Executive Summary

## Background and Rationale

The first 28 days of life (the neo-natal period) is the most vulnerable time for a child’s survival. Children face the highest risk of dying in their first month of life (UNICEF, 2018). The Right to Life as enshrined in Article 21 of the Indian Constitution, and the United Nations Conventions on the Rights of the Child (UNCRC) is a Fundamental Right, and Goal 3 of the Sustainable Development Goals (SDGs) states that by 2030, the aim is to end preventable deaths of new-borns and children under five years of age, and reduce neo-natal mortality rate (NMR) to at least as low as 12 per 1,000 live births and under-5 mortality to at least as low as 25 per 1,000 live births. In the National Plan of Action (NPA) 2016, India has committed to reducing neo-natal mortality to 21 by 2021. India currently contributes to one-fifth of global live births and more than a quarter of neo-natal deaths. In India, the NMR stood at 23 deaths per thousand live births in 2018 (SRS 2018). Around 72 percent of total infant deaths and more than half of under-five deaths fall in the neo-natal period; deaths in the first week alone account for 55 percent of total infant deaths (SRS 2018). The latest round of the National Family Health Survey (NFHS-IV) 2015-16 indicates that only 24 percent of children received a health check-up from a qualified medical personnel within 2 days of birth, and that less than 3 percent of children born at home were taken to a health facility for check-up within 24 hours of birth. The causes, drivers and determinants of these occurrences are myriad and multifaceted which includes infrastructure gaps, parental education and non-optimal health seeking behaviours along with other socio-economic drivers. There are medical causes also of neo-natal deaths like prematurity and low birth weight, birth asphyxia, etc. Over the years, consistent efforts to address the above issues have been made by both the State and Civil Society Organisations (CSOs). While the steps taken to reduce mortality have shown some positive trends over the last few decades, India still has a higher neo-natal mortality rate compared to the world average. The state of Uttar Pradesh has one of the highest neo-natal mortality rates in the country with 32 deaths for every 1000 live births (SRS 2018). The rural-urban differential in the state is also one of the highest in the country with rural areas witnessing 34 deaths for every 1000 live births and urban areas recording 21 deaths for every 1000 live births in the neo-natal period.

In Uttar Pradesh, CRY- Child Rights and You, recognising the pressing need for improving the maternal and child health, has a range of holistic interventions both at the system and the community levels in the grassroots, through a host of measures. The CRY experience shows that the issue of infant and neo-natal deaths is complex with a cluster of interlinked drivers and a need was felt for the study to further explore the socio- cultural determinants and different health aspects of the occurrence. The study findings will guide CRY and other civil society organisations’ (CSOs) endeavours to address issues related to neo-natal health and mortality in Uttar Pradesh and also strengthen the policy dialogue with different stakeholders including policy makers and influencers at different forums.

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## Objectives of the study

The main objectives of the research were as follows:

* To understand the sociocultural determinants of neo-natal deaths;
* To understand the beliefs, traditions and practices of the community regarding new-born care among mothers;
* To document the accessibility, availability and utilisation of healthcare services in relation to neo-natal health.
* To document the experiences of mothers in relation to new-born health and community systems.

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## Research design

The study was conducted in rural areas of three districts of Uttar Pradesh namely – Kaushambi, Sonbhadra and Varanasi. CRY has intervention programmes in all these three districts. Presently, CRY has presence in 60 villages of Kaushambi, 50 villages of Varanasi (Rural) and 28 villages of Sonbhadra district through various program initiatives.

As part of the research methodology in the above districts, the field staff of implementing NGO partners of CRY visited and studied all neo-natal deaths in detail and collected detailed information from the families including demographics, socio-economic status, health-seeking practices etc. (neo-natal deaths that were reported between April 2018 and 31st March 2019). Out of the 55 identified cases, a random sub-sample of 29 mothers was additionally chosen (distributed proportionately with respect to number of deaths in the respective districts) for in-depth interviews. In-depth interviews were conducted in the month of February 2020 and mothers who had lost their child in the last one year prior to the survey were interviewed for detailed exploration. Reflexive notes during the field visits were also documented to substantiate the findings. Descriptive analysis was carried out as per the variables of interest.

