _________________________has explained the idea of the interview and that any questions that I have asked have been answered to my satisfaction. I have read (or had it read to me) and understood the consent form.

I agree, or consent, to the interview about my child___________________ and agree to take part in this study.

Printed Name of Parent/Legal Guardian & Date

___________________________

Parent/Legal Guardian’s Signature

Printed Name of Person Who Explained Consent

___________________________

Signature of Person Who Explained Consent & Date

Printed Witness’ Name (if the Parent/Legal Guardian Does Not Read)

___________________________

Witness’ Signature & Date

For questions or concerns, contact Rajesh Patnaik at +91 674 2397977-80.
Annexure VII

Photo and story release form

**Photo and Story Release Form**

**TITLE OF RESEARCH PROJECT:** Documentation of Special Newborn Care Units (SNCUs) in Orissa

**SUPERVISOR:**
- Dr. A.K. Sen, UNICEF
- Dr. Nandini Sen, KIIT University

**CO-INVESTIGATORS:**
- Carolina Arcila, UNICEF Intern
- Vishal Avinashi, UNICEF Intern
- Kristen Kappos, UNICEF Intern
- Shivraj Singh Negi, UNICEF Intern

By signing this release form, I hereby grant the Researchers and UNICEF permission to use my and/or my family’s photograph and/or story in any of its publications, documents and presentations without payment or any other consideration. I understand and agree that these materials will become the property of the Researchers and UNICEF and will not be returned. I hereby authorize the Researchers to edit, alter, copy, exhibit, publish or distribute the photos.

I confirm that these images are a true likeness of me and the images were taken with my knowledge and consent.

I further confirm that I have read (or had it read to me) and understand the Photo and Story Release Form.

__________________  __________________
Printed Name of Parent/Legal Guardian  Parent/Legal Guardian’s Signature & Date

__________________  __________________
Printed Name of Person Who Explained Consent  Signature of Person Who Explained Consent & Date

__________________  __________________
Printed Witness’ Name (if the Parent/Legal Guardian Does Not Read)  Witness’ Signature & Date

For questions or concerns, contact Rajesh Patnaik at +91 674 2397977-80.
Key Informant Consent Form

Title of Research Project: Documentation of Special Newborn Care Units (SNCUs) in Orissa

Supervisor:
Dr. A.K. Sen, UNICEF
Dr. Nandini Sen, KIIT University

Co-Investigators:
Carolina Arcila, UNICEF Intern
Vishal Avinashi, UNICEF Intern
Kristen Kappos, UNICEF Intern
Shivraj Singh Negi, UNICEF Intern

- The interviewer explained to me the purpose of the research
- I understand that my participation in this interview is voluntary
- I have the right to not answer any question and/or to stop the interview at any time
- I understand that if I have any further questions I can contact Rajesh Patnaik at +91 674 2397977-80
- I agree to the interview being audio recorded YES / NO
- I agree to some of my comments or statements being quoted in the report YES / NO
- I would like to receive a summary of the key findings from this study YES / NO

If you would like a copy of the summary of the key findings, please record your email address
________________________________________________

Declaration:
I, ________________________________ agree to be interviewed for this project.

Signed: ________________________________ (Participant) Date: ___/___/___

Signed: ________________________________ (Researcher) Date: ___/___/___