## Ethical Considerations

During the data collection, the best practices of ethical research were strictly followed. All mothers were duly informed about the objectives of the study beforehand in the local language. Informed consent was obtained for the interview. Mothers were interviewed at their homes and participation in the interview was voluntary.

## Limitations

The study documented the responses of a limited sample, hence offers scope for limited generalizability. However, the findings give an in-depth understanding of sociocultural aspects and access, availability and utilisation of healthcare services related to children in the study areas, and can be used for programmatic interventions and initiating policy dialogues.

## Key findings based on the Case Studies and In-depth Interviews

**Age of the Mothers:** Overall, 74.5 percent of women were between 20-30 years of age and 11 percent were below 20 years of age. In rural areas of Varanasi, a large number of women i.e. 46 percent were within the age group of 22-25 years, and 31 percent were below 20 years of age. In Kaushambi, none of the women was below 20 years and most of them (71.4%) were within the age group of 20 to 30 years. In Sonbhadra, most of the women (64.3%) were within the age group of 20-25 years and 14 percent were less than 20 years.

**Educational qualification of the respondents:** Overall, a majority of the women (61.8%) were non-literate and an additional 20 percent had completed primary education. In rural areas of Varanasi, more than 77 percent were non-literate and almost same percentage was in Kaushambi (75%), which is concerning in relation to health. In Sonbhadra, only 21 percent of women were non literate.

**Factors related to neo-natal deaths**

**Sex of the Child:** It was found that girl children accounted for a slightly higher proportion of neo-natal deaths (52.7%) compared to boys (47.3%). This was the case in rural areas of Varanasi (53.8%) and Kaushambi (60.7%). However, in Sonbhadra, boys accounted for 64.3 percent of the neo-natal deaths.

**Birth order:** Overall, a significant percentage of neo-natal deaths were attributed to 1st (31%) and 4+ (29%) birth orders. In rural areas of Varanasi, the highest proportion of deaths was among children who were first-born and 2nd born (30% each respectively). In Kaushambi, 32 percent cases were first births and the highest deaths occurred among children having 4+ birth orders (39%). In Sonbhadra, there was not much difference of birth order as they were comparatively evenly distributed – 28 percent of the cases each were from first and second birth order, while 21 percent cases of neo-natal deaths were from the third and fourth birth order each.

**Registration, ANC & Counselling:** **Out of the total women, majority of them (93%) were registered with Anganwadi centres and got counselling from the AWW or ASHA workers (88%). In Varanasi Rural, all the women were registered with their local AWCs but only 53 percent received counselling. In Kaushambi, 96.4 percent women were registered and all of them received counselling. In Sonbhadra, the proportion of women registered with AWCs was comparatively lesser (78.6%); however, all the women received counselling.**

A majority (94%) of the women got IFA tablets during the pregnancy and two doses of tetanus toxoid injection (84%). **However, only one in every ten women stated that they got full ANC check-ups (11.2%).** All the women in Sonbhadra received Tetanus toxoid injections and IFA tablets; however only 18 percent received all the 4 antenatal check-ups. In Varanasi Rural, 84 percent of the women received both the Tetanus toxoid injections and IFA tablets; however only 8 percent received all the 4 antenatal check-ups. In Kaushambi 82 percent of women received Tetanus toxoid injections and 96 percent received IFA tablets; however only 11 percent received all the 4 antenatal check-ups.

**In-depth interviews with mothers revealed that most of the interviewed mothers (83%) reported being visited by an ASHA during the time of their pregnancy and were registered by ASHA. Most of the registered mothers (88%) reported that they received counselling from ASHA but only nutrition was the most frequently cited topic by mothers (94%) when asked about the counselling topics discussed by ASHA, followed by institutional delivery (83%), government schemes (78%), safe motherhood (50%) and personal hygiene respectively (56%). Information about importance of ANC somehow was not cited by the mothers.** However, it was observed during the interview that most of the mothers did not know the benefits of nutrition or institutional delivery but they had more knowledge about government financial schemes.

Mothers’ interviews also suggested that one in every five mothers did not visit any health facility during pregnancy. Only 41 percent pregnant women had visited a health facility for check-ups more than two times. Only around half of the mothers (55%) were allowed or permitted to go a health care facility on their own. Those who were not allowed to go on their own had to be accompanied either by husband or mother-in-law to health facility. Only 13 percent of mothers had 4 antenatal check-ups. Only 7 percent mothers in the study received birth registration certificates and majority of the women (86%) stated that they did not receive any death certificate of the child.

**Place of birth:** **A majority of the births occurred were institutional births (78%), out of which 60 percent were at a public health facility and 18.2 percent at a private health facility. The proportion of home births were highest in Sonbhadra (28.6%), followed by Varanasi Rural (23.1%) and Kaushambi (10.7%).**

**Mothers during interview also gave similar information - 62 percent of the deliveries took place in government health facilities, 24 percent of the births took place in private clinics, and 10 percent deliveries took place at home and 3 percent during transit. Among the women who delivered in an institution, 69 percent were discharged on the same day as the delivery and only 28 percent mothers reported the child receiving post-natal check-ups in the first week after birth.** 31 percent of the women approached the Sub Centre (SC) and 24 percent opted for Primary Health Centre (PHC) for their delivery and 7 percent delivered in a Government hospital. One in every fourth delivery took place in a private hospital or clinic. 52 percent of the respondents were within a range of 2 to 3 km of nearest health facility and 56 percent of the respondents were within a reach of 10 km from a community health centre (CHC). The average range of the distance for the nearest Sub-Centre (SC), Primary Health Centre (PHC), Community Health Centre (CHC) and District Hospital (DH) in kms are 2.3, 5.1, 11.5 and 13.6 km respectively. Private facilities were found within a range of 3 to 5 km by 34 percent respondents.

**Health facilities and assistance during the delivery:** **Among the women who had institutional delivery, only one in every ten deliveries (14%) were assisted by a doctor. A majority of them were conducted by an ANM (86%). District wise, in Varanasi rural 80 percent of the deliveries were assisted by an ANM, while 20 percent were done under the supervision of a Doctor. In Kaushambi 88 percent were assisted by an ANM and only 12 percent by a Doctor. The data from Sonbhadra shows that 87.5 percent of institutional deliveries were assisted by ANMs and 12.5 percent by a doctor. The findings also highlight that 17 percent of the deliveries were not assisted by any skilled or trained birth attendant (attended to by *Dais* and relatives).** The experiences related to the facilities available shows that many respondents were satisfied with the availability of ASHA, ANM, and Trained Birth Attendant etc. but less than 5 percent of the respondents replied positively about the cleanliness and hygiene of the facility. The other problems reported by the respondents were unavailability of doctor, electricity problems, having to purchase their own blades, medicines, gloves and unfavourable conduct from the support medical staff. . Qualitative responses stated that though women stated that beds, medicines, ANM, ASHA, Dai and doctors were available in the facility, yet many complained about the unavailability of doctor at the time of emergency. Some shared their views that the behaviour of the nurse was not good and that they had to pay extra money.

**Delivery and pregnancy risks:** **A majority of women had normal delivery (89%), and approximately half of them (44%) had high risk pregnancy in terms of low Haemoglobin counts and low weight of women etc. Out of these high risk pregnancies, 29 percent were home deliveries. The percentage of high risk pregnancies was the most in Sonbhadra (64.3%), followed by Kaushambi (39.3%) and Varanasi Rural (30.8%). Complications during pregnancy were also the highest in Sonbhadra (28.6%). The proportion of women having had a normal delivery was 85 percent or more in all the 3 districts.**

**Cultural and local practices followed during delivery:** **In one in every ten cases, old or unsterilized instrument/blade was used to cut umbilical cord. This was highest in Varanasi Rural (33.1%), followed by Sonbhadra (14.3%), and did not occur in Kaushambi. Half of the new-borns (51%) were not breastfed immediately and/or within an hour of birth and one in every tenth child (12.7%) was fed with something other than breast milk (e.g. cow milk or honey due to varied cultural practices followed in the study areas). Only 28.6 percent of the new-borns were breastfed within an hour of birth in Sonbhadra, followed by 38.5 percent in Varanasi Rural and was the highest in Kaushambi (64.3%). Mothers’ interviews also revealed that only 35 percent children were given colostrum within an hour. Among women who did not give colostrum within an hour, 56 percent reported that the child was never given colostrum.**

During interviews, mothers reported that care from family was lacking. One in every ten women did not have anyone in the family to provide care during pregnancy. There existed a wide range of beliefs, taboos and practices related to pregnancy. **Half of the mothers (52%) followed some or all of the locally popular practices on pregnancy and child birth which included restrictions on travelling, personal hygiene related practices and spiritual/ religious beliefs.**

69 percent of the mothers reported post-delivery complications for their child. 10.3 percent of the mothers reported using home remedies for the complications (remedies mentioned were wrapping the child in hot cotton to get relief from cold, going to traditional healers who knew black magic, witchcraft solutions and having belief in/ praying to Gods/ Goddesses).

**Birth Weights of the new-borns:** 36.4 percent of the neonates were Low Birth Weight (LBW). This was the highest in Sonbhadra (57%), followed by Varanasi Rural (31%) and Kaushambi (27%).

**Probable causes of new-born death** – **There were multiple causes leading to the deaths of neonates. Neo-natal Pneumonia and Respiratory Distress Syndrome emerged as the two highest probable causes accounting for 27 percent and 24 percent of the deaths overall. In Varanasi Rural, Neo-natal Pneumonia and Respiratory Distress Syndrome accounted for 23 percent and 21 percent of the deaths respectively. In Kaushambi similarly, Neo-natal Pneumonia and Respiratory Distress Syndrome accounted for 21 percent and 32 percent of the deaths respectively. In Sonbhadra, 43 percent of the deaths are likely to have occurred due to Neo-natal Pneumonia, and in none of the cases, Respiratory Distress was reported. Overall, 30 percent of the deaths were sudden deaths and in 18 percent of the cases, there was insufficient information.**

**Number of Days after which deaths occurred:** Overall, children died within 4 days of birth on an average, ranging from 5 days in Varanasi rural to 3.6 days in Sonbhadra. **82 percent of the deaths took place within 7 days of birth, and hence are conclusively early neo-natal deaths. This was highest in Kaushambi (86%), followed by Sonbhadra (79%) and Varanasi Rural (77%).** Range of days was lower in Sonbhadra (0 to 15 days) indicating that children survived for very less number of days in the district. 35 percent of the deaths were same-day deaths.

In the interviews with mothers it was revealed that deaths of girl children, among the sub-sample chosen for in-depth interviews, were also slightly higher accounting for 51.7 percent of the total neo-natal deaths. 62 percent of the neo-natal deaths (as revealed in case studies also) were early deaths i.e., within 7 days; 31 percent of the deaths were same-day deaths.1st order and 4+ order births accounted for 72.3 percent of the deaths, in line with the findings from the larger sample presented in the section above.

**Place of death:** **A majority of the deaths occurred at home (58%) and 38 percent occurred in a health facility (private-20% and public–18%). In all 3 districts, most deaths occurred at homes – Varanasi Rural (53.8%), Kaushambi (57.1%) and Sonbhadra (64.3%).**

**Benefits under Central/ State Schemes:** **Around one third respondents (39%) received benefits provisioned under central/state maternity benefit schemes though most of them were registered at AWCs. In Varanasi rural, 30 percent of the women received benefits under any Central/ State schemes. This figure was the highest in Kaushambi with 58 percent of the women reporting benefits under various schemes.** It is notable that none of the women (mostly schedule tribe) from Sonbhadra reported receiving any benefit under any central or State level maternity related schemes.

IDIs revealed that Most of the women (93.1%) had MCPC cards. It was also observed that although pregnant mothers were registered, the MCP card was not kept with them. Around 79 percent mothers reported to have had three meals a day during the pregnancy period, whereas 17 percent did not have access to three meals a day, although a maximum number of the respondents were counselled by the ASHA, AWW, and ANM about the importance of nutrition diet and calcium intake during pregnancy. **93 percent of the women reported receiving Take-Home-Ration, but 22 percent did not use it to supplement their own dietary needs.**

## Conclusions and Recommendations

**The research adequately demonstrates a host of factors which constrain and hinder effective healthcare for mothers and new-borns.** The systemic and the socio-cultural factors leading to non-optimal healthcare and childcare practices emerge clearly. On the supply-side, lack of availability of adequate and trained medical staff (only 14 percent of respondents reported doctor-assisted deliveries), lack of adequate health infrastructure (beds and trained medical personnel were available to only 17 percent of the women) and affordability (less than 40 percent of the mothers had any financial assistance from schemes (despite a majority being from BPL families) emerged as chief barriers.

These constraints combined with the inherent disadvantages faced by mothers due to lack of education, low incomes, poor awareness and unfavourable socio-cultural practices were found to lead to non-optimal health-seeking behaviours and childcare practices. This is evidenced by salient indications from the study such as 41 percent of the women choosing to opt for deliveries at home or in Sub-Centres where doctors were not available, only 28 percent of the mothers visiting any health facility for check-up within 7 days of birth, colostrum-feeding being done only by 35 percent of the respondents etc. These were coupled with other unfavourable childcare practices, leading to a high risk for the survival of the new-borns.

The study showed that the factors that can influence the key decision to seek and practice appropriate care include the beliefs of the woman and her relatives. availability and the competence of trained dais (traditional birth attendant), the socio-economic status of the family, illness characteristics (recognition and severity), distance from the health facility (accessibility), financial and opportunity costs (affordability), previous experience and perceived quality of care. Other factors are the physical accessibility, travel time from home to facility, the availability and cost of transportation and the condition of the roads. The study throws up a multitude of barriers and gaps which paves way for tangible recommendations for ensuring adequate, effective and timely healthcare for mothers and new-borns.

**Preventative Care** – Complete Ante-natal-care (ANC), which is vital for safe deliveries, requires urgent attention. Less than 15 percent of the mothers had received complete ANC, putting the health of both the mother and child at risk. The study takes cognisance of the fact that ASHA workers can play a significant role here and should promote effectively the importance of full ANC check-ups. Proactive measures to identify high risk pregnancies (as experienced by 44 percent of the mothers) and adequate referral mechanisms are also pressing concerns. Outreach workers such as ASHA, ANM and Anganwadi workers should be provided training, as well as adequate additional resources in terms of ‘untied funds’ that can be used for emergency situations.

**Best Practices of Safe Deliveries** - The study found that though the home-deliveries has significantly decreased but still its an existing practice in the study areas (for instance - 29 percent of mothers in Varanasi Rural delivered at home). To promote, institutional deliveries, more outreach workers such as ASHA, ANMs etc. should be recruited. Also the quality of institutional care needs to be improved so that maximum new-born deaths can be prevented and health complications can be addressed. It will also be beneficial if ‘Dais’ (unskilled birth attendants) can be trained so that they can refer the complicated pregnancies to the health systems on time and thus, could promote institutional deliveries.

To demote the deaths during the transits, transport facilities in terms of pick up and drop facility of the existing 102 and 108 ambulance services should be strengthened by the health authorities and should act timely so that the lives of the mother and the child may be saved during emergencies. Community collectives and groups should be formed to meet the emergency needs of the family and pregnant women like transportation, etc. and also to support the health and nutrition needs of the pregnant woman from the most marginalised families.

**Medical Care and Protocols during delivery** - The study findings suggest that hardly any institutional delivery in a government facility was assisted by the doctors (less than 15 percent). Likewise, qualitative findings suggested that in most of the health facilities, there was an acute shortage of human resources such as neonatologists, obstetricians, lab technician, anaesthetists and midwives. Vacant positions of healthcare staff should be filled on an urgent basis and specialised doctors such as gynaecologists and paediatrician should be recruited in the remotest rural areas of Uttar Pradesh like Sonbhadra. The study findings also reflected poor clinical practices in medical facilities (for instance 62 percent of the mothers who delivered at institutions got discharged on the same day, thus, grossly compromising the need of postnatal care to mother and her child). There is an urgent need to train, monitor and ensure strict implementation of best practices of maternal and child care, including discharge protocols. Proper institutional care can significantly bring down neo-natal deaths especially early neo-natal deaths which constitute a significant portion of deaths.

**Ensuring Postnatal Check-ups (PNCs)** – Post-Natal-Visits are accepted as one of the best practices to reduce neo-natal mortality and infant mortality. Once again, the potential role that can be played by the ASHA worker is significant in ensuring the mandated 3 post-natal contacts within the first 7 days following the birth. Urgent attention needs to be given, with adequate allocations, training and monitoring to ensure that PNCs are instituted

**Improving health-seeking behaviours and child care practices** - Information should be disseminated using short films, ‘*nukkar natak’* etc. to the community on the issues pertaining to maternal and child care, ante natal care, danger signs of complications and post natal care using a smart mobile van as these methods are more effective in a community where large proportions of the population is non-literate. Delayed breast-feeding especially to LBW/ premature babies can cause serious medical repercussions including deaths, and therefore it is imperative to impart the right knowledge to the community (the mother and the child’s family). Active participation of men should be sought through government sponsored and promoted community based intervention programmes. Inter-spousal communication seems to be an effective means of enhancing birth preparedness. Therefore, it should be encouraged through active participation of husbands in antenatal care services.

**Community Awareness and Sensitisation** - Individual and family preparedness for birth should be promoted via training on various aspects such as positive attitudes, favourable perceptions towards birth preparedness, high self-efficacy and familial and social support. Several cultural beliefs and traditions that exist in different communities influence care practices (52 percent the respondents confirmed following practices that were culture-induced). Due to neglect in care of the female child and poor access to healthcare for girls, the data reflected that more girls (53%) compared to boys (47%) died in their first month of life. Realizing the presence of such traditions in the community, intensive Information, Education, and Communication (IEC) campaigns should be formulated to address myths and misconceptions and promote healthy and equitable practices. Detailed counselling of the family members should be promoted and conducted to address taboos associated with the prevailing practices.

### Policy Recommendations

This study shows that there is a need to adopt state-specific strategies and multi-sectoral approaches to bring down neo-natal mortality, and move closer towards achieving the targets and goals of INAP, NHM, NAPC and SDGs. Policy options for new-born and child survival should include community awareness, adopting preventive strategies, enhancing local health infrastructure and increasing investment in child health and related maternal and adolescent health polices and schemes; the recommendations are as follows:

1. Birth and death registration should be strictly mandated. Civil Registration and Vital Statistics (birth and death registration with cause of death assignment) should be progressively strengthened for counting every new-born.
2. Micro level research, information and reliable data about mortality are required for improving programmes. The system of reporting NNM should be strengthened and each neo-natal death should be audited to improve new-born health.
3. Periodic monitoring of Annual Implementation Plans should be encouraged by state authorities. Annual health plans should reflect local needs and effective budgeting processes should be put in place. Periodic health facility audits and needs assessment studies at the facility level should be promoted by health authorities to assess gaps in services and take corrective measures.
4. Trained mobile health teams should be deployed for screening and early detection of risks so that immediate actions can be taken during emergencies to reduce the risk of death.
5. Periodic training and assessment of training should be promoted for outreach workers on varied topics related to maternal and child health. Though incentives are inbuilt in national programmes for promoting institutional deliveries, healthy practices such as colostrum feeding, exclusive breastfeeding, nutritious food intake during pregnancy and lactation and maintaining personal hygiene could also be incentivised.
6. Intensive awareness programmes should be promoted to disseminate information about maternal/ child care and available government schemes to enhance coverage. Efforts should also be made to address issues such as early marriage of girls and nutritional deficiencies among adolescent girls through school and community level programmes and activities.
7. Focus should be on promoting postnatal visits, as across the world this strategy has been accepted as the best practice to reduce neo-natal and infant mortality. Hence the role of ASHA is significant. The government guidelines specifies 3 post-natal contacts within 7 days of birth. This is extremely vital and should be monitored and implemented strictly.
8. Also need to focus on improving the quality of institutional care and formulating and implementing the delayed discharge protocols. The institutional care can significantly bring down NMR especially early NMR which in the study findings was also a significant percent (82%) all the NMRs.
9. Steps to be taken by the Health department and government health workers to improve the quality of ANC especially focusing 4th ANC and more so the last ANC within last week of pregnancy and BP/ CR (birth preparedness and complication readiness) can be addressed.
10. Urgent need to shift from generalised strategy to focused approach (narrowed down approach) needs to be applied to reduce NMR to attain the targets of SDG. One strategy is focussing on the tribal pockets as significant numbers of deaths are happening there. Further focus needs to be on the 1st born as it increases the NMR significantly.
11. Most of the recommendations related to addressing adequacy of human resources as per IPHS standards, their training, availability of quality infrastructure etc. are contingent on adequate budgetary allocations. Trends in budgetary allocations for child health as a proportion of overall child budget has been progressively declining from 3.9 per cent (2018-19 BE) to 3.57 percent (2019-20 BE) to 3.4 percent (2020-21 BE). Thus, there is an urgent need to universalise quality health services by increasing public provisioning for health.